DEPTH

Routes: New ways to talk about COVID-19 for better health

Final Report

A focus on Gypsy, Roma and Traveller
communities, and migrant workers
in precarious jobs

LONDON
SCHOOL of
HYGIENE
&TROPICAL
MEDICINE

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EXECUTIVE SUMMARY

Introduction: In mid-2021 NHS Test and Trace/Department of Health and Social Care commissioned the Dialogue, Evidence, Participation, and Translation for Health (DEPTH) research group to explore the impact of COVID-19 in Gypsy, Roma and Traveller communities, and among migrant workers. We undertook participatory qualitative research with members of these communities to co-produce insights into COVID-19 and public health responses, particularly focusing on testing, contact tracing, and vaccination.

Routes: New ways to talk about COVID-19 for better health aimed to: 1) Explore views and experiences relating to COVID-19 and the public health response; 2) Identify rumours, misconceptions, and areas of mistrust; 3) Identify structural and other barriers to effective public health interventions in relation to COVID-19 and potentially other health emergencies.

We carried out interviews with 47 individuals from Gypsy, Roma and Traveller communities and an additional 13 non-Roma migrant workers in precarious jobs, seven from European countries and one each from Algeria, Gambia, India, Jamaica and Zimbabwe across six areas of England. We consulted 25 key informants from different sectors, and conducted 11 dialogue sessions which were designed to co-produce the research design, to discuss the findings and to co-produce recommendations. The project was unexpectedly curtailed at the end and so some of the planned co-production activities were not possible.

We conducted this work in England where the communities are affected by policies including the 'hostile environment' and the Police, Crime, Sentencing and Courts Bill which can contribute to mistrust and fear. COVID-19 occurred in the context of historical and on-going exclusion for the groups we worked with, including police harassment and discrimination. In this climate, formal support can be inaccessible for several reasons including (1) individuals fear repercussions from providing data (arrest, deportation); (2) digital exclusion; (3) low literacy in all groups and/or limited English language in the case of some migrant workers; and (4) ongoing exclusion from health services in general which was exacerbated in the pandemic.

Among Gypsy and Traveller communities, self-led solutions evolved to meet community needs, including community-facilitated testing and contact tracing. These self-led systems sometimes worked in tandem with the NHS systems but also worked independently. Gypsy and Traveller respondents particularly reported receiving and giving community support for testing, and helping with self-isolation. Positive test results were universally reported into personal networks, to notify contacts and help stop the spread.

Free home test kits improved equity by helping everyone to access testing and notify their own contacts. Individuals were able to do self-testing separately from formal test and trace mechanisms if they wished, empowering them to protect themselves by providing the means to identify positive cases, notify contacts and isolate, all within the community rather than through the Test and Trace system which was not always trusted. Gypsy and Traveller participants particularly reported community-led test, trace, and isolate responses. This type of full community response was not mentioned among Roma and migrant workers which might reflect their different context, but could also simply be that they did not mention it at interview.

Testing was used widely among all the groups to keep families safe and avoid spreading the virus. People with COVID-19 took self-isolation very seriously and wished to avoid infecting others. This was challenging in crowded and cramped living conditions.

Experiences of vaccination were shaped by historic and ongoing discrimination which meant that some were suspicious of the motives for promoting vaccination. Some participants told us they or people they knew felt that they did not need to be vaccinated. Many worried about side effects, including effects on fertility. Participants said that their concerns about vaccine safety were not taken seriously or addressed adequately by healthcare workers. Although many reported feeling coerced into taking up the vaccine, we did not find any particular evidence of low uptake of vaccines among our participants. However, while many had had at least one vaccine dose, participants sometimes said they and people they knew had refused subsequent doses. This was particularly the case for booster doses.

Recommendations

Supporting community responses

- Community-led solutions must be at the centre of public health responses. Mutual aid strategies developed by and for communities should receive support, guidance, and resources from public health experts and government.
- For effective community solutions to develop in tandem with health services, there must be better awareness and acknowledgement of the racism and discrimination experienced by the communities participating in this research. Without a willingness to address systemic racism and the wider hostile policy environment, effectiveness of any actions will be limited.
- Official communications about protection and prevention should be made more accessible. It often fell to overstretched third-sector organisations to 'translate' public health information for their communities. Better accessibility includes using formats suitable for low literacy such as audio or other non-text formats.
- Institutional structures should be created to support co-production of health solutions with and by communities to ensure inclusive preparedness and response to future emergencies. For example, individuals and organisations trusted by communities should be identified who can help guide these efforts, build networks, and design strategies locally both in preparation for and during emergencies.
- For future outbreaks, community-specific guidance on infection prevention is a priority, as is specific outreach to provide testing and information tailored to the needs of marginalised communities. For instance, for Travellers living on sites, this might involve guidance on how to make shared facilities safer, demonstrations of how to use test kits where internet is unavailable and providing video/audio information as well as written instructions to ensure low literacy is not a barrier to understanding.
- The importance of community action suggests that recent migrants may be particularly at risk if they have limited community support and/or no recourse to public funds and/or fear or experience poor treatment because of the hostile environment, bureaucratic hurdles, racism, or other forms of discrimination. Further work is needed to assess the best ways to ensure their needs are met.

Recommendations (Continued)

Helping communities self-organise public health responses

- Free, easy access to rapid home testing enabled Gypsy and Traveller communities to implement their own, tailored protective actions against COVID-19. Self-testing and other ways to help communities self-organise responses should be prioritised for all communities. This is likely to be particularly important if urgency requires a large-scale response that can be delivered more rapidly by communities, or if communities do not wish to engage with untrusted formal systems.
- Tailored strategies to meet different needs in different communities can be developed using a community co-production approach. The strategy development process should be transparent to maintain trust, with a mechanism to ensure that co-developed ideas are shared widely to inform strategies elsewhere.
- Consider making it easier for people to report test results if data are needed for planning. For example, this could include collecting aggregate reports from sites without full names and details. Consider supporting individuals or organisations trusted by communities to record 'hidden' cases e.g. by paying for some staff time for this purpose. Low literacy, digital exclusion, and complicated instructions made it challenging for individuals to report test results even if they wished to do so.
- There were no clear benefits to reporting test results to the official system when community-led reporting systems were used. Consider providing clear benefits for reporting positive tests (e.g. introduce policies to ensure that Travellers cannot be moved on for at least 14 days from the date of the positive test to allow them to recuperate).

Improving reporting and contact tracing

- Community contact notification can be rapid and reinforced by individuals and civil society organisations such as charities set up to work for the interests of particular groups. These mechanisms should be acknowledged and supported.
- Care needs to be taken not to create or exacerbate stigma of infection as this would likely shut down these valuable and rapid channels of communication.
- Privacy concerns limit the usefulness of apps for contact tracing, particularly in communities where people experience excessive surveillance, or fear government action against them.

Recommendations (Continued)

- In future take care to co-design app interfaces with different user groups including the most marginalised, and ensure branding does not invoke or play into existing fears about surveillance.

Self-isolation support

- Help should include some or all of the following: provide free hotel accommodation for those unable to self-isolate adequately at home, ensure food deliveries can be made to locations where people are self-isolating, provide financial support to prevent hardship (including in cash to ensure those without bank accounts are included). Some of these may have been available in theory (e.g. food deliveries) but in practice were not available in all locations.
- Consider supporting community/civil society organisations to identify migrant workers in need of help to comply with self-isolation mandates, including by facilitating access to financial support. New arrivals may particularly have limited local support networks.

Vaccination uptake

- Disregard of people's voices and concerns in communication about vaccines risks replicating and reinforcing ongoing experiences of marginalisation and racism in healthcare services.
- Gypsy and Traveller participants noted the contrast between the strong push for vaccination reaching out into communities, and prior and ongoing neglect of health needs in the same communities. Addressing ongoing health needs is important to demonstrate that emergency health measures are genuinely being introduced in the interests of communities.
- Vaccine-related beliefs are linked into other concerns and beliefs about health (for instance the importance of women's fertility which some feared would be affected by the vaccine). These wider priorities should be taken into account when planning health promotion strategies and concerns taken seriously when raised.

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BACKGROUND

Gypsy, Roma and Traveller communities and vulnerable migrants experience severe inequalities in health. All of these groups are named as priority groups under a national *Inclusion Health* agenda (1). The COVID-19 pandemic exacerbated existing health inequalities (2-6).

