



# Tackling racism in UK health research

## Richard A Powell and colleagues set out the barriers and solutions to eliminating inequalities embedded in the UK health research system

Richard Antony Powell,<sup>1,2</sup> Chidi Njoku,<sup>1,2</sup> Ramyia Elangovan,<sup>3</sup> Ganesh Sathyamoorthy,<sup>1,2</sup> Josephine Ocloo,<sup>3</sup>,<sup>4</sup> Sudhin Thayil,<sup>5</sup> Mala Rao<sup>1,2</sup>

Seismic forces are challenging the UK's ethno-racial status quo.<sup>1,2</sup> As a result, many organisations have made public commitments to listen to, learn from, and act on factors sustaining historical and current ethno-racial injustices and inequalities.

The UK health research landscape, with its vast influence on national and global strategy for health and wellbeing, has an opportunity and responsibility to advance a transformative, equity based agenda for change.<sup>3</sup> Racism is currently present throughout UK health research, including commissioning and implementation (both ostensibly underpinned by patient and public involvement), assessment, and dissemination, and we propose actions to produce systemic change. We use an equity approach that moves beyond creating an “equal, level playing field” and instead treats the unequal unequally.<sup>4</sup>

Our analysis is based on an understanding of racism as “the normalisation and legitimisation of an array of dynamics—historical, cultural, institutional, and interpersonal—that routinely advantage white people while producing cumulative and chronic adverse outcomes for people of colour,”<sup>5</sup> based on their physiological appearance or cultural identity (ethnicity). The intersection between ethnicity, race, and health is a product of this systemic discrimination, in which racism—a social construct—not ethnicity causes health disparities.<sup>6,7</sup> However, reducing racism in health research infrastructure will not in itself solve population health problems. We use the descriptors “racialised minorities,”<sup>8</sup> recognising that disadvantage is not uniform among different minority groups, and “ethno-racial” to refer to the phenotype, ancestry, and self-identification of ethnic and racial groups.<sup>9</sup>

### Racism in research commissioning

The setting of research agendas may seem a racially neutral, objective process, but in reality these agendas are influenced by multiple potential biases.<sup>10</sup> The leadership of research commissioning bodies drives the research agenda, determining how questions are framed, what data informs them, and how patients and the public are involved. For example, questions can be framed to imply a “black deficit” (eg, what causes black people to have so many disadvantages compared with white people?), which places the culpability of individuals over structural failures and histories of exclusion.<sup>11</sup>

Although inclusion of minority groups in leadership roles does not guarantee positive change,<sup>12</sup> evidence from other sectors suggests ethno-racial diversity has substantial benefits,<sup>13</sup> including a richer pool of

critical ideas, innovation, and entrepreneurship.<sup>14,15</sup> Diversity also ensures that the workforce and cultural competence of an organisation better reflect changing population mix, and are able to meet the needs of all stakeholder communities.<sup>16</sup> Yet, data on the ethno-racial diversity of commissioning leadership teams is scant at best: the Wellcome Trust is one of very few research organisations to have provided information, acknowledging publicly that all members of its executive team are white.<sup>17</sup>

Similarly exclusionary is the historical under-representation of racialised minority populations as participants in UK research despite comparatively worse rates of ill health.<sup>18</sup> For example, the underdetection of hypoxaemia by pulse oximetry<sup>19</sup> and the underdiagnosis of melanomas by cancer software<sup>20</sup> in black patients result from white patients being used as the default group in the algorithms used to develop and test these medical devices. Another example is the poorly evidenced, racially tailored care that can perpetuate harmful and unscientific ideas about biological differences between people of different ethnicities. These ideas persist in the medical guidelines that inform treatment decisions,<sup>21</sup> driving medical errors and increasing health inequities.<sup>22</sup> The current UK guidance on treating high blood pressure, for example, recommends angiotensin converting enzyme inhibitors for everyone except people of “Black African or Black Caribbean heritage,” who are recommended calcium channel blockers initially.<sup>23</sup>

Despite growing acknowledgement of the harmful implications of these anomalies in medical decision making and technology, research commissioners are failing to invest the resources required to ensure that devices work accurately across ethno-racial groups, and that treatment and care are not based on poor evidence, historical assumptions, and stereotypes. The interests and concerns of minorities must be represented in research planning and prioritisation.

