



Research Report: COVID-19 vaccine hesitancy, medical mistrust, and mattering in ethnically diverse communities

Contributors

Professor Divine Charura, York St John University

Professor Andrew Hill, York St John University

Heather Nelson, Chief Executive Officer, Black Health Initiative (BHI)

Marianne Etherson, York St John University



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YORK
ST JOHN
UNIVERSITY



“As the CEO of BHI it was obvious from our Webinar ‘COVID Conversation’ that there were questions to be answered before the uptake of the vaccination. The distrust of health providers/NHS due to many factors were coming through and the blanket national drive was neither reaching or addressing issues of those who had repeatedly been reported as being ‘vaccine hesitant’. Approaching York St John University was to explore this issue further and we are pleased they accepted. This report is the result of collaborative working and we thank all who took part in the research and NHS CCG Leeds who provided the monies to support the research which we hope will be used as a tool to equity of health for all citizens.”

Heather Nelson

CEO Black Health Initiative (BHI)
Member – NHS Race & Health Observatory

“Our research on mattering, medical mistrust and vaccine hesitancy, will help us better understand the underlying psychological factors associated with COVID-19 vaccine hesitancy, as well as the lived experience of those from diverse communities that influence their decision-making process, health beliefs and health behaviours.”

Divine Charura

Professor of Counselling Psychology
York St John University

“York St John University is committed to empowering people to make informed choices that protect and promote their health and wellbeing. Part of doing so is to better understand why people make the decisions they make. In this regard, our research provides invaluable insight into COVID vaccine hesitancy in diverse communities.”

Andrew Hill

Professor of Sport and Exercise Psychology
York St John University



Heather Nelson



Divine Charura



Andrew Hill



Marianne Etherson



Background

Uptake of the COVID-19 vaccine is lower among ethnically diverse groups (Robertson et al., 2021). This is particularly evident among Black ethnicity groups, in which 1 in 3 report hesitancy in receiving the vaccine (Office for National Statistics, 2021). This data is in line with historical trends in vaccine hesitancy and vaccine uptake more generally in ethnically diverse groups in England (UK Scientific Advisory Group for Emergencies, 2021). In order to promote COVID-19 vaccination among ethnically diverse communities, the factors underpinning the current trend and their hesitancy need to be better understood. In the current study we focus on two factors: feelings of mattering and medical mistrust.

Medical mistrust pertains to both the absence of trust and sense that someone or something is acting against one's best interests; this can include health care providers, systems, and government (Jaiswal & Halkitis, 2019; Bogart et al., 2021). Grounded in historical inequities, discrimination, and negative healthcare experiences, evidence suggests medical mistrust is higher in ethnically diverse groups (Bogart et al., 2021). Medical mistrust is also associated with lower use of medical services, generally, and is thought to be central to Covid-19 vaccine hesitancy among ethnically diverse groups (Razai et al., 2021).

Feelings of mattering may also be important in regards to understanding people's views on the COVID-19 vaccine. Mattering refers to feeling like you are depended on, important and valued (Rosenberg & McCullough, 1981). This contrasts to feeling like you do not matter, are invisible, insignificant or uncared for (Flett, 2018). It has recently been argued that feeling like you matter may help people cope with the COVID-19 pandemic by combating stress, loneliness and isolation (Flett & Zangeneh, 2020). Here, we were interested in the possibility that feeling like you don't



matter was related to COVID-19 vaccine hesitancy due to greater mistrust – a possible extension of feelings of being underserved, undervalued and marginalised.

Aim of the study

The aim of our study was to examine whether medical mistrust and feelings of mattering were related to hesitancy towards the COVID-19 vaccine in ethnically diverse groups.

Research Questions / hypotheses

Our research question was "Do medical mistrust and feeling like you don't matter predict greater hesitancy towards the COVID-19 vaccine?"

Key things we measured

Medical mistrust – Mistrust of healthcare organizations and health professionals.

Mattering – Feeling significant, important, and valued by others versus feelings invisible, insignificant or cared for.

COVID-19 vaccine hesitancy – Uncertainty and ambivalence towards COVID-19 vaccination.