COVID-19 among Gypsy, Roma and Traveller communities

At least 63,000 people in the UK self-identified as Gypsy and/or Traveller in the 2011 census – likely an underestimate of the true numbers (7). Historically, Gypsy, Roma and Traveller communities (sometimes combined under the initialism GRT) have experienced health inequalities and discrimination in the UK (8-10). Gypsy, Roma and Traveller communities experience poor health outcomes compared with other ethnic minorities, and compared with non-GRT communities experiencing comparable socio-economic deprivation (11, 12). Health outcomes in Gypsy, Roma and Traveller communities are made worse by discrimination, social marginalisation, and poor housing environments (often caused by forced movement or forced settlement) (13). People who self-identify as Roma experience poor health and wellbeing compared with non-Roma populations (14).

Individuals from Gypsy, Roma and Traveller communities can encounter barriers to health care access, including *"health service issues"* (e.g. bureaucratic registration requirements such as having a fixed/permanent address), discriminatory treatment by health professionals and receptionists (e.g. *"…hostile, patronising, judgemental, unsympathetic and even abusive attitudes"*, *"…not being listened to, not being taken seriously or staff not taking the time to explain diagnoses and treatments"*), cultural and language barriers, and low health literacy (9, p. 78). White Gypsy/Irish Travellers are less likely than patients who identify as white British to report a positive experience of primary care services (15).

> *Accommodation insecurity, the conditions of [Gypsy and Traveller communities'] living environments, [lack of] community participation, and discrimination all play key roles in exacerbating poor health outcomes, while at the same time these factors also hold the key to effectively addressing and improving the health and wellbeing of these communities* (16, p. 1).

The effects of COVID-19 on Gypsy, Roma and Traveller communities are not always possible to assess using quantitative data sources because individuals are often included in aggregate 'white' ethnic groupings (17). Research by UK charity Friends, Families and Travellers found that 74 out of 100 primary care surgeries refused to register nomadic patients despite rising COVID-19 infections in early 2021 (18). Some individuals from Gypsy, Roma and Traveller communities reported that digital exclusion (including lack of access to the internet and low digital literacy) as well as lack of functional English language proficiency and/or poor literacy prevented them from accessing COVID-19 information and services (19, 20). A 2018 study found that one in five individuals from Gypsy, Roma and Traveller backgrounds had never used the internet (compared with one in 10 in the general population), and over half said that they did not feel confident using the internet; only one-third reported having a household internet connection, compared with 86% in the general population (21). During the pandemic, there was a concern that it might not be feasible for Gypsy, Roma and Traveller communities to comply with COVID-19 restrictions (e.g. those mandating isolation and limiting non-essential travel) and that individuals from these communities with no fixed address might not be able to register for the shielding programme for clinically vulnerable people (22-24). In the absence of government guidance, civil-society organisations, and community groups began asking government to provide COVID-19 advice specific to Gypsy, Roma and Traveller communities. In addition, the same groups developed and circulated COVID-19 advice within their own communities while lobbying local authorities to stop roadside evictions, provide basic amenities (i.e. water, sanitation facilities, and refuse collection) and support the provision of community-led online tutoring and learning resources to support home schooling (19, 25).

COVID-19 among migrant workers

Migrant workers in high-income countries were at high risk of COVID-19 infection, with their risk of infection exacerbated by: *"…high-risk occupations, overcrowded accommodation, and barriers to health care including inadequate information, language barriers, and reduced entitlement"* (26, p. 1). A 2020 UK study found that Black, Asian and minority ethnic migrants in the UK were more likely to report having experienced job and income loss, and increased financial hardship during the COVID-19 pandemic compared with UK-born white British respondents (27).

A 2020 rapid needs assessment of excluded people in England found that those with no recourse to public funds and/or without access to government support (because of having worked informally) were more likely to have become destitute during COVID-19, and international travel restrictions made it harder for migrant workers to return to their home countries (20). Asylum seekers and undocumented migrants said they avoided seeking care for fear of being charged fees if their symptoms turned out not to be caused by COVID-19 (20), and when undocumented for fear of their NHS data being shared with immigration authorities (20, 28). One study reported that a refused asylum seeker was so distrustful of health professionals, the NHS and the government that he feared he would be experimented on if he sought hospital treatment for COVID-19 (20).

Vulnerable migrants face multiple barriers to healthcare access, including lack of understanding of the healthcare system, administrative, language, and technological barriers (20, 28). Fear of being charged for services came after years of warnings that they were not entitled to free NHS care (20). The policy context for these fears includes the 'Hostile Environment' - a set of policies introduced in 2012 by then-Home Secretary Theresa May, *"…to create, here in Britain, a really hostile environment for illegal immigrants"* (29) - which have produced *"discrimination on nationality and racial grounds where it would otherwise not occur"* and where immigration enforcement has been outsourced to healthcare workers and other members of the community (30, p. 3).

A 2021 report describing the experiences of 14 Filipino migrants in the UK found that respondents were hesitant to get vaccinated, fearing detention or deportation *"I'm afraid to go to the vaccine because they're going to get my details. It could be a trap: if they have our details, they can catch us. I'm not going to do the vaccine"* (31, p. 8). Similar fears motivated respondents to avoid engaging with formal systems supporting NHS Test and Trace:

> *"[Respondent name] was afraid to use the NHS Test and Trace app because of his status and the fear of getting caught and deported by the Home Office. He also felt a greater police presence on the street because of the pandemic. [Respondent name] avoided going to any places where he would be asked to use the tracing app"* (31, p. 9).

A report into experiences of COVID-19 among the Chinese and wider migrant community in Manchester and North-West England emphasised the need for culturally competent health services that support vulnerable migrant communities in building resilience during and after the pandemic (32).

Testing acceptability and uptake

There has been little specific information on uptake of SARS-CoV-2 testing services in Gypsy, Roma and Traveller communities or among migrant workers. Research with other marginalised groups may help indicate possible areas of inequality. For instance, in other marginalised groups, low uptake of COVID-19 testing has been hypothesised to be linked to poor communication of the benefits of testing (weighed against the risks), and a failure to provide clear information about the purpose of testing, and assurances around privacy and confidentiality (33).

A report on the city-wide, voluntary COVID-19 rapid antigen testing pilot in Liverpool in November 2020, showed that the pilot reduced COVID-19 hospitalisations, and the 'test to release' scheme reduced key worker absenteeism (34). However, there was lower test uptake in the most deprived areas (32% compared with the average uptake of 43%), and amongst some ethnic groups (lowest, 27.4%, among those identifying their ethnic group as 'mixed' compared with 47.5% for those self-identified as white). Fear of income loss from self-isolation was a key barrier to testing (34), as was inequitable access to digital technologies.

> *[The] provision of free and voluntary asymptomatic community testing is affected by substantial social and spatial inequalities, typical of the 'inverse care' law but with a distinctive digital exclusion factor consistent with the digitally intensive means of accessing testing…* (34, p. 7).

A scoping review of knowledge, attitudes and behaviour relating to COVID-19 testing concluded that across the 47 included studies from multiple countries there were several thematic consistencies including: 1) challenges around interpretation of symptoms and determining the need for a test; 2) broad recognition amongst study participants that testing primarily benefited others; 3) testing involved multiple logistical barriers; 4) people were concerned about the impact of their decision to test on others; 5) there were peripheral costs to testing as well as any costs of the tests themselves (e.g. transport costs, time off work, and self-isolation); 6) trust was important at every stage of the testing process; 7) social, economic, and political vulnerabilities affect access to and acceptability of testing; and 8) testing programmes have the potential to contribute to improving mental health and wellbeing during a pandemic (35).

Vaccination acceptability and uptake

COVID-19 vaccination uptake among school pupils aged 12-17 in England varied considerably across ethnic groups with Gypsy or Roma and Black Caribbean pupils least likely to have received one dose (both 12.4%) versus the most likely group (Chinese pupils, 75.5%) (36). The report notes that the disparities are partly related to levels of deprivation but persist after adjusting for this; adjusted figures are not provided (36). A 2021 study exploring views about participating in COVID-19 vaccine trials reported barriers and facilitators to vaccination specific to Gypsy, Roma and Traveller communities and to ethnic minorities (some, but not all of whom, were migrant workers) (37). Barriers to vaccine trial participation for individuals from Gypsy, Roma and Traveller communities included: limited interest in vaccines; nomadic, communal and restricted living conditions; and the infeasibility and intractability of social distancing and self-isolation. Facilitators to vaccine trial participation for individuals from Gypsy, Roma and Traveller communities included culturally sensitive health information delivered through trusted health worker outreach and community leaders (37).

