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# Understanding the factors associated with willingness to participate in a COVID-19 vaccine clinical trial

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## Introduction

The coronavirus (COVID-19) pandemic has affected some groups more than others in the UK, and the most favourable control scenario besides face coverings, hygiene and social distancing, which could provide long-term protection, is vaccination. Development of vaccines require representation from all population groups in clinical trials, yet there have been severe under-representation among some groups, mostly ethnic minorities.<sup>1</sup> There have been breakthroughs in vaccine development, and research studies are testing the effectiveness of a range of other candidate vaccines to determine their safety and identify the best vaccines for different groups. Hence, there is still a need for participation in clinical trials; as such, understanding the factors that drive participation decision is essential.

Building on a previous study on public perceptions to COVID-19 vaccine trials among ethnic minority and vulnerable communities<sup>2</sup>, a survey was developed to understand the willingness to participant in COVID-19 vaccine trials. Findings from the first study were used to inform the questions asked in the survey, which intended to capture information from a wider population across the East Midlands. This research is conducted in collaboration with the National Institute of Health Research (NIHR) Clinical Research Network (CRN) East Midlands towards supporting the coordination of resources and intelligence related to COVID-19 vaccine studies across the UK.

The study aimed to understand the common barriers to involvement in clinical research and the factors that influenced the willingness to participate in COVID-19 vaccine trials. The survey was live from the 9 – 31 October 2020. There were 411 participants, 79% females, 19% males and the others preferred not to disclose their sex. The survey looked at COVID-19 and vaccine-related health information including long-standing health conditions, clinical vulnerability and shielding advice, previous flu vaccine uptake, confirmed COVID-19 infections, previous participation in clinical trials and willingness to participate in a COVID-19 vaccine trial. Factors that motivated participation, including concerns that discouraged participation, information needs, accessibility and suggestions to encourage participation, were explored.

## Demographic associations with COVID-19 vaccine trial participation

Table 1 shows the associations between demographic factors with personal consideration towards taking part in COVID-19 vaccine trials. The table presents demographic and health status variables investigated, including sex, age, ethnicity, religion, household size and income, past flu vaccine uptake and COVID-19 infections, by consideration to take part in a vaccine trial.

The survey showed that across the region more than two in three (69%) people would consider putting themselves forward to take part in research to find a vaccine to slow the spread of the virus (i.e. those who gave a “Yes” or “Maybe” response). The other main highlights from the demographic findings were:

- Based on **age groups**, those who were older responded more positively to taking part in a COVID-19 vaccine trial.
- Observations by **ethnicity** showed a higher proportion of those who self-identified as White, Asian or Mixed ethnicity responded positively to being included in a trial, whilst those who self-identified as African/Caribbean/Black or Other ethnicity responded more negatively.

1. GOV.UK. Department for Business, Energy & Industrial Strategy. Ethnic minority communities and the elderly called upon to bolster the fight against coronavirus. Press release - 13 October 2020 <https://www.gov.uk/government/news/ethnic-minority-communities-and-the-elderly-called-upon-to-bolster-the-fight-against-coronavirus>. Accessed 4 December 2020 NIHR (2020)
2. Public perceptions towards vaccine trial research within ethnic minority and vulnerable communities. Available from <http://arc-em.nihr.ac.uk/clahracs-store/public-perceptions-towards-vaccine-trial-research-within-ethnic-minority-and> (Last Accessed 10 December 2020)

- For **religious affiliation**, those who self-identified as Sikhs, of no religion or belief and Hindus had the highest proportion of positive respondents, whilst those of Buddhist, Muslim, Spiritual or Prefer not to say had the highest proportion of negative respondents.
- Feedback on past **flu vaccination** showed a greater proportion of individuals who had a flu vaccine last year or in a previous year and previous experience of being involved in clinical trials responded positively to being included in COVID-19 trial.
- Inquiry on **vaccine trial accessibility** revealed a higher proportion of those who expressed a preference for receiving a COVID-19 vaccine also expressed a preference for receiving this at mostly at a GP surgery (n=179) or a hospital (n=130)
- The proportion of **positive respondents increased** in those with higher levels of education achieved, greater household income, and lower numbers of people in the household.

