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

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COVID-19 affects us all but its toll is not equal. Consistent evidence globally has highlighted greater COVID-19 severity with older age, male sex, obesity, and co-morbidities[1,2]. Early data suggested that people of Black, Asian and Minority Ethnic (BAME) groups in the UK and Black, Hispanic and Native American groups in the US were disproportionately affected by severe COVID-19 complication and deaths[3,4].

Initial descriptive data from the Intensive Care National Audit and Research Centre indicated that over 30% of people admitted to intensive care in the UK came from BAME groups despite them comprising around 13% of the of the UK population[5]. Blacks in the US, who represent 13.4% of the nation, account for around 60% of deaths and in predominantly Black communities experience a 6-fold risk of infection[6]. In New Mexico, Native Americans account for 11% of the population but 37% of COVID-19 positive cases[4]. Stark differences also extend to healthcare staff. Within the UK National Health Service, 21 % of staff are from BAME backgrounds but they account for 63% of deaths[7]. In the US, Blacks account for over 20% of COVID-19 cases among health professionals despite only 5% of doctors and 10% nurses in the US being Blacks[8,9].

The extent to which known or unknown factors contribute to the greater COVID-19 burden or severity in BAME people is not known[3]. Research efforts have commenced including randomised trials of treatments and preventive vaccines as well as observational and other studies and it is vital that such research should include representative samples of people with BAME backgrounds. This is not guaranteed.

Past evidence indicates that BAME individuals are under-represented in research[10,11]. For instance, in the UK, type 2 diabetes is disproportionately prevalent in BAME groups with poorer long-term outcomes 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[12]. Four of the 12 studies didn't even report ethnicity. Similar results for South Asians are seen in the US[13]. This lack of attention to ethnicity is being mirrored in COVID-19 research. Of 1518 COVID-19 studies registered on ClinicalTrials.gov, only six studies are currently collecting data on ethnicity[14].

The reasons for under-representation of BAME groups are complex. They may be attributable to participants, healthcare staff or researchers or societal factors, and range from non-participation to exclusion, mostly inadvertent but sometimes by design. Barriers

to participation include language difficulties, lack of 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[15].

A decision to limit trial materials to English, for example, means over 40% of Bangladeshi women and over 30% of Pakistani women aged over 65 in the UK will not understand it[16]. A recent American Community Survey found that 21.9% of the US populations spoke a language other than English at home, with Spanish dominating[17]. And written translation is just the start. Native speakers may be needed and recruitment is likely to need tailored approaches. Cultural issues, for example, may mean that information needs to be provided to families by someone trusted rather than by an unknown member of healthcare staff. These factors will therefore increase costs for these studies and will need to be considered by funders.

The National Institutes for Health in the US has mandated inclusion of BAME groups since 1994 although reporting is generally limited to White, Hispanic or Latino[18]. There is no obligation to record ethnicity in research studies in the UK. The UK's National Institute for Health Research initiated the INCLUDE project in 2018 to widen inclusion of many under-served groups, including BAME[19]. Its work on BAME involvement will recommend that researchers think carefully about who their research results must apply to and that they do all they can to make sure that relevant BAME groups are involved. There are exemplars and best practice toolkits to help researchers to engage, inform and recruit BAME participants to research[20]. We need to use them.

COVID-19 is shining a spotlight on 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 people of BAME groups– often overrepresented 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 results will apply to populations not included in the research.

For BAME involvement in research to improve, thinking about participants' ethnicity when designing and reporting research needs to become as routine as thinking about their age

and sex. Researchers, research funders, 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.

References

1. Yang J, Zheng Y, Gou X, Pu, K, Chen Z, Gou Q, et al. Prevalence of comorbidities and its effects in patients infected with SARS-CoV-2: a systematic review and meta-analysis. International Journal of Infectious Diseases. International Society for Infectious Diseases 2020; 94: 91-5.

