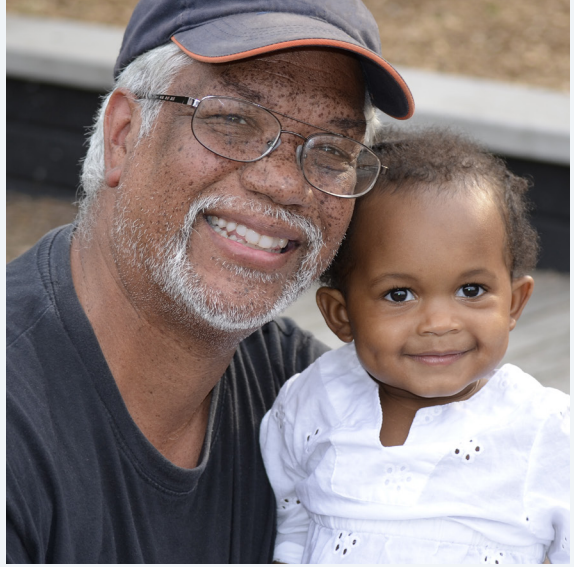
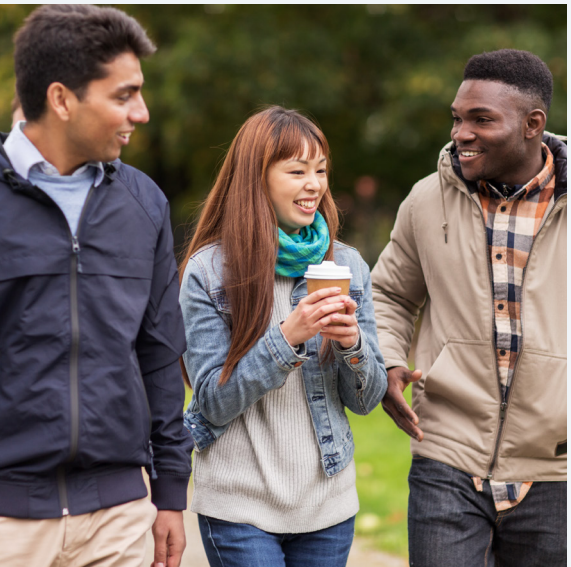


COLLABORATION FOR CHANGE

How does the availability of appropriate information impact COVID-19 vaccine uptake in ethnic minority communities?



This document summarises discussions with community organisations about the availability of appropriate health-related information, how this impacts vaccination uptake in ethnic minority communities, and the evidence that supported the decisions made.

To read the full summary, visit www.collaborationforchange.co.uk

Evidence to decision framework - health system and public health

How important is availability of appropriate information 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:

Availability of appropriate information

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.

		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, all 23 community leaders raised the lack of health information and language barriers influencing health-seeking behaviour. All community leaders commented on the deficit of simple, accurate and trustworthy health information and messages about COVID-19 and vaccination available to their communities. This allowed a space for misinformation to circulate especially via social media (e.g. Whatsapp, Facebook, TikTok) "They are reading social media discussing the issues, with lots of people telling them opinions without searching or not doing investigations - bad advice worse than no advice. Causing serious problems. Rumours include this being a new type of vaccination that won't work". [#grey24; Focus groups; study quality high].[3] • In a UK study done in 2020/21 with 20 advice workers, community liaison, community councilors, talking about the COVID-19 vaccine, negative and contradictory stories on social media led to confusion and hesitancy. This played on lack of knowledge about how vaccines work. There was confusion about which sources could be trusted "There's like all WhatsApp groups and things, there were just stuff flying around on that and videos and all sorts and it was just like awful, what is the truth, what's not.... Oh, it were all just contradicting." [#73; Telephone interviews; study quality high].[4] • 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, found that there was widespread understanding that immunization protects against disease but knowledge of specific vaccines was more variable and sometimes misinformed [#469; Focus groups and interviews; study quality high].[5]	1. Government infomation often changes weekly– do this, now do that. People struggle to understand this information, and why it keeps changing, or it is being provided in a medium we don't have access to, or language they understand. This does not give confidence in the information and this happened with information on the COVID vaccine. 2. The level of the information was not right (i.e giving confidence). Community groups have worked locally with communty leaders (and individuals in community) to produce short videos and translated information. This connected more with people speaking in their own language, and used Facebook, twitter, WhatsApp. [Might also be placed in Factors #5 'Language' and Strategies #2 'Tailoring the message'] 3. Some people talk about information they have got from 'back home' saying we