Table 1: Demographic associations with consideration towards taking part in a COVID-19 vaccine trial

Variables (Number of participants)	Would you consider taking part in a COVID-19 vaccine trial? (n=411)		
	Yes (%)	Maybe (%)	No (%)
Willing to take part in COVID-19 vaccine trial (n=411)	31.63	37.71	30.66
<b>Sex</b>			
Female (n=376)	31.60	37.73	30.67
Male (n=79)	34.18	37.97	27.85
Prefer not to say (n=6)	0.00	33.33	66.67
<b>Age</b>			
18-24 (n=21)	28.57	33.33	38.10
25-34 (n=88)	32.58	28.09	39.33
35-44 (n=86)	26.74	36.05	37.21
45-54 (n=90)	34.07	46.15	19.78
55-64 (n=83)	33.33	40.48	26.19
65-74 (n=34)	32.35	47.06	20.59
>=75 (n=3)	66.67	0.00	33.33
Prefer not to say (n=3)	0.00	0.00	100.00
<b>Have a disability</b>			
Yes (n=46)	23.91	39.13	36.96
No (n=354)	32.77	37.57	29.66
Prefer not to say (n=7)	28.57	42.86	28.57
<b>Ethnicity</b>			
White (n=292)	34.93	41.10	23.97
Asian (n=66)	24.24	28.79	46.97
African/Caribbean/Black (n=24)	8.33	29.17	35.50
Mixed (n=20)	50.00	35.00	15.00
Other (n=9)	0.00	22.22	77.78

Variables (Number of participants)	Would you consider taking part in a COVID-19 vaccine trial? (n=411)		
	Yes (%)	Maybe (%)	No (%)
<b>Religion</b>			
Christian (n=145)	26.53	44.22	29.25
Hindu (n=28)	32.14	35.71	32.14
Buddhist (n=2)	0.00	0.00	100.00
Jewish (n=1)	0.00	100.00	0.00
Muslim (n=22)	4.55	27.27	68.18
No belief (n=21)	33.33	38.10	28.57
No religion (n=157)	42.04	35.67	22.29
Other (n=2)	0.00	100.00	0.00
Pagan (n=1)	0.00	100.00	0.00
Prefer not to say (n=7)	14.29	28.57	57.14
Sikh (n=10)	50.00	20.00	30.00
Spiritual (n=6)	0.00	16.67	83.33
<b>Have a long-standing health conditions</b>			
Yes (n=161)	33.54	36.02	30.43
No (n=234)	31.20	38.03	30.77
Unsure (n=12)	16.67	58.33	25.00
<b>Estimated household income</b>			
Prefer not to say (n=64)	25.00	34.38	40.63
£0-£30,000 (n=81)	23.46	45.68	30.86
£30,000-£60,000 (n=152)	30.92	40.79	28.29
£60,000-£120,000 (n=93)	43.01	30.11	26.88
£120,000-£180,000 (n=15)	46.67	20.00	33.33
<b>Ever taken a flu vaccine</b>			
Yes, last year (n=241)	39.83	34.44	25.73
Yes, in a previous year (n=67)	25.37	43.28	31.34
No (n=91)	17.58	40.66	41.76
Unsure (n=7)	0.00	57.14	42.86
<b>Identified a clinically extremely vulnerable and advised to shield</b>			
Yes (n=28)	39.29	35.71	25.00
No (n=376)	31.38	38.03	30.59
<b>Personally had confirmed positive test for COVID-19</b>			
Yes (n=11)	45.45	18.18	36.36
No (n=394)	31.22	38.32	30.46
<b>Live with someone who had confirmed positive test for COVID-19</b>			
Yes (n=7)	14.29	57.14	28.57
No (n=400)	32.00	37.50	30.50
<b>Ever taken part in clinical trials</b>			
Yes (n=39)	43.82	33.71	22.47
No (n=318)	28.30	38.99	32.70

