

Trust is the most important factor for British South Asians when taking part in genetic research to tailor medications

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Researchers from Queen Mary University of London have gathered detailed insights from the British South Asian community that could lead



to more successful implementation of genetic testing to help tailor the use of routine medications. Their findings are published in *The Pharmacogenomics Journal* and indicate key issues that could affect the take up of this new type of genetic testing among patients.

Despite comprising 10% of the British population, individuals of South Asian heritage have historically been under-represented in genomics studies and <u>clinical trials</u>. British Bangladeshis and British Pakistanis, particularly, have higher rates of several medical conditions such as diabetes and heart disease, and taking multiple medications for these conditions increases the risks of side effects.

Using DNA testing to personalize <u>medication</u> regimes has been proven to decrease the risk of side effects and enhance the efficacy of medications, but there has been little discussion about these new genetic tools outside specialized health settings.

This study brought people from the British Bangladeshi and British Pakistani communities together to identify what they felt to be the most critical elements about the development of clinical services that undertake genetic testing, either to tailor the use of medications or to research optimized medication use.

Researchers led by Dr. Emma Magavern and the Genes & Health Community Engagement Team at Queen Mary University of London carried out focus groups drawn from existing participants in the Genes & Health cohort. In total, 64% of the participants were female, 26% were born in the UK or Europe, with 52% born in Bangladesh and 17% born in Pakistan. Among the participants, 36% reported university level education. Simultaneous translation into Urdu and Bengali was available to all participants.

The findings



The study found that <u>trust</u> was the most important factor in encouraging British South Asians to engage with genetic testing. GPs were felt to be trustworthy medical professionals who could invite individuals to take part in genetic testing, either for research or to ensure their own medications were optimized.

Participants also felt that personalized prescribing with <u>genetic</u> <u>information</u> could enhance trust and contribute to people taking their medication as prescribed more regularly.

Dr. Magavern, from the from the Centre of Clinical Pharmacology and Precision Medicine at Queen Mary, and lead author, said, "Trust was the key condition for the acceptability of using DNA to tailor a patient's medication, and for using those genetic results in research. Community presence in research cohorts was perceived to enhance trust, as does education, outreach, and communication."

Mehru Raza, the Communications & Engagement Manager for Genes & Health, said, "Insights from often-overlooked perspectives in clinical research underscore the critical significance of fostering trust and engaging participants in the research process. Making information accessible and embedded in the community is the key to restoring community confidence in advancements within health care."

Participants voiced some concerns about this use of genetic testing, raising issues including privacy, data ownership, and transparency if any data breaches were to occur. Participants were also concerned that use of this data could make medicines more expensive for the community. These issues must be addressed as this technology is adopted more widely.

The study also found that participants broadly shared a view that misinformation around the COVID-19 pandemic and vaccines had



eroded trust between the community and health care. Rebuilding this trust was possible and required high quality and accessible information about any new developments in clinical care.

More information: British South Asian ancestry participants views of pharmacogenomics clinical implementation and research: a thematic analysis, *The Pharmacogenomics Journal* (2023). DOI: 10.1038/s41397-023-00317-8

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