For non-COVID vaccines, one 2016 study in Gypsy, Roma and Traveller communities found high acceptance of childhood and adult vaccination (38). Trusting relationships with health professionals (as well as continuity of care) positively influenced vaccine uptake among Travellers. Conversely, language, literacy, discrimination, low school attendance, poverty and housing were identified by Travellers and service providers as barriers. Roma communities experienced additional barriers of language and being in a new country where they may not be familiar with how the health system works and how to access services (38). A pre-COVID-19 2020 study involved consultation with Gypsy, Roma and Traveller communities and service providers to determine the best approach to improve vaccination uptake (39). The study found that the intervention most strongly supported by both Gypsy, Roma and Traveller communities and service providers was *'cultural competence training for health professionals and frontline staff'* (39, p. 6).

METHODS

We employed the participatory DEPTH approach – an interdisciplinary approach rooted in co-production, emphasising community involvement, and collaboration with diverse stakeholders to ensure academic rigour and quality (Figure 1). Using a participatory approach is crucial to co-produce inclusive solutions for emergency preparedness, response and recovery to meet the full range of health needs among diverse communities (40).

We took a holistic approach to understanding the broader context of individuals' lives beyond COVID-19 including trust and relationships with healthcare services more generally and, crucially, issues identified as important by communities that affected how they engaged with public health interventions. The aim of using the holistic approach was to ensure that our findings are transferable to other areas of health policy to support inclusive health responses.

Our team includes a researcher from a Traveller background (RS) and we worked with co-researchers in communities to conduct the fieldwork. We conducted nearly all our interviews and dialogue sessions in person in locations convenient to participants, to address known issues relating to digital exclusion. We also reviewed recent literature on the experience of using participatory methods amongst Gypsy, Roma and Traveller communities and with migrant workers (41, 42).

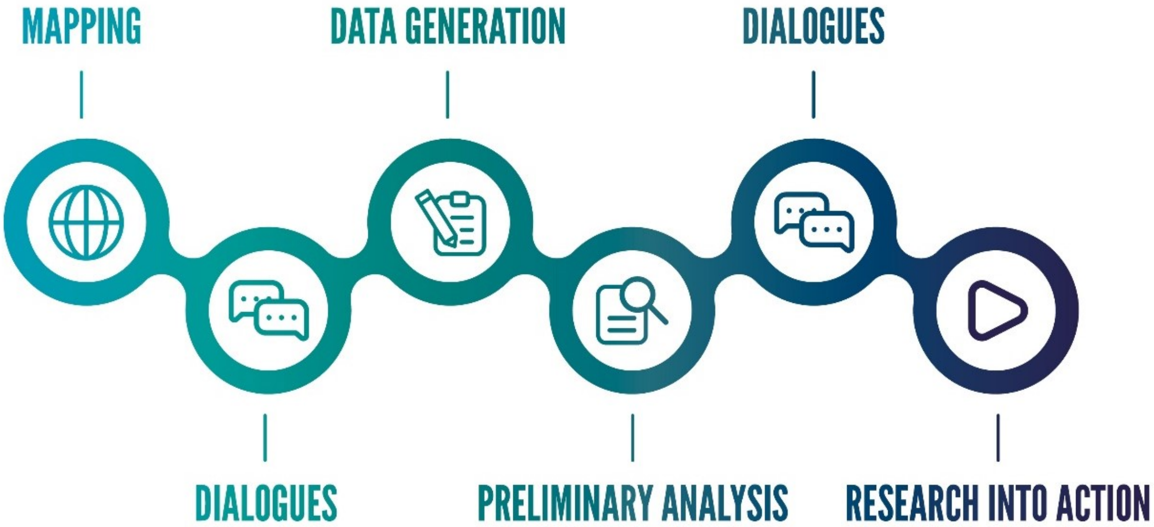

Figure 1 The DEPTH approach

The project involved the following stages corresponding to the DEPTH approach.

Mapping

Mapping involved contacting stakeholders, engaging in preliminary discussions about project focus, clarifying aims and objectives, identifying the extended research team, and reviewing the relevant literature. We also identified suitable study locations and groups with whom to engage, developed relationships with organisations and individuals, and refined our research design accordingly.

Dialogues (first phase)

We then carried out small group dialogues to refine ideas, discuss research questions and invite further participation from key stakeholders.

Data generation

We conducted one-to-one interviews, site observations, and group interviews. Key informants (i.e. individuals who provided insights about the needs and concerns of members of these groups) were interviewed formally or consulted informally. Key informants included members of advocacy organisations and individuals who work with or represent Gypsy, Roma and Traveller communities, and migrant workers. The majority of in-depth interviews with community members, and the dialogue sessions were carried out by individuals from Traveller backgrounds, or with experience working with Roma communities. Interviews were conducted in English or Romanian and transcribed by an external agency. 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.

Preliminary analysis

We identified themes from the interviews and other data sources and documented and discussed our preliminary findings within the academic team.

Dialogues (second phase)

In our second dialogue phase we continued these discussions with the wider community via dialogue workshops with community members and other key stakeholders to inform policy and practice, to co-produce ideas for action, and to analyse the data.

Research into action

Study team members and other stakeholders contributed expertise (e.g. lived experience, academic context, peer support, advocacy, clinical practice).

In all phases, we worked with seven co-researchers from our focus communities who were external to the main research team. They undertook various tasks according to their preference and availability, including: helping refine our approach, recruiting for interviews and dialogue sessions, interviewing and helping facilitate dialogue sessions, and discussing findings. We invited co-researchers to contribute to the interpretation of our findings and where available and interested co-authored academic papers and contributed ideas about wider dissemination strategies.

Sample

Through the mapping phase we identified networks and locations where we would be able to conduct interviews. We were ‘insiders’ in some locations, and where we were ‘outsiders’, it was important that we used trusted networks to enter community spaces. Members of the research team used existing contacts within communities to secure interviews. We aimed for diversity in our sample in terms of age, gender, type of living arrangements, urban/rural location, and participant sub-group (i.e. Gypsy, Roma, Traveller, migrant worker). We worked in five geographical locations across England (South East/East, North East including Yorkshire, South West, West Midlands, and London). We had initially intended to include seasonal migrant workers in agricultural settings in our sample; however, because of project timings and limits on seasonal migrant workers relating to Brexit we decided to limit our enquiry to urban migrant workers.

Mapping

We contacted numerous organisations and others with knowledge or interest in the topic area, and from these contacts arranged 25 mapping conversations with 32 participants.

Interviews

From October 2021 to February 2022 we interviewed 47 people self-identifying as being from Gypsy, Roma and Traveller communities and 27 migrant workers from 11 countries. The migrant workers comprised 13 from Slovakia, five from Romania and one each from Algeria, Bulgaria, Gambia, India, Jamaica, Latvia, Lithuania, Moldova, and Zimbabwe. We asked interviewees to self-identify their ethnicity and many participants self-identified into overlapping categories (Table 1).

Key informants

We consulted 25 key informants: nine via formal interviews and 16 through informal consultations. Key informants included: civil society organisation staff (n=12), Gypsy, Roma and Traveller community members (n=10), migrant worker employers (n=2), and health care staff (n=1).

Table 1 Respondent locations and characteristics

	Gypsy, Roma, Traveller	Migrant worker	TOTAL*
TOTAL	47	27	59
Location			
South East/East	28	16	30
West Midlands	7	6	12
South West	10	0	10
London	0	5	5
North	2	0	2
Gender			
Female	33	11	36
Male	14	16	23
Age			
18-29	17	8	21
30-39	14	10	19
40-49	9	5	11
50+	7	4	8

**15 of the migrant workers also identified as Roma*

Dialogue sessions

Phase 1: We completed eight informal dialogue sessions with small groups 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).

Phase 2: We conducted three formal community dialogue sessions, each with multiple participants from Gypsy, Roma and Traveller communities: one in the South East, and one in the South West in January 2022; followed by one in a coastal location in the South East in February 2022. We also conducted ad hoc one-to-one dialogues to discuss the findings with members of the communities.

Analysis

The analysis followed some of the principles of Charmaz' constructionist grounded theory-building using iterative methods of constant comparison that are particularly useful for studying lived experience (43, 44). We reviewed transcripts to identify codes developed *a priori* relating to the Test and Trace journey, and additional codes which we identified from the data during the analysis process. We applied and refined codes/sub-codes by comparison within and across interviews, grouping these into themes informed by existing literature. As part of the DEPTH approach, we integrated participation to enrich the process, with data analysis informed by a range of academic and other stakeholder views, allowing an interchange between existing theory and literature, 'academic' interpretation, and 'lay' interpretation to generate transferable theorisation and insights (i.e. 'theoretical generalisability'). The analysis ultimately combined different types of expertise, creating synergies of expertise and knowledge(s) (e.g. academic/lived experience) (45, 46). The results presented here will be complemented by academic papers providing additional depth, examples, and analysis.