Variables (Number of participants)	Would you consider taking part in a COVID-19 vaccine trial? (n=411)		
	Yes (%)	Maybe (%)	No (%)
<b>Preferred location to attend a vaccine trial</b>			
Local GP (n=179)	35.75	36.87	27.37
Hospital (n=130)	31.54	36.92	31.54
Outdoors (tents, drive through) (n=42)	30.95	54.76	14.29
Community centre (n=24)	33.33	50.00	16.67
Other (n=3)	20.00	20.00	60.00
<b>Ability to access information and engage virtually</b>			
Yes (n=390)	32.05	38.21	29.74
No (n=16)	25.00	25.00	50.00
<b>Total number in household</b>			
1 to 3 (n=306)	33.33	38.89	27.78
4 to 6 (n=97)	28.87	35.05	36.08
7 to 10 (n=2)	0.00	0.00	100.00
> 10 (n=2)	0.00	0.00	100.00
<b>Highest level of education</b>			
No qualifications (n=3)	0.00	33.33	66.67
GCSE/CSE/O-level (n=29)	20.69	55.17	24.14
Post-16 vocational course (n=16)	31.25	43.75	25.00
A-levels or equivalent (n=51)	23.53	37.25	39.22
Undergraduate degree (n=161)	37.27	39.75	22.98
Postgraduate degree (n=138)	31.88	32.61	35.51
Prefer not to say (n=13)	23.08	23.08	53.75

## Factors that motivate participation in a COVID-19 vaccine trial

Table 2 outlines the motivations to partake in a trial. The proportions presented are a summary of responses regardless of whether participants had indicated willingness to participate in a COVID-19 trial or not. The top three motivating factors (highlighted in **green**) were related to the desire to find a solution to COVID-19, community support and accessibility. In comparison, the least motivating factors (highlighted in **red**) were related to community acceptance, staff gender preference and bridging of language barriers. These ranking may, however, vary across different demographic groups.

Table 2: Motivation for taking part in a COVID-19 vaccine trial among all participants

Motivating factors	(%)
<b>Knowing I am supporting research for faster answers</b>	
Yes	73.45
No	26.55
<b>Having past experience of being involved in research</b>	
Yes	14.69
No	85.31
<b>Helping others in my community</b>	
Yes	51.80
No	48.20
<b>For my own health benefits and recognition</b>	
Yes	31.70
No	68.30
<b>Financial incentives</b>	
Yes	22.16
No	77.84
<b>Acceptance from the community, community leaders and religious leaders</b>	
Yes	2.58
No	97.42
<b>Availability of support groups with other participants</b>	
Yes	22.42
No	77.58
<b>Accessible location and parking</b>	
Yes	22.42
No	77.58
<b>Accessibility support (childcare, transport)</b>	
Yes	75.77
No	24.23
<b>Same-gender research staff</b>	
Yes	1.03
No	98.97
<b>Access to healthcare staff who speak my language (bilingual staff)</b>	
Yes	1.03
No	98.97

Note: **Green** = Top motivators, **Red** = Least motivators

Understanding the main factors that could motivate people who had no clear preference or were currently unwilling to participate, i.e. those giving a “Maybe” or “No” responses, is vital for the planning of the research studies. The lowest-ranked motivations: **having same-gender research staff** and **access to bilingual healthcare staff** who speak the language of the participants, were given only by those who provided “Maybe” and “No” responses. Also, the **availability of support groups with other participants** and **accessible location and parking** were highlighted more among those who had no exact preference or were uninterested. The number of responses for these motivators was, however, too low to make a general assumption. Further insights will be required to understand the effect of these factors on the willingness to participate in COVID-19 vaccine trials.

## Suggested strategies to encourage involvement in COVID-19 vaccine trials

A total of 170 participants provided suggestions to encourage participation in COVID-19 vaccine trials, and these can be categorised under **five themes**: Accessibility, Communication, Publicity, Values and Research approach. Each domain, with specific areas to be addressed and participant comments alongside their demographic groups (sex, age and self-identified ethnicity), are outlined below.

### Accessibility to information, location and support

- Simplified, accurate and detailed information for the general public and on specific health conditions
- Information presented in multiple languages and translators are made available on-site
- Study trial locations and times should be convenient for participants
- Provide options for personalised trials and home visits
- Provide local access to reliable healthcare, childcare and community support, as well as tailored support for specific conditions, e.g. cancer
- Establish access to mental health providers, non-online resources and financial incentives

“ As someone who would be happy to participate, it hasn't been clear to me how I might do that, and my life is too busy to put much time into finding out. Needs to be more accessible.

Female, 35-44 years, White

“ More publicity requesting volunteers, especially in university, college students or people on furlough. Sounds harsh, but the unemployed may be interested if financial remuneration is given.

