

Participants in health research not representative of the UK's diverse population, finds study

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An audit by University of Manchester experts has found that participants in health research are not representative of the U.K.'s diverse population. The study has been <u>published</u> in *BMC Medicine*.



The audit assessed interventional studies, <u>observational studies</u>, <u>clinical</u> <u>trials</u> and other types of human research in Greater Manchester between 2016 and 2021.

They studied electronic database that allowed the authors to evaluate an entire <u>health research</u> system.

Of the 85 studies comprising 21,797 participants included in the research, only 6% included people from ethnic minority backgrounds.

The proportion of ethnic minorities in the Greater Manchester population is 16%, more than 10% higher.

Recruitment to the studies also tended to be concentrated in central Manchester (50%) and within NHS hospital settings (74%), where centers of clinical excellence and research are usually located.

The study samples did provide good representation of the Greater Manchester population in terms of sex: after removing single sex studies, 50% of study participants were women.

However, the team were unable to report which ethnic minority group and social class was least represented because they were unable to source detailed participant information.

Data on smoking—a strong indicator of social class- was also largely absent from the studies they assessed.

And they were unable to obtain any participant information for 53 out of the 145 studies, accounting for about 4,000 participants.

Dr. Holly Hope, joint senior author said, "Our study shows that people from ethnic minorities are being under-represented in health research.



"It also highlights significant gaps in the reporting of basic information about participants in <u>clinical research</u>—especially <u>social class</u> and ethnicity.

"This is a missed opportunity as delivering inclusion in studies is vital to improve health outcomes. If the people most affected by ill health are to benefit from research, they need to be properly involved and represented otherwise we risk increasing health inequities."

She added, "We already know that prevention studies aimed at the entire population underrepresent people who are not white.

"During the pandemic for example, some studies showed there was evidence that the non-white population experienced greatest COVID risk and vaccine hesitancy than their white peers.

"People of South Asian origin are particularly at risk of type 2 Diabetes, so it is important they are included in diabetes research.

"And Black British women are particularly at risk of pregnancy complications and maternal death so it is important they are included in research to improve pregnancy and maternal outcomes."

Dr. Peter Bower, joint senior author of the study, added, "Greater Manchester is one of the most diverse areas in the U.K. in terms of wealth, sociodemographic status and ethnicity, so it's an excellent setting to explore the representativeness of research.

"We would therefore expect to find that our findings are reproducible across other part of the U.K.—and perhaps even more widely than that.

"We hope this study serves as a benchmark from which Greater Manchester can demonstrate progress and more inclusive research."



Other recommendations include tracking representation in health research over time and supporting different health care levels and noncentrally located institutions to undertake research in areas of high disease burden.

The research team are currently scoping development of an in-study digital tool to support research teams to plan for more equitable recruitment by clearly identifying specific underserved groups.

More information: Kathryn M. Abel et al, Representativeness in health research studies: an audit of Greater Manchester Clinical Research Network studies between 2016 and 2021, *BMC Medicine* (2023). DOI: 10.1186/s12916-023-03170-5

Provided by University of Manchester

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