Ethics

Participants were assured that their participation was confidential and entirely voluntary. Participants in formal interviews and the Phase 2 dialogue sessions provided written informed consent. We provided referral information about support services to participants as needed. Formal interviews were recorded and transcribed. For discussions during community dialogues and other conversations (e.g. during mapping phase), we took fieldnotes (with verbal consent). Community 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 INVOLVE guidelines and agreed in advance (47).

We were short staffed in the final phase of this work because of sickness from COVID-19 and staff departures; our request for cover, however, was not granted. We did not wish to contribute to the marginalising processes already affecting participants by reneging on our promises to them, and some core team members chose to work unpaid to finish project outputs. In our past research on participation we have found that projects with no outputs are negative for participants and/or can amplify existing mistrust; in addition when recruiting participants a key incentive is the prospect of having their contributions included in tangible outputs (48).

The curtailment of the project also meant that we did not have funding to draw out and finalise specific co-produced recommendations for future health security responses for these groups, both for infectious diseases and other health emergencies. Key relevant information is contained in this report and in the associated academic papers but this is not as accessible as we had planned.

The study was approved by the LSHTM Research Ethics Committee (No. 26440).

FINDINGS

NHS Test and Trace and the vaccination programme operated in a wider social context of marginalisation affecting Gypsy, Roma and Traveller populations and migrant workers. This shaped engagement – or lack of engagement – with testing, contact tracing and vaccination.

Experiences of surveillance and policing reduce willingness to share data or engage with government mechanisms

Government public health responses were carried out in a policy environment that also included elements of the Hostile Environment, as well as the Police, Crime, Sentencing and Courts Bill which together target all of the groups in focus for this research. The wider environment also had an impact on COVID-19 responses and health via policing, home environments, and constraints and difficulties of everyday life. For example, some participants lived in council-run Traveller sites surrounded by CCTV cameras pointing at their homes/trailers. Some Gypsy and Traveller participants had experienced police harassment and surveillance by local authorities, including harassment during lockdowns.

Poverty, and tough working and living conditions make it harder for individuals to stay safe

Many of the people we spoke to were navigating difficult working and living conditions which had been exacerbated by the pandemic. It was often difficult to self-isolate because of crowded accommodation. Many Gypsy, Roma and Traveller participants were carers, for example for the elderly, newborn infants, and children with special developmental support needs or health conditions. Gypsy and Traveller participants also discussed difficult living conditions, including infrastructure problems on some Traveller sites. These included barriers to emergency care (ambulances not arriving on time, or being locked out of the site), problems with receiving post (test kits, NHS letters) on sites with no postcode, and council neglect (some had no access to water and electricity, outsiders vandalised sites).

Poor treatment in health services reduce trust

Participants discussed experiences of racism from health service staff, having their concerns about the COVID-19 vaccine dismissed, and past and ongoing experiences of poor care.

We present our findings arranged as follows: 1) creating community responses, 2) reasons for reporting positive home-test results; 3) contact tracing, including use of the NHS COVID-19 app; 4) self-isolation on positive test or contact; 5) and decision to vaccinate.

Creating community responses

Communities found solutions outside 'official' test and trace and formal public health response mechanisms

Individuals wish to protect their families and communities. For this, formal testing and contact tracing systems provided a partial solution at best, often because of gaps caused by the discrimination and marginalisation faced by Gypsy, Roma and Traveller communities. We found that among Gypsy and Traveller communities, community solutions for testing and contact tracing sometimes worked in tandem with the NHS systems but also worked independently. Figure 2 shows components of the 'official' test and trace system and the 'unofficial', community-led parts of the system that existed alongside them. Both official and unofficial routes existed through testing, notifying contacts, and self-isolating.

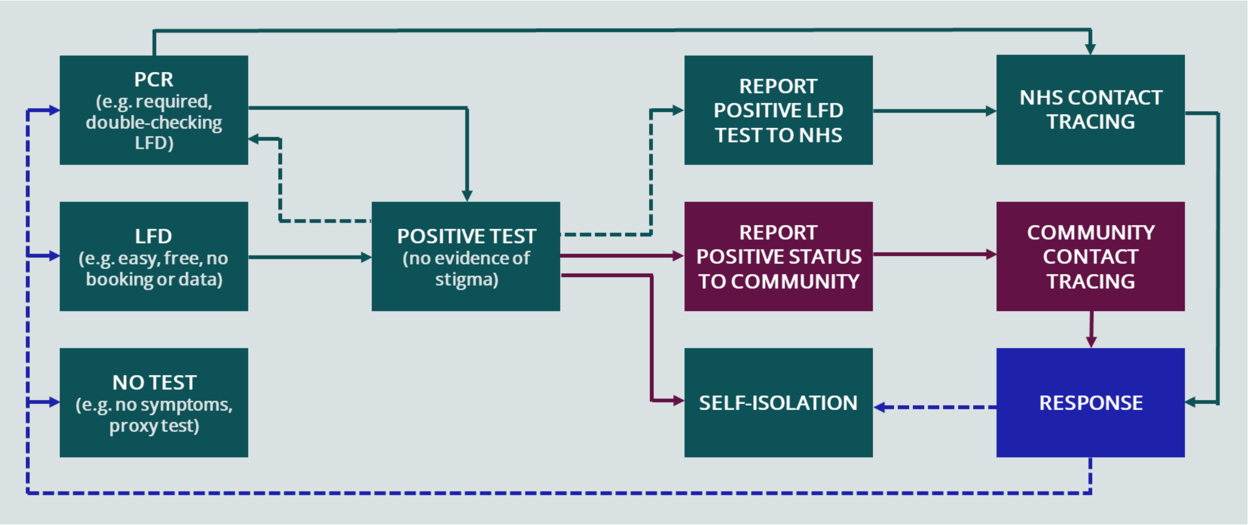

Figure 2 Official and unofficial routes through testing, notifying contacts, and self-isolating (red boxes represent the 'unofficial' parts of the system)

For people who did not wish to engage with the official system, or who were unable to do so, there was therefore the option of using rapid Lateral Flow Device (LFD) home-test kits to determine SARS-CoV-2 infection status – these LFD test kits were widely available free of charge for long periods at the time of the fieldwork. After a positive result, it was then possible to notify contacts and self-isolate, all without providing identifiable data to any government agency. Some individuals with COVID-19 symptoms might not wish to test, but nevertheless still self-isolated to protect others (Figure 3)

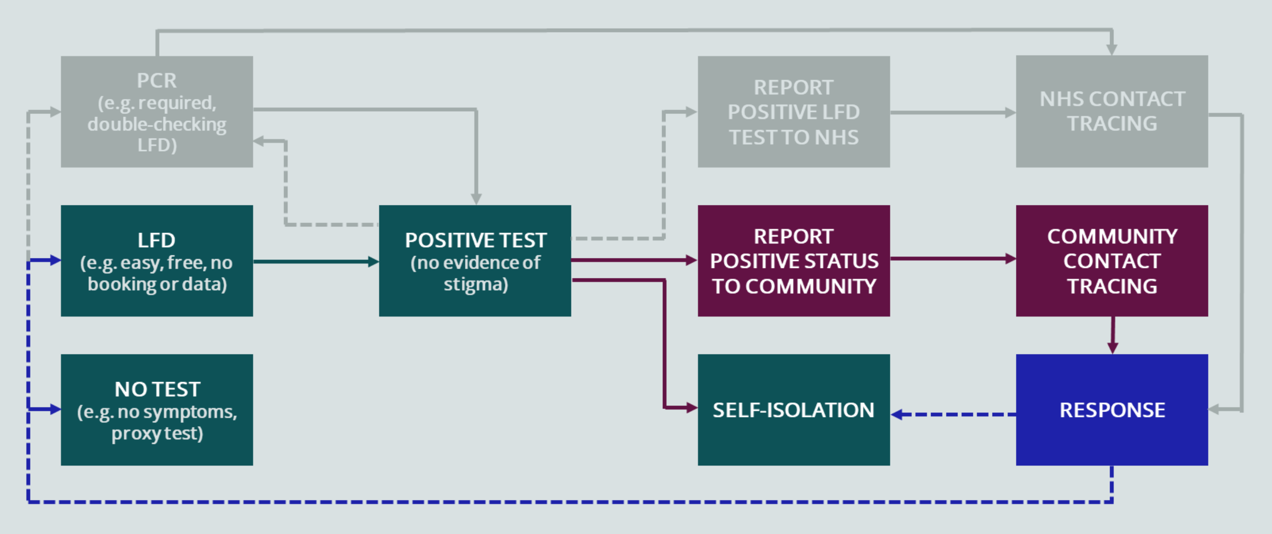

Figure 3 Available routes through testing, contact tracing and self-isolation without providing the government with personal data

COVID-19 tests – reasons for testing and not testing for SARS-CoV-2

The reasons given for either testing or not testing are presented in Table 2.