COVID-19 vaccine likelihood – Willingness and intent to have a COVID-19 vaccination.

General thoughts and feelings towards COVID-19 vaccine – Open questions that provided an opportunity for respondents to report general thoughts and feelings.



Methods	
Participants	<p>150 adults from ethnically diverse backgrounds (mean age = 46.20, SD = 15.13; male = 56 and female = 90, preferred not to say = 2, other = 2):</p> <ul style="list-style-type: none"> Asian or Asian British – Indian (6) Asian or Asian British – Pakistani (5) Asian or Asian British – Bangladeshi (1) Asian or Asian British – any other Asian background (4) Black or Black British – Caribbean (62) Black or Black British – African (36) Black or Black British - other background (19) Mixed – White and Black Caribbean (10) Mixed – White and Black African (1) Mixed – White and Asian (1) Mixed – Any other mixed background (3) Any other ethnic origin group (2)
Sampling	<p>The sampling strategy was one of convenience (based on willingness to complete the online survey) and purposeful (targeting people with ethnically diverse backgrounds).</p>
Data collection method	<p>An online survey was distributed via a weblink to organisations that work with ethnically diverse communities, including the Black Health Initiative and other social media groups and websites. The questionnaire was open for 7 weeks (15 March to 7 May, 2021).</p>
Ethical approval	<p>The study received ethical approval from York St John University.</p>
Type of study design	<p>A cross-sectional design was used (an online survey completed once).</p>



Methods

Measures used	<p>The online survey included a number of different self-report measures.</p> <p>Self-report measures were selected based on their use in previous research, reliability and validity.</p> <ol style="list-style-type: none"> 1. General Mattering Scale (Rosenberg & McCullough, 1981). 2. Anti-Mattering Scale (Flett, 2018). 3. Oxford COVID-19 Vaccine Hesitancy Scale (Freeman et al., 2020). 4. Group-based Medical Mistrust Scale (Thompson, Valdimarsdottir, Winkel, Jandorf, & Redd, 2004). 5. Two expansion questions to follow up the intention to vaccinate against COVID-19 in which respondents could free write qualitative comments. <p>We also provided three opportunities for respondents to elaborate on the on the self-report measures.</p> <ol style="list-style-type: none"> 6. Two expansion questions to follow up the intention to vaccinate against COVID-19a question in which respondents could free write their qualitative answers. <ul style="list-style-type: none"> If you have answered that you are likely to have the COVID-19 vaccination, is there anything else you want to add/say? If you have answered that you are NOT likely to have the COVID-19 vaccination, is there anything else you want to add/say? 7. A general question which gave respondents of the survey an opportunity to elaborate on their general thoughts or feelings around the COVID-19 pandemic, lockdown or vaccination. <ul style="list-style-type: none"> Is there anything else you want to say about your thoughts or feelings around the Covid-19 pandemic, lockdown or vaccination etc?
Approach to data analysis	<p>Descriptive statistics (means and standard deviations) examining typical levels.</p> <p>Multiple regression to examine which of the factors we measured predicted COVID-19 vaccine hesitancy and intention to vaccinate against COVID-19.</p> <p>Thematic analysis was conducted on the expansion and general questions in line with Braun and Clarke (2006). Each theme captures something important about the data and in some way represents a level of patterned response or meaning in the responses.</p>