		JUDGEMENTS	RESEARCH EVIDENCE	COMMENTS
				should do this or that, and this is different from UK gudiance. May choose to follow the guidance from 'back home' rather than UK, information easier to understand and access. A major issue. [Might also be placed in Factors #5 'Language'] 4. Scientists and others talk in media to encourage people to take the vaccine but often this is a 'just get it' message, there is less on the evidence of benefits of vaccine. Need more information coming forward on e.g. pregnant women talking about how they were affected (no ill effects from vaccine), child well, this would be more useful. A lot of of information is about people who don't have vaccine and the bad things that happen to them. More on the benefits. [Might also be placed in Strategies #2 'Tailoring the message'] 5. Information should be translated into a type of language that communities can understand. Not just about one or other world langauge (e.g. English vs another language). [Might also be placed in Factors #5 'Language' and Strategies #2 'Tailoring the message'] 6. Messaging – translation is often not about translation into a different language but more about offering a spoken helpline. Often provision of this happens late. Spoken information is better for many. A lot of the COVID vaccine material was a straight regurgitation of existing material, not very practical, and need more verbal more and more visual presentations. The poor translation element may have miscommunicated the message. [Might also be placed in Factors #5 'Language'

		JUDGEMENTS	RESEARCH EVIDENCE	COMMENTS
				and Strategies #2 'Tailoring the message'] 7. And some people can speak a language but not read it, which means a written translation is no good, want to speak about issues. We also want more lay langage. [Might also be placed in Factors #5 'Language' and Strategies #2 'Tailoring the message'] 8. Information needs to target where it is needed most. We asked for information on hotspots, need local data to target. This is where information is most important. [Not always easy to get local information?] 9. What is happening 'back home' makes a difference. At one point India was handling COVID well, people looking at the information 'back home' were getting message it's going well and this influences behaviour in this country. When the situation in India changed, panic here rose and may have prompted people to start thinking about getting the vaccine. Some miscommunication from both India and UK. 10. It is important who is talking about vaccine – trusted faith and community leaders, plus case studies about what happened with COVID and the vaccine. It is about how I protect myself and my family. [Might also be placed in Strategies #2 'Tailoring the message'] 11. The right messaging – lived experience is very powerful– people who have lost a family member may help with vaccine information. [Might also be placed in Strategies #2 'Tailoring the message'] 12. Need video/visual information because literacy can be low in some communities.

		JUDGEMENTS	RESEARCH EVIDENCE	COMMENTS
				13. There has been frustration in the last two years, collective failure of community organisations to pool resources quickly. E.g. Rotherham may have small Somali community but it is important and we don't have the infratructure to support timely translation. But there are larger communities in other parts of country. Need to work and connect together to pool resources. Messages changing rapidly and if it takes five days to create a video, we will miss boat. 14. Information needs to be consistent. Some scientists saying one thing, but governmemt says something else. E.g. herd immunity, or scientists say close schools but government doesn't do this. Scientists and government don't always agree but could information say what is really going on despite the disagreement. Honesty. At the time decisions are being made, if evidence is not clear everyone should say this. This is a major point. 15. Information is often not culturally appropriate, a shortage of such information. [Might also be placed in Factors #5 'Language' and Strategies #2 'Tailoring the message'] 16. Language can be very important for some communities, especially when combined with a trusted organisation/person to deliver the message. The message on it's own is not enough, it needs trust as well. The approach needs to capture the variation in how communties would like receive information. Using a channel (e.g. TV) is no good if the people you are targeting don't watch TV. [From Factors #5 discussion 26/8/2021].

		JUDGEMENTS	RESEARCH EVIDENCE	COMMENTS
				17. Anti-vax is not the issue driving lower uptake. People are not anti-vaccines, they have unanswered questions. If a community is targeted, and people are there to carefully answer questions, people come, feel comfortable, have specific questions, and if answered, people do feel reassured. They go away more likely to accept the vaccine offer. 18. There is often no referral pathway for answering questions within the NHS. People may be sent to a helpline staffed by people who do not know about you and are unable to give answers about your own personal situation, which is what is really needed to give reassurance. General answers are not what is needed– what does taking the vaccine mean for me? People can be told to talk to a specialist but those specialists do not want to talk, or there is no way to get to them. 19. For questions linked to an individual's specific health concerns, GPs are key. But if reservations are not health-related but, say, faith based, then other organisations become important. [Might also be placed in Strategies #2 'Tailoring the message'] 20. Information needs to be honest. A lot of COVID vaccine messaging is 'Get the vaccine'. It doesn't talk about benefits, the likely risks, what we know, what we don't. Honesty build trust. It doesn't combat directly conspiracy theories that circulate and often it doesn't use the same channels as those theories. Need to aks why information flourishes in the face of more accurate information. [Might also be

