

Public Perceptions Towards Vaccine Trial Research within Ethnic Minority and Vulnerable Communities

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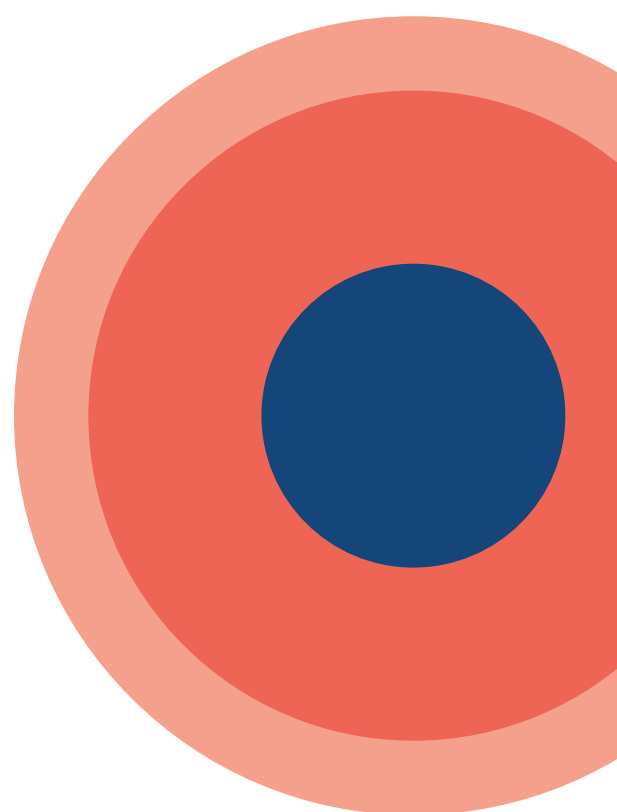
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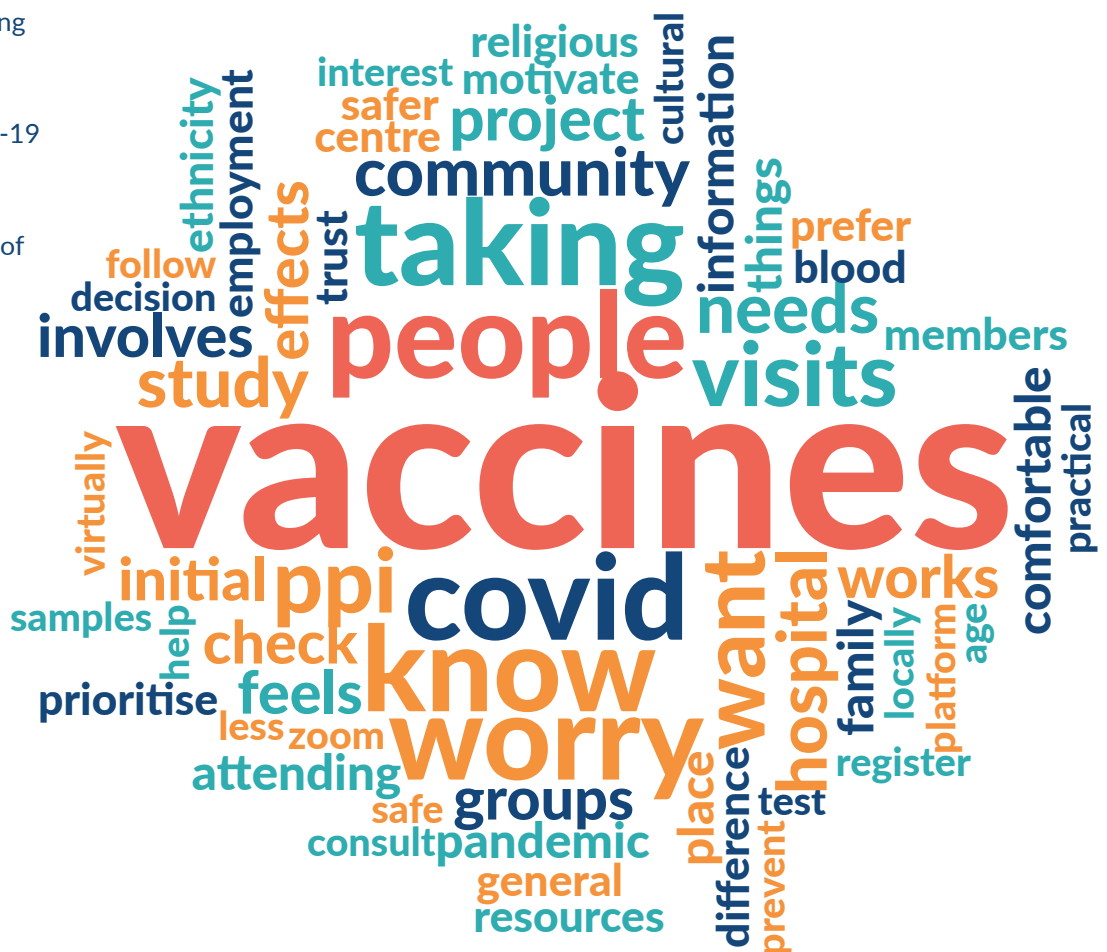
The NIHR Clinical Research Network has established a COVID-19 Vaccine Research Delivery Group. The role of this group is to coordinate resources and intelligence to deliver these new COVID-19 vaccine studies across the UK. This work involves establishing regional facilities which will recruit participants at scale and pace and to this end the Clinical Research Network East Midlands (CRNEM) established The East Midlands Vaccine Research Delivery Group. The CRNEM are leading and managing the regional effort and commissioned The University of Leicester, Centre for BME Health to undertake this community consultation to support our understanding and thus delivery of the COVID-19 vaccine studies.

