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COVID-19 and ethnicity: who will research results apply to?



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The toll of COVID-19 is not equal. Evidence globally shows a greater COVID-19 burden with older age, male sex, obesity, comorbidities, and poverty.¹⁻⁴ Early data suggest that people from Black, Asian, and minority ethnic (BAME) groups in the UK and Black, Hispanic, and Native American groups in the USA are disproportionately at risk of severe COVID-19 complications and deaths.^{3,5} A recent systematic review of published, preprint, and grey literature concluded that BAME communities are at increased risk of infection from severe acute respiratory syndrome coronavirus 2 and have more adverse outcomes, including death.⁶

Descriptive data from the Intensive Care National Audit and Research Centre indicate that 33% of patients critically ill with confirmed COVID-19 in intensive care in the UK were from BAME groups, despite them comprising about 13% of the UK population.⁷ Black people in the USA, who represent 13.4% of the population, comprise between 28% and 70.5% of deaths from COVID-19 depending on the state, and in predominantly Black communities the risk of infection is about three times higher than in predominantly white communities.⁸ In New Mexico, Native Americans account for 11% of the population but 37% of COVID-19 confirmed cases.⁵ Stark differences also extend to health-care staff. Within the UK National Health Service, about 21% of staff are from BAME backgrounds but they account for 63% of COVID-19 deaths among health-care workers.⁹ In the USA, Black people account for 21% of COVID-19 cases among health professionals despite comprising only 5% of doctors and 10% of nurses in the country.^{10,11}

The extent to which known or unknown factors contribute to the greater COVID-19 burden or severity among BAME people is not known.^{3,12} Research efforts are underway, including randomised trials of potential COVID-19 treatments and vaccines as well as observational and other studies, and it is vital that such research should include representative samples of people with BAME backgrounds. Yet such inclusion is not guaranteed.

BAME individuals are under-represented in research.^{13,14} For instance, in the UK, type 2 diabetes is disproportionately prevalent in South Asians and they have

poorer long-term outcomes,¹⁵ but in a review of 12 trials, the mean South Asian involvement was 5.5% despite South Asians representing 11.2% of the UK type 2 diabetes population.¹⁶ Four of the 12 studies did not even report ethnicity. Similar low participation by South Asians was seen in clinical trials in the USA.¹⁷ Giving insufficient attention to ethnicity in clinical trials of chronic diseases is also evident in COVID-19 research. Of 1518 COVID-19 studies registered on ClinicalTrials.gov, only six are currently collecting data on ethnicity.⁶

The reasons for under-representation of BAME groups in research are complex and could be attributable to hesitancy on the part of participants, lack of inclusion by health-care staff or researchers, and other socioeconomic factors and entrenched structural inequalities. These separately and collectively result in a range of outcomes from non-participation to exclusion, mostly inadvertent but sometimes by design. Barriers to participation in research include language challenges, low research awareness or mistrust of research, stigma, cultural values and beliefs about research, poor engagement from researchers, and general inaccessibility to research in deprived areas, including concerns of costs of time and money.¹⁸ Recruitment strategies and information provision approaches that work for the majority population may be ineffective for other parts of the population; there is little tailoring.¹⁹ There is no rigorous evidence on approaches that might, for example,



improve recruitment of particular BAME groups to trials.²⁰

Decisions to limit trial participant information leaflets and consent forms to English, for example, mean 44.9% of Bangladeshi women and 31% of Pakistani women older than 65 years in the UK will not understand them.²¹ An American Community Survey found that 21.9% of the US population spoke a language other than English at home, with Spanish the predominant language.²² And written translation is just the start. Interpreters could be needed, along with culturally sensitive recruitment methods such as gender matching between research staff and potential participants.¹⁹ Ensuring research is culturally and linguistically accessible and inclusive requires the commitment and resources of researchers from the start and the resulting increase in costs for these studies will need to be considered by the funders.

