‘We’re vaccine curious not vaccine hesitant’

Working with community organisations to produce evidence-informed recommendations about increasing COVID vaccine uptake among ethnic minority groups.

Shaun Treweek
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TRIAL FORGE

www.trialforge.org

COVID-19 vaccination in early 2021

Data from January 13th on 23.4 million adults in England showed:

- 43% of White over 80s who were not living in care homes had received their first dose of the COVID-19 vaccination.
- 34% of Indian/British Indian over 80s, 23% of Bangladeshi/British Bangladeshi over 80s, and 16% of African over 80s.

UKRI and others asked..

What are the factors that influence vaccine uptake by ethnic minority people and the strategies that might increase uptake?

UK Research and Innovation

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COLLABORATION FOR CHANGE

Factors & Strategies | Project Partners | Videos | Press Room | Download Report

Enhancing vaccine confidence across ethnic minority communities

A co-produced research study that combines research, evidence and lived experience to understand and improve vaccine uptake in ethnic minority communities

https://collaborationforchange.co.uk/

The Collaboration for Change represents two UK universities, nine community organisations and two small and medium size enterprises, who, in a collective effort, have conducted research on how to improve vaccine uptake among ethnic minority groups.

Uptake of the COVID-19 vaccine varies widely across communities, and the collaboration have been working to help identify the reasons behind these variations, with the aim to ultimately increase vaccine uptake. The methodology included two rapid literature reviews followed by a series of decision making frameworks to bring in the 'true to life' perspectives from community organisations.

A summary report is now available (see below) which highlights the critical factors that impact vaccine uptake, and provides recommendations on how to increase uptake across ethnic minority groups. Our full data are available at ReShare, a UK data repository

Below are some of the highlights of the report:

The Collaboration had 13 partners

CAHN
Caribbean & African Health Network

REACH
COMMUNITY HEALTH PROJECT

UCL

COUCH

ROTHERHAM ETHNIC MINORITY ALLIANCE
REMA

1495 UNIVERSITY OF ABERDEEN
CELEBRATING 525 YEARS 1495 – 2020

egality
diversity in research
equality in health

Kanlungan
Empowering Filipino Migrants

Social Action for Health

ethnic health forum

IPSWICH & SUFFOLK COUNCIL FOR RACIAL EQUALITY

SOUTH ASIAN HEALTH ACTION

MANCHESTER BMENETWORK

Our approach

- What do we know from the global literature about factors that affect uptake of respiratory vaccines by ethnic minority people?
- What do we know about strategies used to increase uptake?
- What do UK-based ethnic minority people think of the above evidence? Does it apply to the UK?
- Produce recommendations.

