

## Correspondence

# The views of ethnic minority and vulnerable communities towards participation in COVID-19 vaccine trials

The COVID-19 pandemic has disproportionately affected Black, Asian and minority ethnic populations and vulnerable groups.<sup>1</sup> Ethnic minority communities have 10–50% higher mortality risk compared with those of white ethnicity in the UK and USA.<sup>2,3</sup> Those with mental health conditions, homeless people and vulnerable migrants are also at high risk.<sup>4,5</sup> If successful, vaccination will provide protection and management of COVID-19, and to ensure optimal uptake and efficacy of vaccination programmes, the involvement of high-risk groups in vaccine trials is crucial. Ethnic minority individuals are, however, generally underrepresented in medical research, and researchers are actively seeking approaches to include more ethnic minorities in COVID-19 vaccine trials.<sup>6</sup> There is, therefore, a pressing need to explore perceptions towards participation in vaccine trials amongst ethnic minority and vulnerable communities towards achieving higher recruitment rates.

A qualitative investigation involving three focus groups and 47 semi-structured interviews were conducted through virtual platforms and telephone calls with  $n = 70$  individuals from different ethnic and vulnerable groups, in July–August 2020. They were recruited through existing Patient and Public Involvement (PPI) networks and included South Asian ( $n = 30$ ), African and Afro-Caribbean ( $n = 17$ ), White Polish ( $n = 4$ ), White British ( $n = 3$ ) and 15 representatives of other vulnerable groups [mental health, homeless and Gypsy, Roma and Travellers (GRT) communities]. Participants were part of an existing PPI network; hence, ethical approval was waived. Verbal informed consent was obtained from all participants. Feelings towards hospital attendance for COVID-19 vaccine trials and research were explored. Responses were recorded, transcribed and analysed using a thematic approach.

There was broad agreement that clinical research was necessary, but most interviewees were extremely uncomfortable with the idea of attending hospitals for vaccine trials and any research requiring physical examinations or blood tests. Primary concerns included fears of contracting COVID-19, side effects, lack of support if problems arose and language barriers. Participants were also suspicious of hidden agendas behind vaccines. They had strong views on the need for

transparency at all stages of trials, from vaccine development to outcomes, and for supporting information that reflected cultural appropriateness. Some issues were more strongly expressed amongst certain groups (e.g. religious concerns amongst South Asians and the need for third sector involvement for homeless people and mental health sufferers). Key barriers and facilitators to participation in trials are outlined in [Table 1](#).

The lack of adequate information influenced widespread apprehension, scepticism and low levels of trust towards vaccine research. Developing interventions to increase participation in vaccine trials will require consideration of the heterogeneous nature of ethnic minority and vulnerable groups. Additional requirement will be the reassurance of hospital safety, or use of neutral settings for trials is essential to alleviate fears of getting infected with COVID-19.

Addressing the concerns highlighted by each group will need targeted information, resources and support services if we are serious about having representative populations for vaccine and other therapeutic trials. Also, healthcare facilities can implement both active and reactive measures to support trial participants, such as establishing a local researcher-participant support platform.

## Acknowledgements

A detailed report of this work is also available on the National Institute for Health Research (NIHR) East Midlands Applied Research Collaboration (ARC) website, titled ‘Public perceptions towards vaccine trial within ethnic minority and vulnerable communities’. September 2020.

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 that 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

**Table 1** Barriers and facilitators to participating in vaccine trials amongst ethnic minority and vulnerable communities

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

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.

We thank the public who participated in our study. We also thank our community engagement staff and interviewers. We greatly appreciate the support of the NIHR Applied Research Collaborations East Midlands (NIHR ARC-EM) and the NIHR Leicester Biomedical Research Centre.

## Funding

This research is part of the overarching NIHR ARC project which the authors work on.

## Conflict of Interest

KK is a member of South Asian Health Foundation (SAHF), Independent SAGE and Chair of SAGE Subgroup on Ethnicity and COVID.

## References

- 1 Raisi-Estabragh Z, McCracken C, Bethell MS *et al*. Greater risk of severe COVID-19 in Black, Asian and minority ethnic populations is not explained by cardiometabolic, socioeconomic or behavioural factors, or by 25 (OH)-vitamin D status: study of 1326 cases from the UK biobank. *J Public Health* 2020;**42**(3):451–60.
- 2 Public Health England (PHE). *Disparities in the Risk and Outcomes of COVID-19*. London: PHE, 2020.
- 3 US Centers for Disease Control and Prevention. Demographic trends of COVID-19 cases and deaths in the US reported to CDC. <https://www.cdc.gov/covid-data-tracker/index.html#demographics> (24 September 2020, date last accessed).
- 4 Yao H, Chen JH, Xu YF. Patients with mental health disorders in the COVID-19 epidemic. *Lancet Psychiatry* 2020;**7**(4):e21.
- 5 Stephenson J. CDC urges COVID-19 testing at homeless shelters after finding swift spread of infection. *JAMA Health Forum*. Published online 5 May 2020. doi: 10.1001/jamahealthforum.2020.0580.
- 6 Treweek S, Forouhi NG, Narayan KMV *et al*. COVID-19 and ethnicity: who will research results apply to? *Lancet* 2020;**395**(10242):1955–7.

Winifred Ekezie<sup>1</sup>, Barbara M. Czyznikowska<sup>2</sup>, Sundeep  
Rohit<sup>2</sup>, Julian Harrison<sup>2</sup>, Nasima Miah<sup>2</sup>,  
Pamela Campbell-Morris<sup>2</sup>, Kamlesh Khunti<sup>1,2</sup>

<sup>1</sup>National Institute for Health Research (NIHR), Applied  
Research Collaboration (ARC) East Midlands, Leicester  
Diabetes Centre, University of Leicester, Leicester LE5 4PW,  
UK

<sup>2</sup>Centre for Black and Minority Ethnic Health (CBMEH),  
University of Leicester, Leicester LE5 4PW, UK

Address correspondence to Winifred Ekezie,  
E-mail: [wce2@leicester.ac.uk](mailto:wce2@leicester.ac.uk)

doi: [10.1093/pubmed/fdaa196](https://doi.org/10.1093/pubmed/fdaa196)