The US National Institutes of Health has mandated inclusion of BAME groups since 1994.²³ There is no obligation to record ethnicity in research studies in the UK. The UK's National Institute for Health Research initiated the Innovations in Clinical Trial Design and Delivery for underserved groups (INCLUDE) project in 2018 to widen inclusion of many underserved groups, including BAME groups, in research. INCLUDE's work on BAME group involvement will recommend in late summer, 2020, that researchers think carefully about who their research results must apply to, whether there are important cultural factors to consider, whether the focus of the research might make it harder for some groups to engage, and whether the proposed design and conduct of the research will make it harder for some groups to take part. Toolkits that help researchers to engage, inform, and recruit BAME participants to research do exist. Recommendations within them include using BAME researchers familiar with relevant culture and languages, using community organisations to develop recruitment strategies, and having less reliance on written materials.²⁴

The COVID-19 pandemic has exposed a problem that has been with us for a long time. Results from COVID-19 research must apply to everyone in the community who will be a candidate for treatment or prevention, and BAME individuals—often over-represented in the toll of the disease—should be an integral part of that effort. Omission has consequences: people could miss out on

important benefits or not be spared harms. If research fails to engage all those who could benefit, there is no guarantee that the results will apply to populations not included in the research.

To improve the involvement of BAME groups in research, thinking about participants' ethnicities when designing and reporting research needs to become as routine as thinking about their age and sex. Researchers, research funders, and public health and policy agencies all have a duty to ensure that concerted action is taken for research studies to serve and represent the whole community, not just part of it.

KK is the national lead for ethnicity and diversity for the National Institute for Health Research (NIHR) Applied Research Collaborations in the UK and Director of the University of Leicester Centre for Black and Minority Ethnic Health. KK receives support from the NIHR Applied Research Collaborations East Midlands (NIHR ARC-EM) and the NIHR Leicester Biomedical Research Centre. NGF has received grant funding from the MRC Epidemiology Unit (MC_UU_12015/5) and NIHR Biomedical Research Centre Cambridge: Nutrition, Diet, and Lifestyle Research Theme (IS-BRC-1215-20014). ST leads work to develop the NIHR INCLUDE approach to BAME group involvement in trials. KMVN declares research reported in this publication was supported by the National Institute Of Diabetes And Digestive And Kidney Diseases of the National Institutes of Health under Award Number P30DK111024. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. We declare no other competing interests.

*Shaun Treweek, Nita G Forouhi, K M Venkat Narayan, Kamlesh Khunti
streweek@mac.com

Health Services Research Unit, University of Aberdeen, Aberdeen AB25 2ZD, UK (ST); MRC Epidemiology Unit, University of Cambridge School of Clinical Medicine, Cambridge, UK (NGF); Rollins School of Public Health, Emory University, Atlanta, GA, USA (KMVN); and Centre for Black and Minority Ethnic Health, University of Leicester, Leicester, UK (KK)

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Informal home care providers: the forgotten health-care workers during the COVID-19 pandemic



The COVID-19 pandemic has placed pressure on many national health-care systems worldwide. Due to the rapid surge in caseloads and resource constraints in health systems, in many high-income settings, the focus has been on disease screening, with those who have severe disease prioritised for hospitalisation. But the COVID-19 pandemic has also led to an unprecedented reliance on home care as one pillar of the health-care system to support people with confirmed or suspected COVID-19. Meanwhile, informal home care provision and challenges faced by care providers, excluding those who are formal and paid, in the home context have largely been overlooked. In such population-wide public health emergencies, home care can be the only care option for people in low-income and resource-constrained settings who do not have access to health-care facilities due to such factors as distance, lack of transport, financial issues, or cultural-linguistic barriers.¹ Of course, people in need of home care are not limited to those with COVID-19. A large proportion of home care recipients include patients with chronic diseases, mental disorders, or disabilities who require essential life-sustaining care, health maintenance

support, and supplementary care during this pandemic. Moreover, home care recipients can include healthy but dependent individuals such as infants, young school-aged children, or older people.¹

In public health emergencies, informal home care providers are a crucial human resource that improves the community's health-care capacity, especially in regions with an ageing population and areas with suboptimal health-care systems.^{2,3} Yet our knowledge of the characteristics of these informal home care providers and the challenges they are facing during the COVID-19 pandemic is limited. The physical, mental, and social wellbeing of home care providers has been largely overlooked in the research literature. Policy planners who advocate for home care often make the assumptions that home care providers possess an appropriate level of health literacy, disease knowledge, psychological readiness, and medical care abilities. Another common assumption is that care recipients live in housing with adequate space where there are facilities for isolated care with ready access to home care materials. However, evidence gaps have shown there is a need for research with appropriate study outcomes to facilitate home care for people who

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