The paucity of data on racialised minorities is itself a barrier to a diverse academic workforce and, by extension, to inclusive health research. In the Medical Research Council's survey of research fellowships, data on the ethnicity and nationality of fellows were “very limited.”<sup>24</sup> The recent release of data showing the diversity of applicants for and recipients of funding from the National Institute for Health Research (NIHR) showed that racialised minority applicants were less successful than white applicants (16.5% success rate v 21.2% for white applicants). This helps to fill the data gap, but NIHR recognises that

<sup>1</sup> Ethnicity and Health Unit, NIHR Applied Research Collaboration Northwest London, London, UK

<sup>2</sup> Department of Primary Care and Public Health, School of Public Health, Imperial College London, London, UK

<sup>3</sup> Centre for Implementation Science, Health Service and Population Research Department, King's College London, London, UK

<sup>4</sup> NIHR Applied Research Collaboration South London at King's College Hospital NHS Foundation Trust, London, UK

<sup>5</sup> Centre for Perinatal Neuroscience, Department of Brain Sciences, Faculty of Medicine, Imperial College London, London, UK

Correspondence to: M Rao mala.rao@imperial.ac.uk

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more work is needed to track, report, and evaluate diversity throughout research organisations.<sup>25</sup>

The absence of routinely collected and reported information undermines our understanding of the extent of biases in the research workforce. When data are reported, racialised minorities are often aggregated into one group, obscuring differences among distinct ethnicities.<sup>26</sup>

Two decades ago, the seminal Stephen Lawrence inquiry in the UK triggered reflection on the need for better health related data, recommending that ethnic group rather than country of birth should be recorded on death certificates.<sup>27</sup> Problems associated with unreliable proxy measures of ethno-racial affiliation were highlighted again early in the covid-19 pandemic, preventing timely understanding of the virus's differential effect on mortality, and delaying equity based remedial measures.

## Patient and public involvement

Patient and public involvement in research is important because it can influence the research questions asked and the outcomes measured. Patients and the public can ensure that researchers measure outcomes that matter to them and their communities, improving the validity of data and the value of research findings.<sup>28</sup>

Racialised minority groups are also under-represented in patient communities recruited to research. Consequently, their participation in research studies is inadequate,<sup>29–31</sup> including in covid-19 vaccine trials.<sup>32</sup> As others have said, “omission has consequences: people could miss out on important benefits or not be spared harms ... there is no guarantee that the results will apply to populations not included in the research.”<sup>32</sup> Omission could also reinforce existing social injustices and health inequalities. [Box 1](#) lists some measures to help eradicate racism in research commissioning

### Box 1: Potential solutions to racism in research

- Include ethno-racial equity in all policies and decisions influencing the research commissioning agenda
- Monitor and improve racialised minority representation in research commissioning leadership roles, on key committees and panels, and in patient and public communities involved in research
- Quantify, report, and resolve variations in research funding, starting with reliable data on funding awards, stratified by ethno-racial group, as the NIHR has started to do<sup>25</sup>
- Prioritise research questions and outcomes of greatest importance to specific ethno-racial groups
- Establish financial incentives to improve diversity in research institutions by developing criteria modelled on the Athena SWAN Charter<sup>33</sup> (linked to improving gender equality in academia), as a condition of NIHR funding

## Racism in academia

Academics are responsible for implementing the research agenda and training the next generation of researchers, yet negative experiences are becoming normalised in a culture of silent acceptance.<sup>34</sup> In 2019, 24% of racialised minority university students reported experiencing racial harassment,<sup>35</sup> but, for example, only half of medical schools collected data on their complaints.<sup>36</sup> Racialised minority applicants are less likely than white applicants to be awarded funding grants by the UK's Wellcome Trust<sup>17</sup> and are under-represented among UK Research and Innovation (UKRI) fellows and principal investigators,<sup>26</sup> echoing US funding

differentials among African-American or black principal investigators.<sup>37</sup>

The mechanisms by which the academic environment and structures reinforce existing inequities are complex, but core challenges include lack of diversity in executive leadership, ethno-racial discordance between students and teachers, unsupportive “soft learning” environments, and poorer research funding for racialised minority academics.

The executive leadership of all major UK medical schools is overwhelmingly white,<sup>38</sup> while 41% of medical students are from racialised minorities.<sup>39</sup> Such snowy white peaks at university potentially foster a networked club culture in which access to senior leadership positions can exclude racialised minority academics. Moreover, evidence suggests ethno-racial concordance between students and teachers benefits learning and achievement in medical and other disciplines.<sup>40 41</sup>

Despite being selected for academic achievement, medical students from minority backgrounds perform worse educationally on average than white peers in the UK.<sup>42</sup> One explanation lies in the learning experience. Learning is an interactive social process between students, teachers, and peers, but these processes are patterned by ethnicity.<sup>43</sup> Learning environments must also be supportive and celebrate difference, a process aided by greater ethno-racial diversity among academics. In 2019, racialised minorities accounted for 22% of lecturers, readers, and senior lecturers in medical schools, but only 14% of medical professors.<sup>44</sup>

Those charged with tackling these inequities could learn from the NHS, where the Workforce Race Equality Standard (WRES)<sup>45</sup> and, more recently, the Medical Workforce Race Equality Standard (MWRES)<sup>46</sup> have been collecting data on race inequality since 2015, holding up a mirror to the service and revealing disparities in career progression, experience, and opportunities that exist for people from racialised minorities compared with white staff. Although change may be slow, data collection has increased awareness and action to tackle many dimensions of structural racism in medicine, ranging from recruitment to bullying, education, and training. Importantly, it has resulted in modest but demonstrable improvements, including a small increase in the diversity of NHS “very senior managers” and trust board membership across England since 2017.<sup>45</sup>

Indicators should be developed to monitor the recruitment, career progression, experience, and achievements (including funding awards) of academics and researchers from racialised minority groups. Strategies must also be developed to address any disparities exposed by these indicators, drawing on lessons from the response to WRES and MWRES in the NHS.