Public perceptions towards vaccine trial research within ethnic minority and vulnerable communities

- 3 focus groups and 47 interviews were held, via virtual platforms and telephone calls, with different groups between July and August 2020 by 6 interviewers.
- 70 people contributed to the study. 55 people (26 males, 29 females) represented different ethnicities, and 15 represented other vulnerable groups, namely mental health, homeless and Gypsy, Roma and Traveller communities.
- South Asian (30), African and African Caribbean (17), White Polish (4) and White British (3) backgrounds participated.
- A webinar on “Vaccine Trials and Mental Ill Health” was conducted with 11 participants.
- Interviews were conducted with representatives of Homeless community organisations and the Gypsy, Roma and Traveller community organisations.

Topics Covered In The Discussions:

1. Feelings towards attending hospital for research
2. Feelings towards COVID-19 vaccine research
3. Feelings around the role of PPI and community involvement



Attending hospital for research:

1. People agreed research was important, but the majority were extremely uncomfortable with the idea of attending hospitals for research, and a few people were unsure how they felt.
2. The main factors identified to encourage attendance were; the assurance of appropriate safety measures in place and clear, detailed information about the research procedure, both of which should be presented to participants in advance. Desired information, preferably in different languages, including details of the screening process, management team, and study duration. Specific platforms for addressing barriers to participation, presence of bilingual staff and reduced COVID-19 infection rates in study areas – hospitals and local cities – were also considered essential.
3. People were happy to participate in research virtually, mainly for safety and convenience; however, certain groups may not be able to access this option due to lack of internet facilities.
4. A selected few stated they would decline to participate in research that required physical or blood tests, as they were riskier. Some others were happy to provide body samples if proper safety precautions were taken.
5. Some people mentioned the pandemic had affected how they thought about research. Yet, although most of them highlighted the need to prioritise COVID-19 research, there was also an equal emphasis on the need not to neglect research in other health conditions, especially cancer, diabetes and mental health.

