Putting the voices and insights of migrants and diverse ethnic groups at the centre of our response to COVID-19

Mayuri Gogoi\*<sup>1</sup>, Richard Armitage\*<sup>2</sup>, Gavin Brown<sup>1</sup>, Bernard Ryan<sup>1</sup>, Helen Eborall<sup>1</sup>, Nadeem Qureshi<sup>2</sup>, Catherine A O'Donnell<sup>3</sup>, Yusuf Ciftci<sup>4</sup>, Manish Pareek\*<sup>1</sup>, Laura B Nellums\*<sup>2</sup>

<sup>1</sup>University of Leicester, <a href="mg432@leicester.ac.uk">mg432@leicester.ac.uk</a>; <a href="mg432@leicester.ac.uk">gpb10@leicester.ac.uk</a>; <a href="mg432@leicester.ac.uk">br85@leicester.ac.uk</a>; <a href="mg432@leicester.ac.uk">hce3@leicester.ac.uk</a>; <a href="mg432@leicester.ac.uk">mg432@leicester.ac.uk</a>; <a href="mg432

<sup>2</sup>University of Nottingham, <u>Richard.Armitage@nottingham.ac.uk</u>; Nadeem.Qureshi@nottingham.ac.uk; Laura.Nellums@nottingham.ac.uk

<sup>3</sup>University of Glasgow, Kate.O'Donnell@glasgow.ac.uk

<sup>4</sup>Doctors of the World UK, yciftci@doctorsoftheworld.org.uk

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<sup>\*</sup>Joint-first authors

<sup>\*</sup>Joint-senior authors

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## <u>Abstract</u>

There is increasing evidence of inequities in COVID-19 infection, disease severity, and mortality across diverse ethnic groups. Despite calls to ensure ethnicity is integral to COVID-19 research, opportunities have been missed to engage with individuals from ethnic minority groups, and even more notably, recent migrants. There is an urgent need to strengthen patient and public involvement and engagement (PPIE) and participatory research, as well as collaboration with healthcare workers from diverse migrant and ethnic backgrounds. This will require addressing multiple barriers to involvement, and a commitment to community-centred research to address the acute needs of the populations hardest hit by the pandemic.

## Letter

Evidence demonstrates that individuals from ethnic minority groups are at increased risk of COVID-19 infection, severe disease, and mortality,<sup>1-4</sup> even accounting for socioeconomic deprivation.<sup>5</sup> Despite calls to ensure ethnicity is integral to COVID-19 research,<sup>6</sup> opportunities have been missed to engage with these communities, and even more notably, recent migrants. Wide participation is needed to avoid continued tragedy in future pandemic waves.

Community engagement during COVID-19 has lacked urgency and transparency. The absence of the insights and voices of migrants and diverse ethnic groups was highlighted by the omission of stakeholder contributions in Public Health England's (PHE) report on COVID-19 disparities,<sup>7</sup> which was criticised for failing to advance understandings of risk factors and discrimination, or provide actionable recommendations.<sup>8</sup> Community viewpoints were subsequently published two weeks later,<sup>9,10</sup> following condemnation by over 30 organisations.<sup>8</sup>

A key finding of PHE's disparities report was the relationship between country of birth and COVID-19 mortality.<sup>7</sup> However, this went unreported, and an opportunity to robustly examine migration as a risk factor for poor outcomes was missed, echoing the stark absence of attention to country of birth and migration status during COVID-19. This highlights the need for safe and confidential mechanisms to improve collection and reporting of migrant data across health services and research, supported by adequate funding.<sup>3</sup>

Despite the risks faced by newly-arrived migrants during COVID-19,<sup>11</sup> these groups have not been meaningfully included in engagement activities or recommendations, reflected in their underrepresentation in PHE's stakeholder report.<sup>9</sup> Migrant views are also notably absent as new strategies to monitor or react to COVID-19 develop, including testing, contact tracing, or social distancing and lockdown measures.