## Racism in assessment of research excellence

A UK university's research performance is appraised and ranked every six years using a system called the research excellence framework. The 2021 round of assessments—delayed by the pandemic—includes a measure of diversity and equality as part of the evaluation of “the vitality and sustainability of a university's research environment.” However, it remains unclear what proportion of the overall environment score—which accounts for only 15% of a university's overall assessment—will be determined by equality and diversity.<sup>47</sup> Furthermore, equality and diversity are assessed from written submissions. There is no requirement for data on how minorities experience a university environment, despite evidence that equality and diversity strategies correlate poorly with

actual working conditions and progression for women and minorities.<sup>48</sup>

The UK's research excellence framework should be reformed to improve assessment of ethno-racial equity within universities, for both workforce and students. Importantly, academics and students from racialised minorities should be full partners in the design and implementation of these reforms. Related frameworks from other countries, including the US—where the National Institutes of Health seek to tackle structural racism and promote racial equity and inclusion internally and within the larger biomedical research enterprise<sup>49</sup>—could inform this process.

The ultimate goal is a more effective multidimensional assessment of research performance that does full justice to the importance of diversity, inclusion, and ethno-racial equity based on a dataset agreed by all stakeholders.

### Racism in research dissemination

Substantial evidence exists of widespread ethno-racial bias in academic publishing.<sup>50–53</sup> In the US, journals have been criticised for denying ethno-racial bias, refusing to publish research identifying racism,<sup>54</sup> and recruiting and tolerating overwhelmingly white editorial boards.<sup>55</sup> In the UK, *Nature* has acknowledged that it is “one of the white institutions ... responsible for bias in research and scholarship,” declaring that science “has been—and remains—complicit in systemic racism.”<sup>56</sup> Similarly, the *Lancet* described itself as having “a deep colonial history.”<sup>57</sup>

It is important for journals to show a commitment to equity. Journal editors are powerful gatekeepers, determining what gets reviewed (by whom) and published, and publications matter. Publications and other academic outputs account for 60% of the overall score of institutions in the latest research excellence framework.<sup>47</sup> For academics, journal publications, membership of editorial boards, and invitations to review papers are key measures of success and requirements for career progression. Publications are also important for securing research funding; developing the analytical, reviewing, and writing skills of trainees; and disseminating knowledge and research.

The potential power of journals to effect change in key societal issues was shown by *The BMJ's* 2020 themed issue on racism in medicine,<sup>58</sup> which substantially contributed to the subsequent decision to launch an NHS Race and Health Observatory.<sup>59</sup> In recognition of the role of journals in embedding justice and equity in research and scholarly communication, *The BMJ* has pledged a commitment to equality, diversity, and inclusion,<sup>60</sup> as have others.<sup>56–57</sup> Stated commitments of high impact journals to address inherent biases in the publication process, improve the publication chances of racialised minorities, and increase the publication of ethno-racial research are welcome. But journals could and should be more ambitious, committing to measurable targets and timetables to achieve justice and equity for under-represented groups. Journals could start by publishing regular data on the diversity of their authors, reviewers, and editorial boards. They could also audit and publish the proportion of content dedicated to ethno-racial research.

### Commitment to change

For too long health research architecture in the UK has been guilty of reinforcing instead of reducing systemic ethno-racial inequities, fortifying “persistent, pervasive racism that exists across societies.”<sup>61</sup> Stakeholders in the UK must change their structures, systems, and processes to reflect the diversity of the population, optimise innovation, and inform inclusive decision making.<sup>62</sup> They must implement a transformative, anti-racist, equity based research

agenda. By committing to this agenda, we can make substantive and permanent change tackling the structural determinants of health inequalities.

#### Key messages

- Racism is evident across the UK health research landscape, from funding bodies through to peer reviewed journals
- UK organisations are beginning to listen to, learn from, and act on factors maintaining historical ethno-racial injustice and social inequity
- Stakeholders must collectively commit to improving equity, diversity, and inclusion in health research, by changing structures, systems, and processes
- Ethno-racial equity requires a research community determined to ensure that health research does not reinforce and exacerbate existing health and social inequities

Contributors and sources: The authors have experience advocating for change in the UK NHS and research funding agencies. MR, GS, CN, ST, and JO have experienced ethno-racial discrimination within and outside academia, and JO is also a patient and public involvement representative and lived experience researcher. RAP has researched and commented on services received by, and provided to, people from racialised minority communities in the UK and diverse ethnic populations internationally. The article is based on peer reviewed publications, grey literature, and primary data collection by the authors. MR conceived this article. RAP initially drafted the paper, with all co-authors reviewing and contributing to its revision and finalisation. MR is the guarantor.

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