Feelings around COVID-19 vaccine research:

When asked for thoughts specific to COVID-19 vaccination research importance, potential participation, concerns and support needs, all groups felt the following:

1. The majority of people reported feeling anxious and scared of getting involved or were simply not interested in participating in vaccine trials. The specific information requested before participation included the; associated risks, side effects, research procedure, patient safety, the responsible organisation, and details of the vaccines development history including the previous progress, success rates and outcomes.
2. Concerns were raised on the possibility of contracting COVID-19 directly from the vaccine or while interacting with infected people, and the availability of support for participants if things went wrong.
3. A few people were also suspicious of possible hidden agendas behind the vaccines, the ever-changing government legislation, and how organisations intended to use Black, Asian and Minority Ethnic (BAME) communities as “guinea pigs” for the trial.
4. Consequently, people requested transparency at all stages, including details of the vaccine ingredients, evidence of any adequate non-human trial previously conducted, research document development, cultural appropriateness, and regular proactive updates. Also highlighted, was the need for co-production of the trial design with individually targeted groups.
5. To further minimise the discomfort of participation, demands were made for the trial to be tailored to people’s different circumstances and vulnerabilities. This included the provision of; financial incentives, accessible locations,

transportation, car parking, language support, group support, childcare, remote participation options (e.g. phone, postal and online), conducting the research in a safe, neutral setting – local GP and community settings – with a qualified third-party staff, and equal participation from all ethnicities and health group categories (e.g. mental health). A few people wanted non-BAME ethnicities to first start on the trials, and BAME communities join in later, as an assurance of equal participation.

6. To participate in any COVID-19 vaccine trial, people indicated that they needed to consult with family, friends, and religious leaders. This was not necessarily intended to convince them, but rather to inform their households and loved ones who might be affected by the outcomes and also possibly encourage them to participate as well. This thought pattern supported the most reported motivations for wanting to participate in the trial, namely making personal contributions to the identification of a solution for overcoming the pandemic, supporting all of humanity and getting life back to normal.
7. Individuals who had children and elderly family members, those currently taking medications, with personal underlying health conditions or living with someone with any such condition, including periods of mental health 'mania', were sceptical about participating due to assumed higher risk. These risks were mainly associated with the scarcity of available information addressing their situations before enrolment. For instance, there were no mental health questions in the NHS national vaccine registry process.
8. Generally, there were no specific cultural or religious constraints that would hinder participation, and also no age, gender or employment disparity in the responses. Nevertheless, people identified the need for gender-specific appointments, and that research schedules should avoid being on cultural and religious days of importance, including fasting periods.

Overall, there was consensus across all the groups on the need for PPI and community views and opinions since the vaccine would directly affect them. There were, however, some issues more strongly expressed within certain groups. Addressing these matters would ensure research trials were based on community and culturally sensitive best practices, which would encourage participation, community education and allow for recognition of individual contributions.

BARRIER	FACILITATOR
Details of the procedure	Written information or video of participant experience
Assurance of safety measures	Information video of what to expect and safety measures in place
Details of previous participants outcomes	Testimonies from previous participants
Side effects and risks	Written information
Lack of follow up support	Written or video of how to access support
Language barriers	Use of translation services for written and verbal information
Fear of contracting covid -19 from the vaccine	Myth busting / FAQ sheet
Accessible locations	Where possible use alternative sites Where not possible explain why
Equal participation from all ethnicities	Recruitment campaigns to explain the need for representation from all ethnic groups
Reassurance from friends/ family and religious leaders	National and local endorsements from religious organisations and leaders
Information reflecting cultural and religious appropriateness	Scheduling and staffing of clinics

South Asian Communities

Although hesitant, most South Asian participants were open to participating in research but not necessarily attending hospital-based research. The main areas of concern within this group were the vaccine ingredients and research process in relation to their religious values and beliefs. Some participants were worried the vaccine contained animal product, such as gelatine, meat and pork, which were prohibited in various religions. They also strongly advocated for the research to not fall during Ramadan or fasting festivals.

“ I would not like to attend hospital for research purposes at present. Although it is critical to get research done when the virus situation in the UK is very serious, I would not feel comfortable going to hospital unless absolutely necessary.”

South Asian, participant

“ (The vaccine) needs to make sure what is included in the vaccine and its halal and certified.”