Results and Conclusions

<p>Results</p>	<p>Descriptive statistics for respondents are reported in Table 1.</p> <hr/> <p>Key findings 1:</p> <ol style="list-style-type: none"> 1. Approximately half of the participants indicated they would definitely or probably get a COVID-19 vaccination (44.7%). 2. Approximately a third indicated they were keen or positive towards the idea of COVID-19 vaccination (31.3%). 3. A similar amount would encourage, or strongly encourage, others to get a COVID-19 vaccination (38.7%) 4. However, approximately a third of the participants indicated they would definitely not or probably not get a COVID-19 vaccination (39.3%). 5. Approximately one fifth of participants indicated they were against it (20.7%) and would refuse it (22.0%). 6. A similar amount would suggest to others not to get it (20.7%). <hr/> <p>Key findings 2:</p> <ol style="list-style-type: none"> 1. Perceptions of mattering and not mattering did not predict reported COVID-19 vaccine hesitancy. 2. Perceptions of mattering and not mattering did not predict reported likelihood of getting the COVID-19 vaccine. 3. Medical mistrust did predict COVID-19 vaccine hesitancy. <ul style="list-style-type: none"> The more participants reported that they were suspicious of doctors, health care workers, and medicine, the greater their hesitancy towards the COVID-19 vaccine. 4. Medical mistrust did predict reported likelihood of getting the COVID-19 vaccine. <ul style="list-style-type: none"> The more participants reported that they were suspicious of doctors, health care workers, and medicine, the lower the reported likelihood of getting the COVID-19 vaccine. The more participants reported that they were suspicious of doctors, perceived a lack of support from doctors and health care workers, the lower the reported likelihood of getting the COVID-19 vaccine.
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Results and Conclusions

Results

Key findings 3:

In line with quantitative analysis results in key findings 1 and 2 we found a plethora of responses to the expansion and general questions we asked. The findings in this section were conceptualised from a thematic analysis of the expansion and general questions. There were a number of revealing qualitative comments about how participants who had not had the vaccine at the time of our research felt about the COVID-19 vaccine. We conceptualised the qualitative comments into 4 themes as follows:

1. Believing it's important to take the vaccine and seeing it as a social responsibility

A small number of participants despite being hesitant, voiced in their qualitative responses that they felt it was important to take the vaccine for a number of reasons. Some included they had to do so because of having a sense of wider responsibility to society whereas others felt they had to do it as they saw it as a rule to be followed. These perspectives are relayed by the following quotes:

"I think it's important to follow the rules"

"Everyone should take the vaccine to protect all of the population"

"need to stay safe and feel the need to keep others safe"

"Ethnic minorities have a role to play in the management and spread of Covid-19 and should take this responsibility seriously"

Despite these comments which relayed some reasons of why it may be important to take the vaccine, the majority of the quotes which informed the themes revealed as noted in the next 3 themes that follow, the reasons of the participants' Covid-19 vaccination hesitancy. The participants also communicated through the quotes that follow, their general mistrust as well as the external pressure they were feeling to have it.

2. Feelings of being hesitant and pressured/forced to take the vaccine and having limited/no choice

A number of repeated responses from the participants evidenced that they felt pressured or forced to take the Covid- 19 vaccine. Some stated:

"I'm only doing it because the government seem to be saying that they won't let me travel without it"

Results

Some spoke of feeling hesitant but expressed feeling under pressure to take the vaccine because of their profession:

"...feeling pressured to take it"

The next theme that follows was conceptualised as focusing on mistrust and the reasons for it are relayed through the quotes.

3. General mistrust linked to personal experiences, and relating to the health system rather than an anti-vax position

"I would like more information about the COVID vaccine trials on my ethnic group"

"As a black man I don't trust what is being said"

"..... I can understand the distrust about medical care from an ethnicity distrust perspective but NOT from an overall anti-vax perspective".

"I would get it, but it is still in the trial stage. I'll wait awhile"

"Location is important so that I feel comfortable and trust the process".

Other participants listed reasons for their mistrust. An example is of the quote below which noted a range of historic studies that they relayed was a cause of medical mistrust within those from minority ethnic groups in the UK.

"Unethical medical experimentation that has occurred for over a century may be the cause of the fear and mistrust of doctors and medicines for example..... and..... The Tuskegee Study of Untreated Syphilis in the Negro Male was an unethically unjustified study conducted between 1932 and 1972 by the United States Public Health Service..... basing on such examples it is difficult to trust medical professionals and their practices peradventure history repeats itself on Ethnic Groups"

Some participants responded that they were hesitant to take the vaccine but felt that not doing so would potentially result in being socially and medically restricted.

4. Being hesitant, reluctant and concerned about being socially or medically restricted if not vaccinated

There were a number of qualitative comments that relayed hesitancy to get vaccinated but also concern that to not be vaccinated would impact social activities, civil liberties, and future health and care.