Individuals made decisions about testing mostly for predictable reasons e.g. having symptoms, compulsory testing for school/work/hospital visits or being a contact of a positive case. Most testing was driven by the desire to keep families safe and avoid spreading COVID-19 to the wider community. Participants tested when they were going to visit vulnerable people, for example.

Testing was facilitated by tests being available free of charge. Gypsy and Traveller communities also organised to help collect and distribute tests, and helped others to make bookings, and access testing centres. Participants told us that it had sometimes been difficult in the earlier stages of the pandemic response to get a test because of lack of availability or of knowledge, but this was no longer the case once we were discussing this during this study – although many mentioned they would find it easier to access tests if they were available from supermarkets.

Table 2 Reasons for testing and for not testing

YES, DID A VIRUS TEST	NO, DID NOT DO A VIRUS TEST

• Symptoms (self or family member)
• Care for immediate contacts
• Avoid spreading (i.e. care for wider set of others)
• Compulsory for school/work/hospital visit/attending certain venues
• Contact with a case
• For travel (private testing)
• Easy to access, particularly when communities organised help:
  • Others collected and distributed LFD test kits
  • Others helped book PCR
  • Others helped access testing centres
  • Tests available free of charge
	• No symptoms
	• Had not been in contact with case
	• Not much social contact
	• (Early in pandemic) Did not know how to test
	• Misperception of risk (e.g. proxy testing, not believing in COVID-19)
	• No time
	• Did not trust government information

Some people with low literacy levels or limited understanding of English found it hard to understand the self-test instructions. A migrant worker told us that he had failed to do a test successfully until he looked online and found a YouTube tutorial. One key informant said that their organisation had produced videos with the instructions for members of Gypsy, Roma and Traveller communities who could not read or who found the instructions confusing. Occasionally migrant workers said or implied that they had avoided testing because they did not want to risk a positive test. For instance one person told us that when he had symptoms in his home country, he self-isolated but did not go to hospital to do a test because he would have been required to quarantine in hospital at his own expense had he tested positive.

Participants' perceptions of test utility and disease transmission affect choices about testing. For instance, one interviewee suggested that she used herself as a proxy for her children, testing herself rather than the children.

> *I won't test my kids because they're kids. […] if it's as contagious as they say it is, I kiss, cuddle my kids multiple times throughout the day, then I should catch it. If they've got it. So, I tested myself [when her child had symptoms] and I was absolutely fine, so…" (woman self-identified as English Gypsy)*

One migrant worker (who could not read or write), told us that he did not "*believe in this virus*".

> *I've never had the COVID disease, I haven't had contact with people, or if I have, well, I'm not sure. I did the tests, even if I don't believe in this virus, I did, to confirm for myself. And they were all negative. And now if I have to get another test, it will show the same result.*

A woman living on a Traveller site who was a key worker during lockdown doing cleaning work was constantly worried about being infected and bringing the virus home to her vulnerable parents. She tested at least once every week, and chose rapid tests as soon as she heard about them even though the test centre was further away:

> *When you've done the [PCR] test and then you're waiting on the day or something, you think to yourself, oh God. Like what if I have got it, what if I haven't got it. So what if I need to do something and then I have got it and then I'm going around spreading it to someone, do you know what I mean?*

> *[...] So it gives you that little bit of a thing where you got the, the results quicker and you haven't got the worry.*

A Roma participant told us he made his symptomatic mother get out of bed to get a PCR test along with himself, his father, and the rest of the family who were all asymptomatic. One migrant worker who worked in a children's home liked the fact that free LFDs were provided by the government. He tested regularly and found the process straightforward.

One woman (self-identified as Traveller) said she did not "*massively over-test*" because she did not have symptoms but tested for "*security*" if she had been in contact with a positive case. She said it was "*never about me, it was always about people around me*". Her children had used LFDs "*a few times*", "*not often*" when they had symptoms. She said nobody had visited the site to tell them how to access testing in test centres. Another woman (self-identified as English Traveller) said she found it hard to use digital resources to book tests and procure LFDs. When she had symptoms she was unable to book a test online so called 111 who did it for her. She referred to using the website as a "*nightmare*" and "*daunting*".

Implications

Free and simple access to rapid home testing was essential to help communities take protective action against COVID.

Improving systems that allow and support community-led responses should be a priority for future policy, particularly for groups reluctant to engage with government systems that require personal data. For emergencies involving outbreaks, this would also ensure rapid contact tracing and action to prevent further spread.

Reasons for reporting positive rapid home test results to government

Reasons for reporting positive rapid home tests to government are given in Table 3.

Migrant workers said they had to test using LFDs for work, with results reported directly to their employers, and some were also asked to report the results online. Parents and carers reported children's LFD test results to their school. Most said they had sought a PCR test after testing positive via LFD. Individuals engaged in the formal system to access payments for self-isolation.

Table 3 Reasons for reporting or not reporting positive rapid home tests results to government

YES, REPORTED TO GOVERNMENT	NO, DID NOT REPORT TO GOVERNMENT
Yes, via school/employer	No access to internet
Yes, online through dedicated government website	Did not know how to report
	No, sick with COVID-19

Only one person mentioned registering the positive LFD result directly. Under most circumstances, people did not report their negative LFD test results.

Implications

Reporting positive LFD home-test results direct to the NHS required individuals to navigate a fairly complex website and fill in numerous personal details. This was challenging for people with low literacy, who had no internet access (common on Gypsy and Traveller sites); who were too sick with COVID-19 to respond; or who did not wish to give personal data to the government.

Consider making it easier for people to report if data are needed for planning (e.g. collect aggregate reports from sites without full details) and consider supporting individuals or organisations trusted by communities to record ‘hidden’ cases.

Consider providing clear benefits for reporting positive tests (e.g. introduce policies to ensure that Travellers cannot be moved on for at least 14 days from the date of the positive test to allow them to recuperate).

Contact tracing mechanisms

The types of contact tracing mechanisms people reported are shown in Table 4. These were either via ‘official’ routes e.g. NHS Test and Trace contact tracers, or community-led routes. The community-led routes appeared to be the main ways people would find out that they had been exposed to someone with COVID-19.

Table 4 Reasons for community-led contact tracing

WHY AVOID OFFICIAL NHS TEST AND TRACE?	COMMUNITY-LED MECHANISMS
• Loss of money/job (self and contacts) • Unwilling to disclose contacts • Precarious legal status (risk of arrest, deportation etc) • NHS COVID-19 app unpopular	• Tell family, friends, contacts in person and via networks • No evidence of stigma, people willing to tell others to protect them • Use creative methods of informing contacts e.g. WhatsApp groups, Facebook, signs on caravan doors

Experiences of surveillance, policing and discrimination in official institutions were common among our participants and affected their willingness to engage with government systems, particularly using the app to share data on movements and contacts. Mapping conversations suggested that people were sometimes unwilling to disclose contacts via the app or to contact tracers, and some would avoid engaging because of their precarious legal status.

Many Gypsy and Traveller participants mentioned community-led contact tracing by individuals or organisations, through personal and social networks. Only one participant mentioned having been involved in NHS contact tracing.

> *I mean, up here [Traveller site] we had to put signs on our gate [...] 'please don't come in' [...] because there was this couple over there that had [COVID-19]. And then everybody was like, maybe we should put a sign on your gate so people don't come in or, like, the postman doesn't come in. Because remember they found out we had it, they were like, 'you should put a sign on your gate'. (Woman self-identified as Gypsy)*

> *I would tell people, be like I've got COVID-19, I'm not worried about it, but you do what you want to do but I'm going to stay in for a week, you go and get yourself tested, that's it. (Man self-identified as Gypsy)*

Implications

Community contact notification can be rapid and supported by individuals and civil society organisations. These mechanisms should be acknowledged and supported.

Care needs to be taken not to create or exacerbate stigma of infection as this would likely shut down these valuable and rapid channels of communication.