South Asian, participant

“ I live in a multicultural society where often cultural views distort scientific facts so people would not trust science and data even if it shows that there is minimal risk.”

South Asian, participant

Consideration needs to be made to present detailed culturally relevant documentation on vaccine ingredients to prove they are alcohol and animal-product free with, for Muslims, halal certification. In addition, reassurance of hospital safety or use of neutral settings for the research study are essential to alleviate fears of being infected upon visitation to hospitals.

African and African Caribbean Communities

Members of the African and Caribbean communities were the most suspicious about the speed of the vaccine development and the intentions of companies involved. They believed that since Black people were previously always placed ‘at the back of the line for everything’, especially in healthcare and research, current insistence on their involvement was worrisome. There was high mistrust on what would be done with their DNA, and some even presumed the potential intention was to use the vaccine as a means to wipe out the entire Black race.

“ I have no interest at all and will not take part in any research, I am not a big fan of vaccine, especially unsafe vaccine that I believe have an agenda behind it, and I do believe that there is an agenda. Vaccines normally take years to develop, the fact that this is being done in such a short time – or maybe they had the vaccine ready waiting for something to happen.”

African Caribbean participant

“ Everything would worry me, it is the law of average for these companies, someone will be used as guinea pigs, and it is my belief that this could be detrimental to Black people.”

African Caribbean participant

Some Somali participants reported strong cultural and religious views against the vaccine, which included the possibility of ostracising those involved in vaccine trials, as they would be considered to be infected with COVID-19. Cultural concerns included a fatalistic approach to health (i.e. everything was predetermined) and social stigma from blood tests/donations due to fears of needles. The fear of getting infected with HIV in such a manner might prevent people from participating.

Clear evidence of participation from all ethnicities, demonstrating equal participation, would be required, so this group do not feel like they are the only ones participating in vaccine trials. Outcomes from people who previously participated in the trials, at different phases, was highlighted as a criterion to be satisfied before participation could be considered.

Overall, having answers to most of the common questions related to vaccine safety for this group before they were even asked, was considered proof that Black participants were valued, and their contributions were worth the effort.

Mental Health Communities

There were perceptions that unless trials were explicitly about mental health or illness, researchers had little or no interest in engaging with mental health service-users. There were significant worries over unwanted disclosure of mental health details, loss of confidentiality, barriers in relation to informed consent for vaccination and mental capacity to making relevant decisions. Research distrust amongst people experiencing mental ill health included previous negative experiences and fear of the newness of the COVID-19 vaccine. Other factors that may influence participation include family history of mental ill-health, taking various medications, prioritisation and timing of the trials as people may be more inclined to get involved in research when they are 'relatively well';

“ You will not know how your body and mind will react to the additional medication involved in a vaccine trial.”

Mental ill health webinar participant

“ You can either have a mental health focus for your treatment or a physical health one. You can't have both.”

Mental ill health webinar participant

Suggestions were made for researchers to be specific on the potential personal benefits of taking part in the trial, of communicating effectively to mental health service-users, of the inclusion of mental health-related factors in the study calls and vaccine registry screening process, and for the establishment of support groups. The support groups could include people who knew each other and could be facilitated by the trial organisers. Another recommendation was to include mental health supporting organisations in the vaccine trial process, as they can act as intermediaries and offer further support and advice. Research on the association between mental health and COVID-19 among people with pre-existing mental health conditions/illnesses was also requested.

Homeless Communities

Homeless people were thought not to be fully aware of the pandemic and its relationship to research activities. They were also usually reluctant to visit hospitals except for emergencies. This group were not always reachable, so may require more face-to-face engagement at their communal locations like food banks. Therefore, vaccine and hospital safety concerns were not the top concern within this group.

Effective engagement with homeless people would need to be facilitated via third sector organisations (e.g. voluntary sector professionals and other agencies involved in their care such as housing departments and GPs) as they provide an effective bridge between services and the homeless community. Such organisations could be responsible for their registration using localised approaches, providing support with filling forms online, and providing further detail on the research information and benefits for them as a community. This approach would also help minimise the probability of high dropout rates, which is likely to occur due to the limited commitment and level of involvement within the community.