"I will do it reluctantly as I am a student who feels like my options would be restricted if I didn't take it"

"Especially because of the impact on my civil liberties if I don't have the vaccine"

"I need to travel so it's not really about my health"

"I need to establish some normality and the vaccine could do that for me"

"I am doing it for convenience's sake with fear that if I refuse it might affect my future care and treatment"

Contribution or attribution

Based on the design used in this study, we can conclude that there is evidence that medical mistrust is related to COVID-19 vaccine hesitancy and likelihood of getting the COVID-19 vaccine.

However, we cannot conclude that medical mistrust causes COVID-19 vaccine hesitancy and likelihood of getting the COVID-19 vaccine.

Table 1. Responses of participants to COVID-19 vaccine hesitancy and intentions questions.

Question	Response	Number of respondents	%
1. Would you take a COVID-19 vaccine (approved for use in the UK) if offered?	Definitely	51	34.0
	Probably	16	10.7
	I may or I may not	24	16.0
	Probably not	33	22.0
	Definitely not	26	17.3
2. With the COVID-19 vaccine now available:	I will want to get it as soon as possible	28	18.7
	I will take it when offered	34	22.7
	I'm not sure what I will do	13	8.7
	I will put off (delay) getting it	42	28.0
	I will refuse to get it	33	22.0
3. I would describe my attitude towards receiving a COVID-19 vaccine as:	Very keen	23	15.3
	Pretty positive	24	16.0
	Neutral	16	10.7
	Quite uneasy	56	37.3
	Against it	31	20.7
4. If a COVID-19 vaccine was available at my local pharmacy, I would:	Get it as soon as possible	36	29.9
	Get it when I have time	14	9.0
	Delay getting it	21	12.6
	Avoid getting it for as long as possible	30	18.6
	Never get it	42	28.0
5. If my family or friends were thinking of getting a COVID-19 vaccination, I would:	Strongly encourage them	31	20.7
	Encourage them	27	18.0
	Not say anything to them about it	26	17.3
	Ask them to delay getting the vaccination	33	22.0
	Suggest that they do not get the vaccination	31	20.7

Table 1. Responses of participants to COVID-19 vaccine hesitancy and intentions questions.

Question	Response	Number of respondents	%
6. I would describe myself as:	Eager to get a COVID-19 vaccine	20	13.3
	Willing to get the COVID-19 vaccine	39	26.0
	Not bothered about getting the COVID-19 vaccine	18	12.0
	Unwilling to get the COVID-19 vaccine	50	33.3
	Anti-vaccination for COVID-19	22	14.7
7. Taking a COVID-19 vaccination is:	Really important	31	20.7
	Important	31	20.7
	Neither important nor unimportant	38	25.3
	Unimportant	24	16.0
	Really unimportant	20	13.3
8. How likely to do you think you are to get a COVID-19 vaccine?	Very unlikely	38	25.3
	Unlikely	14	9.3
	Somewhat unlikely	25	16.7
	Somewhat likely	19	12.7
	Likely	18	12.0
	Very likely	35	23.3

Closing remarks

It is important to note that vaccine hesitancy is not the refusal of a vaccine. Rather, it is a marker of undecidedness – a delay in acceptance or refusal of a vaccine despite availability (SAGE Working Group on Vaccine Hesitancy, 2014).

Exploring predictors of vaccine hesitancy has the potential to help policymakers to inform interventions that better inform the public and potentially increase vaccine confidence and uptake.

The findings of this study suggest that COVID-19 vaccine hesitancy and likelihood of getting the COVID-19 vaccine are related to medical mistrust in ethnically diverse groups.

The reasons for medical mistrust among ethnically diverse groups are likely to be complex and not easily addressed. Meaningful engagement with these communities is required in order to better understand the specific issues that underpin mistrust and help address health inequalities, including COVID-19 vaccination.

Funder statement

Financial support for this research was provided by Leeds City Council and NHS CCG Leeds via the Black Health Initiative.

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