COLLABORATION FOR CHANGE

How do perceived vaccine benefits and harms impact COVID-19 vaccine uptake in ethnic minority communities?

This document summarises discussions with community organisations about the varied concerns around the harm of vaccines, such as the potential risks for those with existing health problems, and how this impacts vaccine uptake in ethnic minority communities. This document also details the evidence that was used to form the decisions made.

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Evidence to decision framework - health system and public health

How important is vaccine harms vs benefits 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: *Vaccine harms vs benefits*

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.

	CRITERIA	JUDGEMENTS	RESEARCH EVIDENCE	COMMENTS
PROBLEM	**Is the factor a important?**	*Don't know* ☐ *Varies* ☐ *No* ☐ *Probably no* ☐ *Probably yes* ☐ *Yes* ☒ ***Detailed judgements***	• In a UK study done in 2020/21, 23 community leaders talking about the COVID-19 vaccines raised fear of vaccine side effects as an issue a number of communities. These were linked to having underlying health conditions [and not being sure how the vaccine would affect them] "We have a lot of pre-existing health conditions – so worrying about vaccine side effects.", Congolese community. There was also concern about religious compatibility. In the Congolese community there was also a perceived pre-disposition to non-communicable disease and this was a reason for caution in the older generation, especially around side effects and interactions with medication. [#grey24; Focus groups; study quality high].[3] • In a UK study done in 2013-2015 with 174 Traveller participants (mainly Romanian Roma and Irish) talking about many vaccines, including in pregnancy and older people, there was widespread understanding that immunisation protects against disease. "it's a very good thing because it protects them from diseases, from illnesses. When they come into contact with the viruses, the body can fight it if they have the right vaccines." A small number of Travellers had a fear of injections and did question the value of immunisation, usually following a belief that someone in their community had been harmed by a vaccine "We're not putting needles or testing you for this and that. It's not the Travellers' way of doing things." [#469; Focus groups and interviews; study quality high].[4] • A UK study reported in 2019 that discussed a range of vaccinations with 20 Polish and 10 Romanian community members and 20 health care workers found that community members considered immunisation useful, the flu vaccine was the dominant vaccine	1. Things are changing re. factors in favour of taking the vaccine, it's now not just only health-related considerations. Other things abvout taking part in society are relevant now e.g. travel, going to events, being able to get or keep a job, attend university lectures. People weigh things up about the importance of vaccine, depending on background eg. Their religious background. Eg in some communities re. whether vaccine is halal, there is an emotional aspect attached to it. [Might also be placed in Strategies #2 'Tailoring the message] 2. The current pandemic and the agenda around what individuals/organisations are doing is changing at such a fast pace, and messaging changes. In Manchester the current priority is to focus on young people (e.g. Covid chats), previously it was to engage with

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		members reported refusing. Refusals were mainly based on the perception that this vaccine is unnecessary or not as important as other vaccines because flu is less serious. There was also concern that having the flu vaccine could cause flu-like side effects. [#761; Interviews; study quality high].[5] • A UK study done in late 2019 with 17 healthcare staff and 8 senior management of mixed ethnicity talking about COVID-19 vaccines found that some people had fears about side effects linked to existing vulnerabilities "So when the vaccine coming now, I say no I will not- I need to read, I need to know 90% for me you know it, it could be that you know especially my system's rubbish, I have vitamin D deficiency, I have anaemia now, I don't know why. So you know my body has, I don't know whether to fight the new thing." ['Other' ethnic group] There was a concern about the unfairness of being forced to take the vaccine when it was perceived as having a limited evidence base behind it "I don't think it's fair to force people to take something that's only been trialled and tested for six months." [Black African] [#stgy372; Interviews; study quality high].[6] • A US study reported in 2016 involving over 100 people (White and Black) talking about the flu vaccines found that many people thought flu was not serious "just like a bad cold" especially when compared to more serious diseases like polio. Some believed flu could be serious, but only people at high-risk, not people like themselves. The most common reason among non-takers was that the flu vaccine was unnecessary because a) their natural immune system would handle flu or b) other common sense behaviours prevent flu "I've never had the flu before, even without getting the shot, so apparently I'm doing something right or whatever the other ways, washing my hands. Whatever it is, I've never felt the need to get the shot." [African American] Individuals actively weigh the risk of disease against risk of side effects. White participants were more likely to simply 'trust' a vaccine while African Americans were more likely to engage in thoughtful discussion. They were aware of concerns in their community but asked questions and made an active choice to trust "I don't distrust government or distrust medical professionals. I do ask questions. You ask questions of more than one person, but you don't come with the premise of distrust" [African American] [#336; Focus groups and interviews; study quality high] [7].[7] • In a UK study done in 2020/21 with 20 advice workers, community liaison, community councilors, talking about the COVID-19 vaccine safety was a major concern even among those willing to take the vaccine. "No, I will not be taking a [COVID-19] vaccine … One, they didn't have enough studies. It takes at least a year and a half, two years or three years for them to complete a study and they did it in four months." [#73; Telephone interviews; study quality high].[8] • A US study done in 2020 with 24 participants talking about COVID-19 vaccines also found that safety was a major concern because vaccine development was rushed. There were specific concerns linked to the virus being a novel virus [or vaccine?] with no established safety profile. Participants did not want to be in the first round of those	South Asian, not on young people in schools etc. Trying to keep up. In terms of what we say today, might be very different in a few months time. General point is what is being said today might not be applicable in a year's time. 3. We are learning, what are the key issues we are hearing and changing messaging constantly. 4. The weighing up of benefits and harms provides an opportunity to provide health education re. vaccines. What they are they, how they help. Learn what community needs. Understanding how vaccines work in a non-scientific way may help to avoid problems in the future. 5. When we talk about harms in most instances it not so much about harm now as what sorts of harms might be possible. What might happen in 5, 10 years? Doubts about that can lead people to not take the vaccine because we don't know what the future harm might be. [Might be also be placed in Strategies #2 'Tailoring the message'] 6. 'Harm' might be wrong word, maybe disbenefits (i.e. benefits vs disbenefits) [It's about pros and cons]. 7. As a strategy for reaching people, WhatsApp has been a good way to tailor messages, even for people who are not so tech savvy, or had low literacy. [Might be also be placed in Strategies #2 'Tailoring the message'] 8. Major public health organisations should have ongoing ways of countering messages and misperception but using the same platforms, may mitigate the impact. [Might be also be placed in Factors #1 'Availability of appropriate