Use of the NHS COVID-19 app for contact tracing

The reasons people did or did not use the NHS COVID-19 app are shown in Table 5.

Engagement with the NHS COVID-19 app was poor. Some participants had downloaded it, but then deleted it. Participants said they did not want their whereabouts to be tracked, they felt they were being spied on. As well as unwanted surveillance, many felt the app was inconsistent and unreliable, and some found the alert ‘pings’ unmanageable or did not see them as an indication of genuine risk.

Table 5 Use of the NHS COVID-19 app for contact tracing

YES, USED APP	NO, DID NOT USE APP OR DID NOT ACT ON NOTIFICATIONS

• Some downloaded it at first and tried to use it but most discontinued use	• Surveillance: worries about being spied on, location tracked
	• Technology:
	  • problems with the app
	  • inconsistent and unreliable pings
	  • unmanageably frequent
	• App alerts not considered to indicate genuine risk

It was common to refer erroneously to the system and the NHS COVID-19 app as ‘Track and Trace’ (which is the name of the Post Office system for tracing items) instead of ‘NHS Test and Trace’. The misnomer ‘Track and Trace’ likely plays into surveillance fears and suggests that the branding could be improved.

> *I did [have the NHS COVID-19 app], but then I deleted it. [...] Because I didn't want the government seeing where I'm going. [...] Especially venues and all that. [...] So I just deleted the app. Because they track your position all the time. [...] And no, no way am I letting the government knowing where I am, what I'm doing [...] How I'm spending my money. (Roma interviewee)*
>
> *I download the app, but like I can't help it because they keep beeping everywhere I go like [...] If you're near people that have been pinged, that they should isolate, your phone is going to ping again. [...] And then if, if you were near me because of I got pinged because I was near somebody, you're going to for, get a warning as well [...] So it was full of scams, I don't believe none of it. [...] I didn't respond to it, and I end up deleting it because I just don't believe it. (Migrant worker)*

Implications

Privacy concerns limit the usefulness of apps for contact tracing, particularly in communities where people experience government surveillance, or fear government action against them.

In future take care to make interfaces and branding more user-orientated and ensure that the name does not invoke or play into existing fears about surveillance.

Self-isolation on positive test or contact

The reasons and means for self-isolation, or reasons for not self-isolating, that participants reported are shown in Table 6.

When they tested positive for SARS-CoV-2, participants took self-isolation very seriously. All participants who had been infected said they had tried to self-isolate and they often described making huge efforts to avoid infecting others. For some, self-isolation was difficult to achieve because of crowded living conditions, lack of financial support, or lack of childcare. Some said they had heard of others who did not self-isolate when positive because they could not afford to stop working.

Table 6 Self-isolation on positive test or contact with a case

YES, SELF-ISOLATED	NO, DID NOT SELF-ISOLATE
• Huge efforts to avoid infecting others if testing positive • Masking at home • Trying to stay strictly separate from others for as long as possible • Repeated LFD testing at end/after self-isolation period	• Did not isolate when contact of a case • Assumption app is wrong • Cannot afford to stop work • Test negative so keep working

When they were the contact of a case, on the other hand, some participants had not self-isolated. They said this was because they had tested negative, had no symptoms, needed to work to earn money, and/or they thought they were not at genuine risk. Losing money or having to use annual leave to self-isolate was a barrier to self-isolation for contacts of cases.

Gypsy and Traveller participants described having support from their communities e.g. helping obtain food during self-isolation and lockdowns, helping others who could not read and write or who did not have access to the internet. They helped each other to book tests, collected and distributed LFDs, and helped explain COVID-19 information. Migrant workers on the other hand did not report these types of support networks.

One woman, who self-identified as Gypsy, told us how she had symptoms so booked a PCR test (which was positive) via drive through to avoid infecting others. She wore a mask at home, even in bed, to protect her partner and children. The family used LFD tests after the isolation period to double check they were clear of infection and also waited a further four days before visiting vulnerable relatives.

One woman, self-identified as Romany Gypsy, said four of her children had had to self-isolate in one room: "*I had four at one time, all tested positive for Covid, so they were all shut in that room there. […] And literally, the room's no bigger than you could swing a cat in*".

A migrant worker said his colleagues were "*feeling sick*" with COVID-19 for three days from Friday to Sunday but returned to work on Monday morning because "*they were feeling all right*" and did not want to lose money.

Implications

Some may need additional help to be able to self-isolate adequately.

Help should include some or all the following: provide free hotel accommodation for those unable to self-isolate adequately at home, ensure food deliveries can be made to locations where people are self-isolating, provide financial support to prevent hardship (including in cash to ensure those without bank accounts are included and including for those with no recourse to public funds)

Groups in dialogue sessions said they needed guidance on making shared facilities COVID-19-safe on Traveller sites.

Decision to vaccinate

Reasons given for vaccination, not yet having decided to vaccinate, or deciding not to vaccinate are shown in Table 7.

Vaccine uptake happened in the context of a general feeling among our participants that the vaccine was being forced on people, and that the vaccine and COVID-19 legislation were being introduced largely as forms of government control. Some unvaccinated participants felt coerced and were frustrated over the pressure they experienced (e.g. work requirement, healthcare workers trying to persuade them to get vaccinated). Some participants reiterated ideas that were also common in the general population, including that the government used inflated COVID-19 death statistics and exaggerated its severity to scare people and convince them to be vaccinated.

Vaccinated participants also talked about feeling coerced but said they had gone ahead with the vaccine anyway – to protect others around them or, particularly in the case of Roma participants, because it was required for international travel. Many participants had been vaccinated and told us about persuading others (e.g. family members) to get vaccinated as well.

Table 7 Decision to vaccinate

YES, DECIDED TO VACCINATE	NO, NOT YET DECIDED TO VACCINATE/ DECIDED NOT TO VACCINATE
• Work requirement • Travel (mostly to visit family in home country, especially commonly reported among Roma participants) • Underlying health conditions • Caring for others Children, vulnerable family members	• I don’t want to be forced into it • I am strong enough without it • COVID-19 not severe/just ‘relabelled’ flu • The vaccine will not prevent infection • Worries it will affect fertility • Other worries (side effects, speed of vaccine development) • Vaccine as a form of government control • What is in the vaccine? • No information or no definitive information • Information not in accessible format (written, wrong language) • Nurse/doctor did not answer questions

The push for vaccination by health services contrasted with the healthcare neglect Gypsy and Traveller communities described experiencing in other circumstances. Healthcare neglect included little follow-up and rehabilitation after operations; difficulties accessing GPs (e.g. receptionists obstructing access to GP appointments, racism); poor quality care at hospital (neglected during hospital stay, reports of being in pain dismissed); and problems with access for ambulances to sites both because of council-installed barriers, and a perception that ambulances “*didn’t really want to come in*” *(woman self-identified as Traveller)*.

Participants repeated worries common in the general population as reasons they had not been vaccinated: the feeling that the vaccines were developed too quickly, and worries about side effects and vaccine contents. They also mentioned that the vaccine does not prevent infection. Some also expressed a sense that being fit and strong would be sufficient to fight COVID-19. Some participants mentioned worries about the vaccine affecting women’s fertility.

Unvaccinated participants wanted better information to help them make their decision; specific information addressing their particular concerns with regards to side effects and fertility for instance. Some participants were frustrated because they had consulted nurses or doctors but had not received a satisfactory response to their concerns, for instance describing being patronised. Some participants mentioned that some migrant workers did not have enough information in their dominant language.

Key motivations cited for having been vaccinated were having an underlying health condition, being a carer for others and wanting to protect them, and desire to travel abroad to see family members or to go on holiday. Some had been vaccinated after seeing others with COVID-19. Some participants, particularly mothers, said they tried to persuade other family members (young adults, adolescent children, elderly parents) to get vaccinated and that they sought information for them, in order to respond to their concerns.

A woman self-identified as Traveller said she had not had the vaccine because there was not enough research into it and she saw herself as "*strong*" enough to fight COVID-19. Similarly, her sons were not vaccinated because "*they're young fit and healthy*". She had, however, encouraged her husband and mother (both with underlying conditions) to be vaccinated because she was concerned they would be at risk if they were infected.