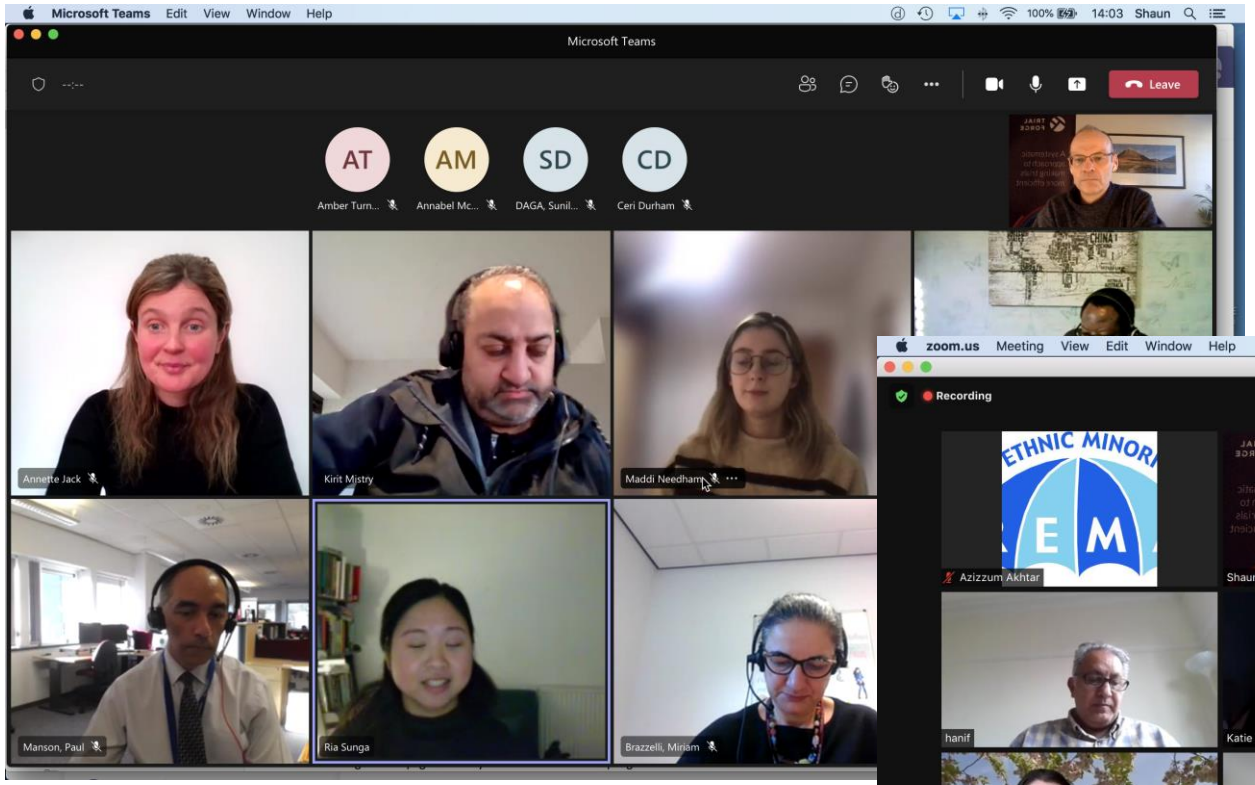
Partners were fully involved

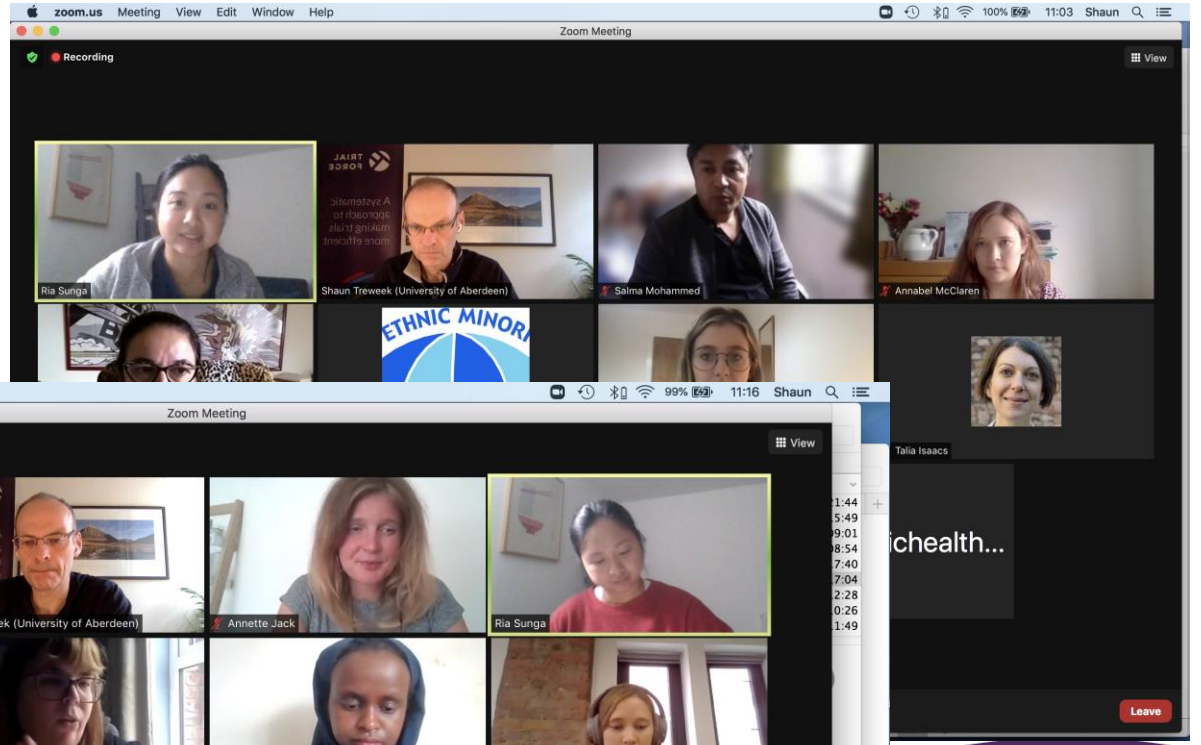
- Five of the community organisations were grant holders. The remaining four were brought on-board once we were funded to increase the perspectives represented.
- All community organisations received around £2500.
- All 13 partners contributed to all aspects of the project once started.