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		receiving the vaccine and they wanted more transparency about vaccine development and adverse effects. [#18; Focus groups' study quality high].[9]	information' and Strategies #2 'Tailoring the message']. 9. Discussions of harm depend on where a person in their life, e.g. young people interested in future, pregnant women to unborn child, sometiems older people didn't share the concerns because they said we have lived our lives and whatever happens, happens. The message needs to be tailored to perception of harms. E.g. messages for teachers need to consider the potential harm from children. For people with pre-existing serious health conditions, information needs to address this. This will be heavily reliant on facts, countries, race, conditions, health, and hard to provide this without real evidence. [Might be also be placed in Factors #1 'Availability of appropriate information' and Strategies #2 'Tailoring the message']. 10. Events such as the death of Lisa Shaw from blood clots linked to the AZ vaccine will reenforce the worry of those who already had concerns. But the Lisa Shaw case highlights that harms done to White people attract more attention than real or potential harms done to ethnic minorities.

	CRITERIA	JUDGEMENTS	RESEARCH EVIDENCE	COMMENTS
BENEFITS & HARMS OF THE FACTOR	**How big are the anticipated benefits?**	*Don't know* ☐ | *Varies* ☐ | *Trivial* ☐ | *Small* ☐ | *Moderate* ☒ | *Large* ☐ **Detailed judgements**	• A 2018/19 US study of 1666 pregnant women from under-served populations and linked to influenza vaccines found that the most common reasons for vaccine refusal overall were classed as 'perceived barriers', within which the most common barriers were concern about getting sick from the vaccine (18.5%), concern about getting flu from the vaccine (15.4%) and not liking jabs (14.7%) [#135; Survey; study quality high].[10] • A US study done in 2015/16 involving 1420 adults from a range of ethnic backgrounds discussing the flu vaccine found across ethnic groups the most common reasons (around 30%-45%) for non-vaccination were vaccine safety and disease susceptibility and severity (i.e. of flu) [#282; Survey; study quality moderate].[11] • A US study done in 2016 involving 7398 people of many ethnicities discussing the flu vaccine found that Black people (41%) were more likely than Hispanic people (27%) and White people (25%) and Other ethnicity (21%) to report concerns about getting flu from the vaccine. Black people (40%) were more likely to report concerns about side effects from the vaccine than other ethnicities. The overall reason for not getting the vaccine was the same for all ethnic groups– 'unlikely to get very sick from the flu'. [#327; Survey; study quality moderate][12] • A US study done in 2020 involving approx. 1000 Black and 250 Latinx adults discussing the COVID vaccines found the strongest predictor of vaccine uptake was trust that the vaccine was safe. [#1594; Survey; study quality moderate].[13] • A US study done in 2012/13 involving 1565 Hispanic women found that a major predictor of regular flu vaccination was confidence in the safety of the vaccine [#796; Survey; study quality low].[14] • A US study done in 2017/18 involving 281 African American patients with heart failure discussing flu vaccination found that major reasons for declining vaccinations included fear of getting sick and dying from the flu vaccine (66%) and fear the vaccine could make their heart condition worse (34%) GP [#224; Survey; study quality very low].[15] • A UK 2020 survey of a representative sample of 2076 adults asked about taking the COVID-19 vaccines found that of 477 who said they were unlikely or unsure about taking the vaccine, compared to White people, ethnic minorities were more likely to change their mind if a GP or health professional gave them more information about how effective the vaccine was (35% vs 18%), the potential side effects (32% vs 19%) and the ingredients of the vaccine (32% vs 18%). [#grey 6; Survey; study quality very low].[16] • A UK 2021 survey of 334 Muslim respondents from a survey of over 1000 ethnic minority people discussing the COVID vaccines found that 18% thought the vaccine was poisonous and this was why they would not take it. Some	1. Where people have vaccine and get severe reactions, it gets heard about and puts people off. Small numbers of poor harms e.g blood clots can be perceived as having more importance than benefits in general. [From Factors #2 discussion]. 2. People with, say, diabetes feel more scared because of this comorbidy. [From Factors #2 discussion]. 3. Found highest hesitancy for vacine among Black people, many more from these communities said how they knew someone was ill because of vaccine. Higher than other rates than other communities.
	How big are anticipated harms?	*Don't know* ☐ | *Varies* ☐ | *Large* ☐ | *Moderate* ☒ | *Small* ☐ | *Trivial* ☐ **Detailed judgements**		
	How certain are we about the above?	*No included studies* ☐ | *Very low* ☐ | *Low* ☐ | *Moderate* ☐ | *High* ☒		