Gypsy, Roma And Traveller (GRT) Communities

The Gypsy, Roma and Traveller community members were seen to have very limited interest in taking vaccines in general. Due to their nomadic lifestyle and communal and restricted living conditions, social-distancing and self-isolation have been challenging and have raised significant concerns on the impact of the pandemic within these communities. GRT communities also tend to have a fatalistic approach to health issues, believing “what is meant to be, will be”; hence, delivery of health information needs to be through culturally sensitive and trusted health and other outreach workers and via community leaders.

There are general concerns over the impact of the pandemic on Gypsy, Roma and Traveller communities. Some sites lack running water and refuse disposal facilities, for example. Therefore, many COVID-19 cases are likely to have gone undetected. It was highlighted that more focus needed to be given to understanding the impact of COVID-19 on these communities.

COMMUNITY GROUPS	BARRIERS	FACILITATORS
South-Asian	<ul style="list-style-type: none"> Assumed prohibited animal product content in the vaccine Research may fall during Muslim Ramadan fasting and other religious and cultural festivals 	<ul style="list-style-type: none"> Culturally relevant documentation on vaccine ingredients with halal certification Consideration of religious and cultural engagements in research schedule
African and African-Caribbean	<ul style="list-style-type: none"> Vaccines developed to eradicate Black people Contracting COVID-19 from the vaccine and getting ostracised from the local community 	<ul style="list-style-type: none"> Evidence of different ethnicities participation Outcome information from previous trial participants
Mental Health	<ul style="list-style-type: none"> COVID-19 researchers not interested in engaging mental health service-users Unwanted disclosure of mental health details and loss of confidentiality Anxiety and fear on the originality and lack of research on COVID-19 vaccines 	<ul style="list-style-type: none"> Inclusion of mental health-related factors in trial study calls and vaccine registry screening Inclusion of mental health supporting organisations in trial processes Clarity on potential personal benefits from participation Establishment of support groups for mental health sufferers
Homeless	<ul style="list-style-type: none"> Reluctant to visit hospitals except for emergencies Often hard to maintain contact with, leading to high dropout rates 	<ul style="list-style-type: none"> Participation coordination by third sector organisations and agencies involved in the care of homeless people Face-to-face engagement at communal locations like food banks
Gypsy, Roma and Travellers (GRT)	<ul style="list-style-type: none"> Fatalistic ideology and limited interest in vaccines Nomadic, communal and restricted living conditions Social-distancing and self-isolation not feasible 	<ul style="list-style-type: none"> Culturally sensitive health information delivered through trusted health worker outreach and community leaders Further research on health needs and the impact of COVID-19 on GRT communities

Conclusion

Overall feedback showed general apprehension, scepticism and low levels of trust within all groups. This was significantly influenced by lack of information as well as speculation concerning the possible hidden agendas of vaccine developers and the government, both of which will undeniably have an effect on each group in turn. Considering previous evidence that has suggested the groups included in this study are generally more susceptible to COVID-19, this tends to exacerbate underlying fears that participation in vaccine trials would mean greater exposure to infection and worse health outcomes.

Addressing the concerns highlighted by each group would therefore require targeted information and support services to reassure them of the safety of participation in vaccine trials. It is also vital to take into consideration the heterogeneous nature of the groups when developing interventions, particularly those related to increasing participation in vaccine trials.

Next Steps

- Use the findings of the focus groups and interviews to develop a survey to enable us to understand views and attitudes from a wider number of participants
- Analyse the responses and use the findings to inform the development of materials to aid recruitment and facilitate participation in vaccine research
- Develop and implement a comprehensive communications strategy to disseminate the findings and recommendations widely



The National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care East Midlands (CLAHRC EM) is a partnership between Nottinghamshire Healthcare NHS Foundation Trust and the Universities of Nottingham and Leicester.

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