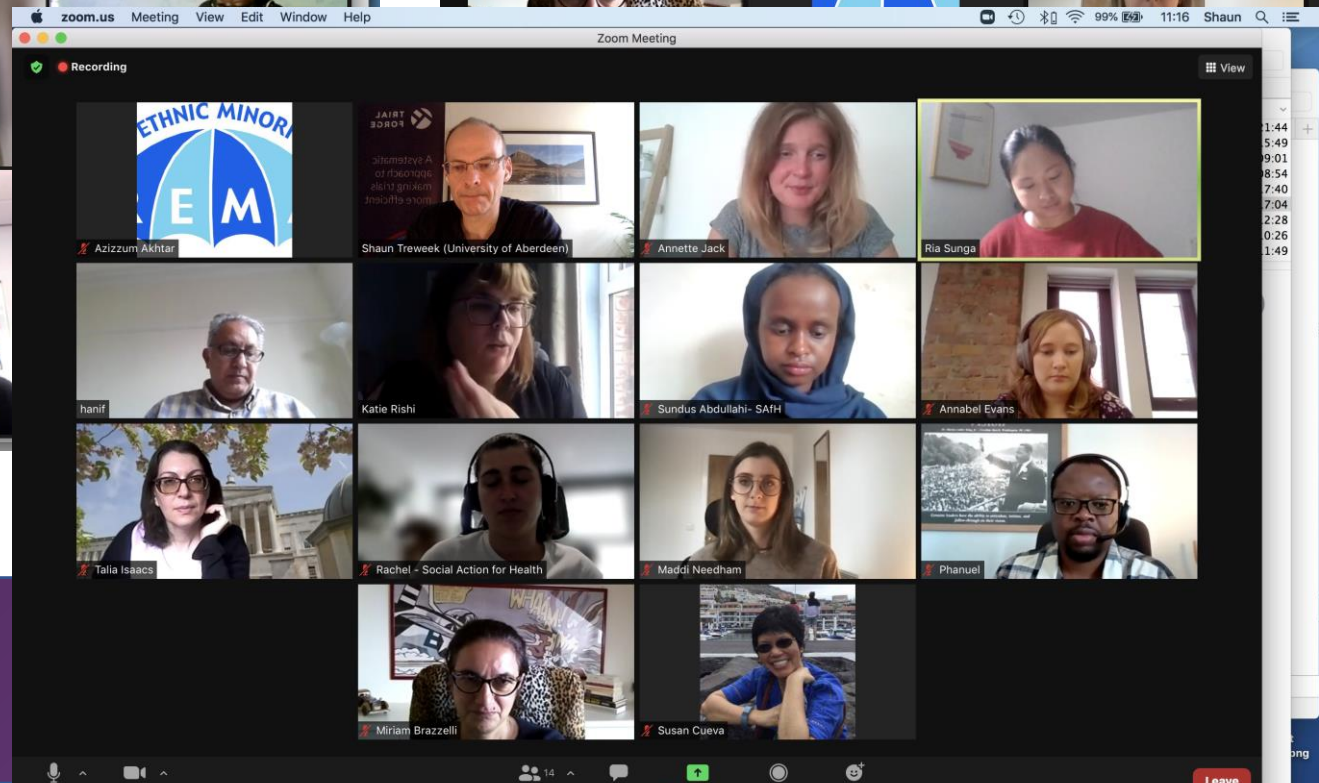
egality
diversity in research
equality in health

https://egality.health/

The central PPI part of the project..







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Factors and strategies

Factors

- Trust in organisations
- Trust in individuals
- Appropriate information
- Appropriate language
- Discussion of harms vs benefit
- Convenience

Strategies

- Use trusted messengers
- Tailor the message
- Enhance convenience

How important is trust in organisations as a factor affecting COVID-19 vaccine uptake by ethnic minority groups?