One woman acted as representative of Gypsy and Traveller communities at a health forum. She had concerns about the vaccine and pregnancy that were shared in her community. She asked about this in the forum:

> *They got a doctor to come in and answer people's questions [about vaccination] […] She [the doctor] was basically saying that I can't answer those right now, I'm busy, um, and then she sent an email because […] 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, um, well not rude, but to the point. 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. I've asked this question for them, and you've spoken to me like that, I can take that […] But yeah, I went with all these pressing questions about obviously fertility. 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.*

One woman self-identified as English Traveller told us she asked a nurse whether the vaccine caused infertility. She wanted to persuade her children to get the booster. Her children had had two vaccine doses because they were carers for their vulnerable father, but they did not want the booster because of rumours that the vaccine could sterilise you. She felt she could not convince them without information but did not receive this from the nurse.

Implications

Disregard of people's voices and concerns in vaccine communication risks replicating and reinforcing ongoing experiences of marginalisation and racism in healthcare services. Others may also have experienced dismissive reactions when they repeated vaccine rumours.

It is important to recognise that marginalised communities have historically experienced medical abuse, including Roma genocide under National Socialism and that their vaccine concerns are also manifest in the context of their experiences of ongoing discrimination.

Participants contrasted the strong push for vaccination reaching out into communities, and prior and ongoing neglect of general public health needs in these communities. Addressing ongoing health needs is essential in order to demonstrate that COVID-19 or other future emergency health measures are genuinely being introduced in the interests of communities. The healthcare system must be trustworthy.

Vaccine-related beliefs are linked into other concerns and beliefs about health (for instance importance of fertility for women, and concepts of physical strength as protective). These wider priorities should be taken into account when planning health promotion strategies and concerns taken seriously when raised.

Implications (Continued)

Roma participants were particularly likely to report that they had had the vaccine in order to travel. This appears to contradict reports that as a group they have a low uptake of vaccination. It is possible that they are not always recorded correctly as Roma, particularly if they avoid identifying themselves as such to avoid discrimination. It is also possible that the restrictions on travel meant they were willing to undergo vaccination in this case in order to be able visit family overseas.

LIMITATIONS

While we attempted to engage the most diverse range of participants possible, this rapid qualitative study does not claim to provide a comprehensive overview of all Gypsy, Roma and Traveller community needs and experiences relating to COVID-19. Participants were very generous with their time, and in sharing their experiences, and so although the compressed timeframe for the work and concurrent Omicron-variant wave of the COVID-19 pandemic meant we recruited fewer participants than planned in the north of England, it seems plausible that experiences outside our study sites would be similar to those described here.

Conclusions about the needs of migrants in precarious jobs and vulnerable migrants are necessarily limited as this group is smaller within our sample (as a feature of the commissioned work). Migrant workers are extremely diverse in country of origin, time since arrival, and other work and lived experience that mean that our findings, while indicating important needs and experiences, would need to be corroborated with substantially larger studies with diverse communities of migrant workers to explore in much more detail the important details, diversity and nuance of their lives during the COVID-19 pandemic.

CONCLUSIONS

Policies including the ‘hostile environment’ and the Police, Crime, Sentencing and Courts Bill likely exacerbated mistrust and fear created by historical and ongoing exclusion including police harassment and discrimination for Gypsy, Roma and Traveller communities and for migrant workers. In this climate, formal support can be inaccessible because individuals fear repercussions from providing data (arrest, deportation), because of digital exclusion, because of low literacy, and because of ongoing exclusion from health services in general which was exacerbated in the pandemic. Self-led solutions evolved in Gypsy and Traveller communities to meet community needs, including community-facilitated testing and contact tracing.

Gypsy and Traveller respondents particularly reported receiving and giving community support for testing, and helping with self-isolation. Roma respondents and other migrant workers did not report community-led responses. This may simply be because they did not raise it at interview, or it may indicate comparative lack of connectedness with other community members.

The free home test kits improved equity by helping everyone to access testing and notify their own contacts. The availability of these kits meant that testing and contact tracing could be carried out separately from formal test and trace mechanisms, empowering communities to protect themselves. Testing was used widely to keep families safe and avoid spreading the virus. Positive COVID-19 test results were universally reported into personal networks, to notify contacts and help stop the spread.

Those of our participants who had had COVID-19 said they took self-isolation very seriously. However it was sometimes challenging because of constrained living conditions and although nobody told us of failing to self-isolate when they were infected themselves, many faced barriers to self-isolating when they were the contact of a case, possibly because the cost-benefit calculus changed when there was only a possibility of being infected but still losing income, for instance.

Vaccine uptake was discussed in relation to historic and ongoing discrimination – for instance participants questioned why there was a sudden interest in Gypsy, Roma and Traveller health when general health in the communities had been neglected for so long. Some perceived they were personally at low risk of becoming severely ill with COVID-19, and some worried about side effects. Our findings that Roma participants had often been vaccinated because they wished to travel overseas appear to be at odds with statistics suggesting low vaccine uptake in this group (e.g. ONS reports of low vaccine uptake among Roma children (36)). One possibility is that not all Roma are recorded as such in official statistics because they may avoid identifying themselves as Roma in the context of ongoing discrimination.

RECOMMENDATIONS

Based on our findings and the implications set out in each section, we make the following recommendations. A fundamental point that underlies all of them is that community-led solutions must be at the centre of public health responses.

Supporting community responses

Mutual aid strategies developed by and for communities should receive support, guidance, and resources from public health experts and government.

For effective community solutions to develop in tandem with health services, there must be better awareness and acknowledgement of the racism and discrimination experienced by the communities participating in this research. Without a willingness to address systemic racism and the wider hostile policy environment, effectiveness of any actions will be limited.

Official communications about protection and prevention should be made more accessible. It often fell to overstretched third-sector organisations to 'translate' public health information for their communities. Better accessibility includes using formats suitable for low literacy such as audio or other non-text formats.

Institutional structures should be created to support co-production of health solutions with and by communities to ensure inclusive preparedness and response to future emergencies. For example, individuals and organisations trusted by communities should be identified who can help guide these efforts, build networks, and design strategies locally both in preparation for and during emergencies.

For future outbreaks, community-specific guidance on infection prevention is a priority, as is specific outreach to provide testing and information tailored to the needs of marginalised communities. For instance, for Travellers living on sites, this might involve guidance on how to make shared facilities safer, demonstrations of how to use test kits where internet is unavailable and providing video/audio information as well as written instructions to ensure low literacy is not a barrier to understanding.

The importance of community action suggests that recent migrants may be particularly at risk if they have limited community support and/or no recourse to public funds and/or fear or experience poor treatment because of the hostile environment, bureaucratic hurdles, racism, or other forms of discrimination. Further work is needed to assess the best ways to ensure their needs are met.

Helping communities self-organise public health responses

Free, easy access to rapid home testing enabled Gypsy and Traveller communities to implement their own, tailored protective actions against COVID-19. Self-testing and other ways to help communities self-organise responses should be prioritised for all communities. This is likely to be particularly important if urgency requires a large-scale response that can be delivered more rapidly by communities, or if communities do not wish to engage with untrusted formal systems.

Tailored strategies to meet different needs in different communities can be developed using a community co-production approach. The strategy development process should be transparent to maintain trust, with a mechanism to ensure that co-developed ideas are shared widely to inform strategies elsewhere.

Consider making it easier for people to report test results if data are needed for planning. For example, this could include collecting aggregate reports from sites without full names and details. Consider supporting individuals or organisations trusted by communities to record ‘hidden’ cases e.g. by paying for some staff time for this purpose. Low literacy, digital exclusion, and complicated instructions made it challenging for individuals to report test results even if they wished to do so.

There were no clear benefits to reporting test results to the official system when community-led reporting systems were used. Consider providing clear benefits for reporting positive tests (e.g. introduce policies to ensure that Travellers cannot be moved on for at least 14 days from the date of the positive test to allow them to recuperate).

Improving reporting and contact tracing

Community contact notification can be rapid and reinforced by individuals and civil society organisations such as charities set up to work for the interests of particular groups. These mechanisms should be acknowledged and supported.

Care needs to be taken not to create or exacerbate stigma of infection as this would likely shut down these valuable and rapid channels of communication.

Privacy concerns limit the usefulness of apps for contact tracing, particularly in communities where people experience excessive surveillance, or fear government action against them.

In future take care to co-design app interfaces with different user groups including the most marginalised, and ensure branding does not invoke or play into existing fears about surveillance.

Self-isolation support

Help should include some or all of the following: provide free hotel accommodation for those unable to self-isolate adequately at home, ensure food deliveries can be made to locations where people are self-isolating, provide financial support to prevent hardship (including in cash to ensure those without bank accounts are included). Some of these may have been available in theory (e.g. food deliveries) but in practice were not available in all locations.

Consider supporting community/civil society organisations to identify migrant workers in need of help to comply with self-isolation mandates, including by facilitating access to financial support. New arrivals in particular may have limited local support networks.