2. Jordan RE, Adab P, Cheng KK. Covid-19: risk factors for severe disease and death. BMJ 2020;368:m1198 doi: 10.1136/bmj.m1198.

3. Khunti K, Singh AK, Pareek M, Hanif W. Is ethnicity linked to incidence or outcomes of covid-19? BMJ 2020;369:m1548.

4. Haynes N, Cooper LA, Albert MA. At the Heart of the Matter: Unmasking and Addressing COVID-19's Toll on Diverse Populations. Circulation 2020; doi: 10.1161/CIRCULATIONAHA.120.048126.

5. ICNARC report on COVID-19 in critical care 22/5/2020 https://www.icnarc.org/DataServices/Attachments/Download/96b455be-059e-ea11-9126-00505601089b [Accessed 18/5/2020].

6. Yancy CW. COVID-19 and African Americans. JAMA; 323: 1891-92.

7. Cook T, Kursumovic E, Lennane S. Exclusive: deaths of NHS staff from covid-19 analysed. https://www.hsj.co.uk/exclusive-deaths-of-nhs-staff-from-covid-19-analysed/7027471.article [Accessed 29/5/2020].

8. Centres for Disease Control and Prevention. Characteristics of Health Care Personnel with COVID-19 — United States, February 12–April 9, 2020. https://stacks.cdc.gov/view/cdc/86727 [Accessed 28/5/2020].

9. Wingfield AH. The Disproportionate Impact of Covid-19 on Black Health Care Workers in the U.S. Harvard Business Review 2020, May 14th.

10. Smart A, Harrison E. The under-representation of minority ethnic groups in UK medical research. Ethnicity & Health 2017; 22: 65-82.

11. Stewart S. Minorities Are Underrepresented in Clinical Trials. American Academy of Family Physicians, Dec 4th 2018. https://www.aafp.org/news/blogs/leadervoices/entry/20181204lv-clinicaltrials.html [Accessed 28/5/2020]

12. Khunti K, Bellary S, Karamat MA, Patel K, Patel V, Jones A, et al. Representation of people of South Asian origin in cardiovascular outcome trials of glucose-lowering therapies in Type 2 diabetes. Diabetic Medicine 2016; 34: 64–8.

13. Sardar MR, Badri M, Prince CT, Seltzer J, Kowey PR. Underrepresentation of women, elderly patients, and racial minorities in the randomized trials used for cardiovascular guidelines. JAMA Intern Med 2014; 174: 1868–70.

14. Pan D, Sze S, Minhas JS et al. The impact of ethnicity on clinical outcomes in COVID-19: A systematic review EClinicalMedicine 2020 (in press).

15. Redwood S, Gill PS. Under-representation of minority ethnic groups in research — call for action. British Journal of General Practice 2013; 63: 342-343.

16. English language skills. https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/demographics/english-language-skills/latest#by-ethnicity. [Accessed 11/5/2020].

17. Spoken language at home https://data.census.gov/cedsci/table?q=language&hidePreview=false&tid=ACSST1Y2018.S1601 [Accessed 23/5/2020].

18. NIH RCDC Inclusion Statistics Report. https://report.nih.gov/RISR/#/home?facet=Ethnicity [Accessed 23/5/2020]

19. Innovations in Clinical Trial Design and Delivery for the under-served (INCLUDE). https://www.ncl.ac.uk/medicalsciences/research/crn/#researchinnovation [Accessed 17/5/2020]/

20. Increasing participation of Black Asian and Minority Ethnic (BAME) groups in health and social care research. http://arc-em.nihr.ac.uk/clahrcs-store/increasing-participation-black-asian-and-minority-ethnic-bame-groups-health-and-social [Accessed 14/5/2020].

Author contributions

All authors contributed equally to the writing of the manuscript.

Declaration of interests

KK is national lead for ethnicity and diversity for National Institute for Health Applied Research Collaborations and Director for University of Leicester Centre for Black Minority Ethnic Health. NGF, KMVN and ST declare no conflicts of interest.

Disclosures

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