Problem: Uptake of the COVID-19 vaccines is lower in some ethnic minority groups

Factor influencing uptake: *Trust in organisations*

Main outcomes: Vaccine uptake

Setting: UK

Perspective: Population

Background: Although uptake of the COVID-19 vaccines in the UK is generally high, uptake is lower among some ethnic minority groups [1,2]. For example, by 27/7/2021, 90% of White 50-54 year olds had been vaccinated, compared to, for example, 59% of those of Caribbean heritage, 70% of those of African heritage or 87% of those of Indian or British Indian heritage [1]. These differences persist across age groups, although the size of the difference varies. There is continuing debate about the factors that affect vaccine uptake (not just for COVID-19) among all ethnic groups, including ethnic minority groups.

Subgroup considerations: None.

	CRITERIA	JUDGEMENTS	RESEARCH EVIDENCE	COMMENTS
PROBLEM	**Is the factor a important?**	*Don't know* ☐ *Varies* ☐ | *No* ☐ *Probably no* ☐ *Probably yes* ☐ *Yes* ☒ ***Detailed judgements (see 'COMMENTS')***	• In a UK study done in 2020/21, 23 community leaders talking about the COVID-19 vaccines raised widespread distrust of government and the NHS as a problem, though it is more entrenched in some communities than others. Past policy ('hostile environment') contributed to this "[In the] Turkish speaking community, they have seen people die in hospital but not at home, so there is no trust in the NHS." [#grey24; Focus groups; study quality high] [3]. • A US study done between 2012 and 2014 with 119 adults, with a range of different ethnic groups talking about flu vaccination found trust in pharma to be low with almost all participants expressing concern that pharma favoured profits over the needs of the public. "These people, it's a business. They don't make money curing you. They make money selling you drugs. They're drug dealers" (African American). In some cases concerns about profits were larger than concerns about the vaccine. Trust in government varied with White people trusting institutions but questioning competency while African Americans were less trusting and questioned government motives "I have major trust issues with my government across the board…a lot of people are trust motivated. If you don't have my trust then I'm not going to pay you much mind no matter what you say" (African American). There was a suggestion that trust may be greater in younger people "However, most of us, I'm glad to say, or it seems, have loosened that mistrust. I trust people…I trust you, but I got to verify it." (African	1. Personal experience is important: it can support or reduce trust, depending on whether it is good or bad. A central feature of trust re. vaccination is the consistent pattern of inequalty experienced by minority groups prior to Covid-19 (women in childbirth, cancer care etc). Improvement has been talked about for a long time but not addressed so why trust an organisation now? They did not deal with our previous concerns. 2. The 'hostile environment' rhetoric in the UK is an important influencer of trust regarding a person's position in society. This is not just about vaccines and NHS but e.g. Windrush scandal, Grenfell Tower fire. These set the tone for minority ethnic voices not being heard or believed. The growing far right movement and how

‘The ‘hostile environment’ rhetoric in the UK is an important influencer of trust regarding a person’s position in society. This is not just about vaccines and NHS but e.g. Windrush scandal, Grenfell Tower fire. These set the tone for minority ethnic voices not being heard or believed.’

‘Mistrust is this context is entirely justifiable; it is based on past behaviour by organisations. This is not about reprograming ethnic minority communities but reprogramming organisations.’

Conclusions

Type of recommendation	We recommend that the factor be consider a barrier	We suggest that the factor be considered a barrier	We suggest that the factor is neither a barrier or an enabler	We suggest that the factor be considered an enabler	We recommend that the factor be considered an enabler
	☐	☐	☐	☐	☒

Recommendation/decision

Evidence from the UK and the US, plus our own experience, suggests that having trust in the organisations promoting the COVID vaccine is among the most important factors linked to whether people from ethnic minority groups accept the offer of the vaccine. Conversely, not having trust in those organisations makes uptake less likely. There has been a historical neglect of engagement with ethnic minority communities by organisations that promote vaccine uptake. These organisations need to engage with community groups and members, listen to the concerns raised and move to make changes (including to vaccine delivery) as suggested by those communities.