		JUDGEMENTS	RESEARCH EVIDENCE	COMMENTS
				placed in Strategies #2 'Tailoring the message'] 21. Many ethnic minorities live in communities, meaning an adverse event linked to the vaccine (whether correct or not) can quickly become the accepted view of the whole community. 22. Some ethnic minority communities live in multigenerational households and this fact has not been used in public health information provision. Vaccine delivery did not recognise that many older people could not get to a vaccination centre so the family waits until everyone can go. The delivery system should be tailored to allow household vaccination, recognising how people live [Might also be placed in Strategies #3 'Flexible venues & times']. 23. Major public health organisations should have ongoing ways of countering messages and misperception but using the same platforms, may mitigate the impact. [From Factors #4 discussion 26/8/2021]. 24. 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. [From Factors #4 discussion 26/8/2021].

	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 *(see 'COMMENTS')***	• Harms are most likely linked to what emerges to fill the vacuum the lack of information leaves. People may get information from their home countries, especially where information in their own language is not available [#grey24; Focus groups; study quality high].[3] • A 2018/19 US study of 1666 pregnant women from under-served populations and linked to influenza vaccines found that compared with those who initially refused vaccine and were later vaccinated, women who refused consistently and were not vaccinated were more likely to cite 'perceived barriers' (58.2% vs. 27.9%), many of which were information-related. They were also more likely to cite reasons in the 'perceived benefits' category (i.e., will the vaccination prevent influenza?) (38.5% vs. 7.6%) [#135; Survey; study quality high].[6] • 2014 US study of 178 people from underserved groups and linked to influenza vaccines found that predictors of getting vaccinated included perceived benefit (x9 chance) and perceived safety (x7) [#979; Survey; study quality low].[7]	1. An example discussed was an African Caribbean individual who has been afraid of needles for over 20 years. What sort of information is available for individuals like this? How can we encourage this person to be confident? Wait for nasal spray? (this was an option that had been suggested to the individual). Wait for other options in next few months? 2. Even if accurate, having too much information can also be misused. The information might be correct but it is part of a larger body of information, and people may combine it with this large body in ways that not correct, or may skew it. The information can then be misconstrued. How different pieces of information are put together is important. More is not always good. Too much is a problem sometimes. 3. Work done by one of the Collaboration partners found that people thought there was too much information on social media and the internet, which was overwhelming. Some of it was fake, some true, but which is which? People get stuck and don't know what to do. 4. Mistrust of mainstream organisations leads to people using 'unregulated information'. Migrants (e.g. Somali community) tend to get their news from rest of world. When stories came out about the AstraZenica vaccine and blood clots and the EU said its citizens won't get the AZ vaccine, that influenced decisions here in the UK. Our information comes from elsewhere, it's global. Ethnic minority communities have strong links with other countries, some of
	How big are anticipated harms?	*Don't know* ☐ | *Varies* ☒ | *Large* ☐ | *Moderate* ☐ | *Small* ☐ | *Trivial* ☐ **Detailed judgements *(see 'COMMENTS')***		
	How certain are we about the above?	*No included studies* ☐ | *Very low* ☐ | *Low* ☐ | *Moderate* ☐ | *High* ☒		

	CRITERIA	JUDGEMENTS	RESEARCH EVIDENCE	COMMENTS
				their information will come from those countries. This is not just for the vaccine but for COVID in general. 5. These overseas links mean the importance and impact of global information, rather than UK information, will be greater for ethnic minority populations than the majority population. Anything going out globally needs to be considered. 6. Not having clear information can have a large effect. Also depends on the source of the information though. Sometimes have good information, even translated, but if don't have right source behind the information (i.e. one that is trusted) this reduces the impact of the information on decisions. Need to channel information through the right sources. 7. From the point of view that we want 100% covered by the vaccine, information that is poor, or delivered badly, will have a large negative impact. 8. Often information has some tailoring but this is for the usual suspect barriers, things like the language, having pictures of people who are like people targeted. But there is less attention on other factors– and identifying these needs collaboration and partnership to tap into the non-usual suspect barriers. 9. The politicisation of the vaccine and information around it cannot be forgotten.
Having 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*	**See the research presented in the 'Is the factor important'? section.**	