	CRITERIA	JUDGEMENTS	RESEARCH EVIDENCE	COMMENTS
			(11%) did not see COVID as a credible danger, or thought nature should take its course (16%). theories [#grey 17; Survey; study quality very low].[17] • An Australian study one in 2017 involving 273 Aboriginal community members discussing the flu vaccine found that vaccinated participants were more likely to report the vaccine as very effective (79% vs 46%) and less likely to report that they ever got flu (60% vs 71%, and less likely to report that the vaccine can cause flu (44% vs 58%) [#232; Survey; study quality very low].[18]	
BALANCE	**Is the factor a barrier or an enabler?**	*Don't know* ☐ / ***Varies*** ☒ / *Favours barrier* ☐ / *Probably favours barrier* ☐ / *Does not favour either* ☐ / *Probably favours enabler* ☐ / *Favours enabler* ☐ **Detailed judgements**	**See the research presented in the 'Is the factor important'? section.**	1. Whether the factor is a barrier or an enabler depends on an individuals judgement as to how the balance of harms vs benefit weigh up.

Conclusions

	We recommend that the factor be consider a barrier	We suggest that the factor be considered a barrier	We suggest that the factor can be either a barrier or an enabler	We suggest that the factor be considered an enabler	We recommend that the factor be considered an enabler
Type of recommendation	☐	☐	☒	☐	☐

Recommendation/decision Evidence from the UK, the US and Australia, plus our own experience, suggests that the perceived balance between the potential benefits of the COVID-19 vaccine and the potential harms of the vaccine is an important factor in decisions about having the COVID-19 vaccine. The issues that fall on either side of that balance are changing: earlier in the pandemic both harms and benefits were mainly health-related, now they include the ability to participate in society as rules change. The harms that people have concerns about depends on where a person is in their life: the young have different concerns to the old. Stories of harm, real or not, can travel far and have an impact beyond the actual likelihood of experiencing the harm. Organisations promoting vaccine uptake need to counter misinformation using the same platforms as those spreading the misinformation.

Justification

The balance of potential harms vs potential benefits is an important factor when it comes to accepting the offer of the COVID-19 vaccine. Early in the pandemic worries about harms were mainly health-related and linked to how the vaccine affected those with pre-existing illnesses or conditions. This remains but judgements now also include consideration of to what extent an individual can participate in society without being vaccinated. Examples of participation affected by vaccine status include international travel, attending events and education, or getting or keeping a job.

The discussion around benefits vs harms varies depending on where a person is in their life. The young may worry more about the future ('What impact might the vaccine have on me in ten years' time?'), those who are pregnant worry about the effect on their unborn baby and older people may be less concerned about future potential harms of the vaccine because of more immediate concerns about COVID-19. Messaging should consider these differences. Uncertainty should be acknowledged. No-one knows for sure what the very long-term effects of the vaccines are. Organisations need to counter misinformation using the same platforms as those spreading the misinformation.

Stories of harm, real or not, can travel far and have an impact beyond the actual likelihood of experiencing the harm. Some of the fears about harm are associated with poor understanding of how vaccines work. Although the UK majority population also had concerns about harms, the issues in ethnic minority groups had more impact and are likely to include some different issues from the majority population, particularly linked to comorbidities. Knowing what is of most concern to a particular ethnic group needs close collaboration with groups working closely with those ethnic minority communities. Knowing what these issues are for ethnic minority groups and providing reassurance/information is important because the impact of this factor is expected to be at least moderate.

Subgroup considerations

'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.

Concerns about harms vs benefit of the COVID-19 vaccine vary between specific ethnic groups; there is no universal set of concerns.

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.

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