Justification

Mistrust of organisations such as the Government, the NHS and the pharmaceutical industry by ethnic minority groups is based on many years of discrimination, and past failure, by these organisations towards ethnic minorities. There has been a historical neglect of engagement and interest in the views of ethnic minority groups. For many years UK health systems have said that ethnic minority groups have poorer health outcomes, demonstrating that the health system is failing ethnic minorities. But those poorer outcomes have persisted. Why should ethnic minority groups now trust that same health system with regard to COVID-19 vaccines?

In the UK, the 'hostile environment' rhetoric, and scandals such as Windrush and Grenfell Tower set the tone for minority ethnic voices not being heard or believed. This influences belief in health systems and vaccines promoted by organisations that have a history of racial, religious and other discrimination against ethnic minority communities. Some organisations are trusted (e.g. community and faith organisations) and work to improve vaccine uptake should identify and work with these organisations.

Subgroup considerations

The level of trust varies across ethnic groups; 'ethnic minority' does not mean a single homogenous group that shares the same values, beliefs and preferences. The concerns of individual communities need to be listened to and addressed. Differences between ethnic groups include language, culture, faith, education, place of birth, gender etc. There are important nuances that must be recognised and addressed.

Research priorities

1. How best to engage with communities to build trust.
2. Improved approaches to data collection linked to recording ethnicity and identify.
3. More meaningful collaboration with community groups/3rd sector at the start of research planning to support its design and planning, not once funding has been awarded and the research design is fixed.
4. Work to ensure that all health research is explicitly designed with diverse populations in mind (this does not happen on its own, as we have seen for decades). COVID has changed the path of some background illnesses, need to consider how this affects the new path of the pre-existing health condition.
5. Better assessment of the quality of care received by ethnic minority individuals and the health outcomes.

Report (late 2021); method (early 2024)

COLLABORATION FOR CHANGE

Collaboration for change: Promoting vaccine uptake

A co-produced study that combines evidence, literature and lived experience to understand and improve vaccine uptake

ELSEVIER

Check for updates

Journal of Clinical Epidemiology 168 (2024) 111268

Journal of Clinical Epidemiology

METHODOLOGICAL CONSIDERATIONS RELATED TO EQUITY, DIVERSITY, AND INCLUSION IN CLINICAL EPIDEMIOLOGY

Using the GRADE evidence to decision framework to reach recommendations together with ethnic minority community organizations: the example of COVID-19 vaccine uptake in the United Kingdom

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Abstract

Objectives: To make recommendations regarding factors that affect COVID-19 vaccine uptake by ethnic minority individuals in the United Kingdom, together with strategies that could be used to increase uptake.

Study Design and Setting: The results of two rapid systematic reviews—one identifying factors that affect respiratory vaccine uptake in ethnic minority adults and the other identifying experimental evaluations of strategies to increase vaccine uptake in ethnic minority adults—were put into Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) Evidence to Decision frameworks to support discussion with a panel of ethnic minority community organizations, community-focused small companies, and academics of the relevance of the review findings to the UK COVID context. Aided by the frameworks, the panel made recommendations for factors that need to be addressed to increase vaccine uptake, and for which strategies might be used to increase uptake.

Results: Our two reviews contained 31 relevant research studies published in English between 2016 and 2021, all of which were from the United Kingdom (8/31), the United States (20), and Australia (3). We identified six factors—two linked to trust, three linked to information, and one on accessibility—that affected uptake. Strategies that had been evaluated fell into three categories: using trusted messengers, tailoring the message, and increasing convenience. These were put into GRADE Evidence to Decision frameworks and discussed over a series of meetings with individuals from nine ethnic minority community organizations and two community-focused small companies and academics. Community partners provided insight into why ethnic minority individuals in the United Kingdom had lower vaccine uptake, particularly with regard to the impact of nonhealth-related UK Government policy on individuals' heath decision-making.

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https://www.jclinepi.com/article/S0895-4356(24)00023-4/fulltext

Summary

- Working from start to finish with our community partners makes me confident that what we found is meaningful and credible.
- The combination of academic rigour and community partner insight helped us engage with policymakers and others..
- ..but not clear to what extent (and how) findings have been put into practice.
- Think ‘vaccine curiosity’ rather than ‘vaccine hesitancy’.

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