Vaccination uptake

Disregard of people’s voices and concerns in communication about vaccines risks replicating and reinforcing ongoing experiences of marginalisation and racism in healthcare services.

Gypsy and Traveller participants noted the contrast between the strong push for vaccination reaching out into communities, and prior and ongoing neglect of health needs in the same communities. Addressing ongoing health needs is important to demonstrate that emergency health measures are genuinely being introduced in the interests of communities.

Vaccine-related beliefs are linked into other concerns and beliefs about health (for instance the importance of women’s fertility which some feared would be affected by the vaccine). These wider priorities should be taken into account when planning health promotion strategies and concerns taken seriously when raised.

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APPENDIX: SUGGESTIONS FROM DIALOGUE SESSIONS

These are the summarised suggestions emerging from the Phase 2 dialogue sessions with Gypsy, Roma and Traveller participants; they came directly from the communities and are only lightly edited. Some of the suggested interventions may have already existed at the time of the dialogues, and awareness may have been low, or the interventions may have been implemented subsequently.

COVID-19 testing

Accessing LFDs tests

- Keep LFDs free (to avoid penalising and excluding poorer people from being able to protect themselves and from engaging in society and events)
- Provide LFDs in places people go to anyway (e.g. supermarkets, community organisations, churches, petrol stations, youth groups, high streets)
- Option for ordering and collecting more LFDs on behalf of other families:
    - This is already possible by using multiple e-mail addresses and checking out as a guest
    - Keep the guest account option

Accessing PCR tests

- Have walk-in PCR testing centres that do not require online pre-booking
- Have PCR testing facilities in supermarket car parks
- Have a phone line to book a PCR test
- Provide help with booking tests (this is already happening, but organisations are not resourced to do this)
- Telephone free line to get information about how to get a test (good for people on the move, or who cannot read)
- Allow PCR tests without giving personal data
- Reduce waiting time to get PCR results so that people can return to work if negative

Information

- Because information is coming through social media:
    - There is a need for more information from trusted organisations and note that older generation learns from younger (and some may find the information boring)
- Provide information on tests in other formats (i.e. not written)

Other

- Allow partners (with negative COVID-19 test) into hospitals for all pregnancy related appointments
- Be transparent on the financing of testing contracts
- Provide tests that don't involve nasal swabs
- Provide payment incentives for people who are unwilling to get tested and for pensioners (NB: our interviews do not suggest that reluctance to test is a major problem in this setting)

Reporting and contact tracing

Community-led protective mechanisms

- Accept internal community contact tracing and protection mechanisms:
    - Acknowledge many people are not on official records
    - Give ways to contact trace that do not require personal data
    - Acknowledge communities use Facebook groups etc to protect own community
- Allow people to self-organise via civil society organisations
    - Can let people know about being a contact without giving away personal data to outsiders (e.g. measles outbreak contact tracing and notifications go through an organisation)
    - Helps address concern information will be used against you after the pandemic
    - Can find people not on official records (e.g. people staying with others locally)
- Redirect resources to community organisations (e.g. can hold workshops)

Formal public health response mechanisms

- Acknowledge structural racism to build better trust with health services (e.g. harmful consequences of immigration and police enforcement against minoritized communities)
- Show long term interest in community ill health, not just COVID-19
- Acknowledge that government have lost people's trust. They should lead by example
- Be transparent about COVID-19 deaths/how death certificates work
- Call to offer help, not to control people. Avoid or shorten contact tracing calls to check if people are self-isolating and focus on providing support/information
- Option of non-permanent address/telephone number only on passenger locator forms:
    - People come looking for people at 'care of' address but they are not there
- Recognise that people cannot talk when ill
- Make sure the NHS COVID-19 app works for people who cannot read and write (NB not many people are using the app any more)
- Option to register test without a QR code/smartphone:
    - Have a phone line for reporting results, not just online via the QR code so people can read out the serial number
    - Phone line that gives an option to choose the preferred language to speak with the operator, option to send to an email address
- Design an app to upload test results: "*They spent all the money on test and trace. Why not spend it on an app for uploading test results?*"
- Work places:
    - A designated member of staff for testing to whom you report results and this person reports to the government website on your behalf.

Self-isolation

Support and resources

- Don't move roadside Travellers on for 14 days if they test positive. There is currently no provision for people testing positive in this situation
- Halt eviction processes for COVID-19-positive cases
- Make sure people have everything they need for self-isolation:

  - Give food packages, free electricity and medicines to people who are self-isolating
  - Make sure people can get food delivered (especially roadside Travellers)
  - Council should ensure availability of food delivery on sites and roadside camps
  - Acknowledge underlying racism that means deliveries will not come to sites and roadside camps
  - Structural racism means that sites are often quite far away
    - Allow people to buy electricity over the phone rather than in the shop
    - Ensure people can meet their needs during self-isolation when they live on cash (e.g. cash payments for food deliveries)
- Explain people's entitlements (e.g. someone should contact the person or visit to explain)
- Give money readily to people self-isolating and ensure there are cash options (e.g. some people can't get compensation via bank account)
- Provide proper financial compensation (sick pay) for everyone who is self-isolating (independent of vaccine status):
  - Don't give fines to people who are self-isolating for not sending children to school
  - They may not be able to take children to and from school
- This would avoid spreading COVID-19
- Better internet provision for home-schooling
- Council should take more responsibility to help people who are self-isolating:
  - Adult social services for the elderly
  - Be aware that some residents do not access help from council liaison because of experiences of poor treatment by that person

Self-isolation spaces

- Provide guidance on how to set up a camp that makes self-isolation possible
- Better management of communal areas when people are isolating to prevent too much mixing when people are isolating:
  - People are currently self-organising this
  - System for refuse collection

- Free and optional access to hotels for people who test positive:
    - Need to be able to find out about this via phoneline
    - Not possible to self-isolate in a caravan

Vaccination

Information about vaccines

- More education and information in simple language:
    - What it does, how it protects you
- People want unbiased and honest information on:
    - Contents of the vaccine
    - Transparency about benefits and drawbacks
    - Complete transparency about side effects of the vaccine (e.g. headaches, deaths, blood clots, long term effects)
    - Fertility (people should be informed if there even is a small risk of infertility)
    - Provide the evidence that it does not affect fertility, acknowledge evidence gaps (e.g. any links to miscarriages after vaccination) and don't dismiss questions regarding fertility
    - Comparison of risks of infertility to other risks (e.g. smoking)
    - Information about whether one can still breastfeed
    - Concerns about the booster; how the vaccine protects for a short period of time

Sources of information

- Information via trusted sources e.g. leaflet not Facebook, through trusted member of community rather than NHS, workshops
- Train organisations to give accurate information to counter antivax messages (e.g. catholic priest, prison staff)
- Hearing directly from people who had the vaccine and then had children afterwards

Choice

- Do not penalise and stigmatise those who do not want to be vaccinated/are not vaccinated and do not present vaccination as a personal choice if it isn't: "*The system should be less coercive; it's inhumane…you should be told you have the option* *and then people will do it*", "*Who suffers if they tell health care workers that they have to have vaccine*".

- Don't push the vaccine on people (e.g. some Traveller organisations tweeting that everyone should get the vaccine is off-putting)
- Stop discriminating against non-vaccinated people at events and health services, same rules should apply for everyone (either everyone should be made to test, or nobody)
- Communication about the vaccine needs to avoid trying to persuade people to get vaccinated. It needs to be neutral information, not trying to push it on you and it needs to come from a neutral party:
  - "*Don't have a finger in the NHS pie*"
- Allow people to choose which vaccine they want:
  - Tell us what type of vaccines are available on any given day
  - Explain differences between vaccines
- Be transparent about how COVID-19 deaths are counted and do not use COVID-19 deaths to push the vaccine on people: "*When COVID-19 first came around I was working in a care home. People were dying of old age and they were saying it's COVID-19 just to push the vaccine*"

Mixed messages and hypocrisy

- Why do you suddenly care about me when you didn't before?
- Why do you only care about us when it works out to your benefit (e.g. ambulances not coming onto sites for urgent care while mobile vaccination units do arrive at sites)?

Mobile vaccination clinic

- Give advance warning of vaccinations on site – not just a couple of hours' notice
- Have an option to request nurse or doctor to explain vaccine information on site
  - Counterpoint: Consider other options as not everyone might want to speak to a nurse or doctor
  - Counterpoint: Healthcare workers should only come to explain about vaccines if they are explicitly invited.