	CRITERIA	JUDGEMENTS	RESEARCH EVIDENCE	COMMENTS
		☐ ☐ ☐ ☐ ☐ ☐ ☒ **Detailed judgements *(see 'COMMENTS')***		

Conclusions

	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
Type of recommendation	☐	☐	☐	☐	☒

Recommendation/decision

Evidence from the UK and the US, plus our own experience, suggests that the availability of appropriate information (i.e., tailored to the specific information needs of its audience and delivered in a way that is culturally and linguistically acceptable) is an important factor in decisions to accept the COVID-19 vaccine. This is about more than translation from one world language into another but ensuring the information is provided in a form that ethnic minority individuals find acceptable, answers their concerns and pays attention to information coming from countries outside the UK with which they may have ties. Knowing what is needed requires collaboration with ethnic minority groups.

Justification

Information plays a key role in the vaccine decisions of all ethnic groups. Information that has, however, been designed for the majority population is unlikely to be as effective for ethnic minority individuals who may have different information needs. Moreover, how information is provided and, crucially, who provides it needs careful attention. Correct information channelled through organisations that do not have the trust of ethnic minority individuals will not be effective in increasing vaccine uptake (see also Factors #2 and #3).

Anti-vax is not the issue driving lower uptake. People are not anti-vaccine, they have unanswered questions. If a particular community is targeted, and trusted people are there to carefully answer specific questions, people come, feel comfortable, ask their questions and go away more likely to accept the vaccine. Often, however, people are sent to helplines staffed by people who cannot answer the questions people have. GPs have a key role because they can provide information that is specific to an individual's health. Where concerns are not health-related but, say, faith-based, other organisations also become important.

Information needs to be honest (i.e. don't just say 'Get the vaccine' but talk about benefits, risk, what we know, what we don't). This will build trust. It should also use the range of channels used by ethnic minority individuals and directly counter misinformation on those channels where it exists using a trusted messenger (see Factors #3 and Strategies #1).

Ethnic minority groups have strong links outside the UK and global information about vaccines plays a larger role in decisions made by ethnic minority individuals than it does for the majority population. What is being said (and what is happening) in 'home countries' – countries with which people have family links – is an important source of information for many people in ethnic minority communities. UK information provision needs to pay attention to information being promoted in 'home countries'. The latter is often more accessible, easier to understand and trusted but not always scientifically correct. Overcoming this information needs trusted partners who can channel information appropriately.

COVID-19 has been fast moving and the information needs change rapidly as the COVID situation in the UK and other countries changes. Knowing what information needs to address, and how, needs close collaboration with groups working closely with ethnic minority communities.

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. Different ethnic groups get their information from different places, especially and most obviously linked to 'home countries'.

There is no such thing as information for ethnic minorities. Information must be tailored to the information needs of specific ethnic groups.

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 they obtain from that care. Improved methods to address differences in outcome between ethnic minority and the majority population.

References

1. OpenSAFELY. NHS Covid vaccination coverage 2021 2021. Available from: https://www.opensafely.org/research/2021/covid-vaccine-coverage/#weekly-report (Accessed 3 August 2021).

2. Robertson E, Reeve KS, Niedzwiedz CL, Moore J, Blake M, Green M, et al. Predictors of COVID-19 vaccine hesitancy in the UK household longitudinal study. Brain Behav Immun. 2021;94:41-50.

3. Crawshaw AF, Hickey C. Summary report: COVID-19 vaccination scoping workshops with migrant community leaders in Hackney: perspectives to inform future research [unpublished]. London: St George's,University of London Hackney CVS; 2021.

4. Lockyer B, Islam S, Rahman A, Dickerson J, Pickett K, Sheldon T, et al. Understanding COVID-19 misinformation and vaccine hesitancy in context: Findings from a qualitative study involving citizens in Bradford, UK. Health Expect. 2021;04:04.

5. Jackson C, Dyson L, Bedford H, Cheater FM, Condon L, Crocker A, et al. UNderstanding uptake of immunisations in travelling aNd gypsy communities (UNITING): A qualitative interview study. Health Technol Assess. 2016;20(72):vii-175.

6. Goggins ER, Williams R, Kim TG, Adams JC, Davis MJ, McIntosh M, et al. Assessing Influenza Vaccination Behaviors Among Medically Underserved Obstetric Patients. J Womens Health. 2021;30(1):52-60.

7. Padilla ME, Frietze G, Shenberger-Trujillo JM, Carrillo M, Loya AM. Influenza and Intentions to Vaccinate in an Underserved Hispanic Population: The Role of Theoretically Derived Constructs. J Pharm Pract. 2020;33(3):326-33.