Migrants should be explicitly integrated within the COVID-19 narrative through patient and public involvement and engagement (PPIE) and participatory research, as well as collaboration with clinical and non-clinical healthcare workers from diverse migrant and ethnic backgrounds (see Fig 1). Such involvement of migrants and other underrepresented groups is essential to guide research, inform policy and practice, and promote accountability. This is critical in light of concerns that urgency in developing the evidence base is taking precedence over robust ethical approval processes, informed consent, and PPIE.<sup>12</sup> Research ethics committees and funders should critically evaluate proposals indicating these communities will not be recruited as they are considered too hard to reach.

Achieving meaningful engagement necessitates addressing multiple barriers to involvement across very diverse communities, including mental and physical health and disability, caring and employment responsibilities, and legal status, alongside the implications this may have for entitlement to healthcare, fears around immigration enforcement or stigmatisation, and trust and willingness to engage with researchers.<sup>13</sup> Transparency and inclusion is also vital, and requires ongoing communication (particularly whilst social distancing), sharing and facilitating access to updated information (e.g. appropriate languages, multiple formats, and provision of professional linkworker services), and inclusion of stakeholders in planning and

responding to the pandemic. The shift to the virtual space during COVID-19 may also impact on recruitment, accessibility, and development of trust and rapport, particularly for those facing barriers due to internet access, digital literacy, or language. This digital divide will disproportionately affect ethnic minority and migrant groups.<sup>14</sup>

The expertise these individuals bring through their lived experience, and its value in informing appropriate, effective, and equitable policy and practice, should be meaningfully recognised. 13 As such, engagement with migrants should be mutually beneficial, for example the provision of PPIE payments or material contributions in recognition of the expertise these individuals have shared.<sup>15</sup> Such contributions should be prompt and appropriate, and organisations should consider access to banking (including online banking), permission to work, and recourse to public funds, ensuring such contributions don't have legal repercussions for those participating. Providing payments in cash can overcome some of these barriers. However, social distancing restrictions have made it necessary to consider virtual methods of providing PPIE payments. Mobile wallets, credit, and vouchers may bypass these barriers, though it is important to consider their accessibility for those who are digitally excluded, as well the relevance and convenience of selected vendors. Defining material contributions as a recognition or 'thank you' for shared expertise, and determining the amount of these contributions by the type of activity (e.g. research interview, stakeholder meeting, or co-producing a resource), rather than an hourly rate, may both avoid framing such payments as income, and support meaningful engagement. It is also important to consider that PPIE payments may also incentivise participation, which could be coercive or lead to risk-taking by target groups. Discussing these issues with target communities may be an effective and inclusive strategy for determining how to recognise PPIE contributions.

There is an urgent need to reorient research, policy, and practice to address the acute needs of the populations hardest hit by the pandemic. To achieve this, it is imperative to commit to community-centred research.<sup>16</sup> In line with good PPIE practice,<sup>17</sup> research teams must innovatively strengthen involvement to ensure research is appropriate and impactful, and proactively involve migrants and diverse ethnic groups from the outset.

The increasing recognition of inequities in COVID-19 outcomes, and pledges to challenge disparities across political, health, and academic sectors, will only be realised with financial commitments. Funding bodies should adequately and equitably support migrant-focused research, and promote inclusion of migrant-specific PPIE activities. We must move beyond descriptive needs assessments, to generate concrete actions responding to these populations, aligning with their requests for community-based research, co-produced policy and health services, and targeted communications.<sup>9</sup> Ultimately, organisations, funders and journals will be judged by their actions - not their words.

## Acknowledgments

MP is supported by the National Institute for Health Research (NIHR) Applied Research Collaboration East Midlands (ARC EM), the NIHR Leicester Biomedical Research Centre (BRC), and an NIHR Development and Skills Enhancement Award. MP is a member of the Health Data Research (HDR) UK COVID-19 Taskforce. MP, LBN, and MG receive funding from the UKRI/MRC (MR/V027549/1). LBN also receives funding from the Academy of Medical Sciences (SBF005\1047), and the Medical Research Council/Economic and Social Research Council/Arts and Humanities Research Council (MR/T046732/1. MP, GB, BR, MG, and HE acknowledge funding from the Leicester Institute for Advanced Studies through the Migration, Mobilities and Citizenship research network. KOD is a Member of the Scottish Government Expert Reference Group on COVID-19 and Ethnicity.

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