Female, 55-64 years, White

“ Bring trial to local community - currently need to travel 2.5 hours to nearest center. As I work full time this is impossible - and for many the travel is prohibitive

Female, 45-54 years, White



## Communication resources that are detailed and explicit

- Include details of the trial purpose, benefits, impact, effectiveness, risks, safety concerns, side effects, control measures and comparative safety evidence with references
- Direct communication of the risks in advance and for specific conditions
- A clear outline of vaccine content and the importance of participation
- Details of study trial duration, schedule and step-by-step processes
- Frequent updates of trial progress at all stages of the study, including previous and current trials and phases
- Present testimonials and health conditions of previous participants
- Set up good signposting to accurate information to be able to reduce misinformation
- Make support options available, and that can be offered to participants known

“ I think it takes a certain sort of person to take part in vaccine trials; it's a very personal decision based on circumstance. All you can do is make the information as widely spread as possible and be open and honest about the possible benefits and risks and things that are in place to reduce risk/ support any side effects –

**Female, 25-34 years, White**

“ I think you must look at providing a significant amount of information about what the vaccines contain, how they have been tested thus far and the possible risks. Don't assume that the information will be too complex to understand. Many people I know say they would not have a COVID vaccine (despite having other vaccines) as it is still very much an unknown quantity.

**Female, 35-44 years, Pakistani**

## Publicity to raise awareness, educate and enlighten

- Conduct public campaigns with accurate information and using realistic adverts
- Avoid social media ads, best to use word of mouth, especially for communicating benefit and risks
- Use local representatives and ethnic minority medical staff
- Show examples of high profile individuals who have taken the vaccine, e.g. politicians, celebrities
- Increase community-level engagement and awareness activities
- Offer education opportunities in multi-language formats including videos, surveys
- Directly invite and educate more ethnic minority communities
- Use publicity to suppress false information

“ Don't use Social Media targeted ads. Use word of mouth from GP to Patients, i.e. Letters or Phone Calls. Promote the good - explain the bad and don't be scared of it

**Male, 25-34 years, White**

“ Social media campaigns designed by advertising companies that know how to do this. There are too many bad NHS & government adverts that just result in an eye-roll. But good campaigns that resonate with the people you're trying to reach would help people get involved. Also, bad advertising makes me subconsciously question the professionalism of a company, and that's really not what you want when you're talking about clinical trials...

– Female, 25-34 years, White-Asian

“ Layout what the process is and what's expected of people in something simple like an infographic. Demonstrate the large numbers of people they can relate to that are already participating. Have people who have previously contributed to research talk about the personal benefits they felt.

Female, 35-44 years, Indian

“ Have information sheets in different languages. Videos in different languages to help BAME understand the importance of clinical trials

Female, 25-34 years, African

“ Get black medical professionals to use their social media platforms to give clear and trustworthy information. –

Female, 25-34 years, African

“ More advertising openly and honestly about the importance of participants to take part. National TV should air adverts, as well as leaflets from schools, would let people know that the information is reliable.

Female, 25-34 years, Bangladeshi

### Values expected to be reflected for increased interest in participation include:

- Evidence of honesty, openness and transparency of the vaccine trials to eliminate hidden agendas
- Presentation of reassurance and encouragement to support people who participate
- Intentional actions implemented to gain and increase the trust of people, particularly through government and media interpretations and projections of COVID-19.
- Show respect for personal decisions and do not force or coerce people to participate
- Establish government stability to increase trust, e.g. minimise the frequency of changes in decisions made
- Increase emphasis on employer support and social responsibility of everyone

“ The key has to be honesty. People need to know what is in the vaccine and it needs to be proved that this virus isn't going to burn itself out after a period of time as peoples immune systems start to harden to it.

Female, 45-54 years, White

“ For people not to be bullied into engaging with the trial, it should be a choice, not something we should be constantly contacted about. My decision should be respected, if I say no, I should not be contacted again.

Female, 25-34 years, Indian

“ Somehow trust must be established between the UK government and the general public. Currently, for people like me - deeply sceptical about government and media interpretations and projections of Covid-19 - becoming involved in a vaccine trial would be a huge leap of faith.

Male, 55-64 years, White-Asian

## Recommendation for trial design and research approach

- Find other alternatives to vaccines and conduct natural (homoeopathic) holistic vaccine trials not scientific.
- Reduce risk concern of those with families
- Use students and expert patients as participants
- Remove political influence and reduce politicisation of vaccine
- Use NHS data to inform research planning
- Use normal vaccine development timeframe for the trials a not rushed timeline
- Present proof that ethnic minority communities are not targeted, particularly black communities, and conduct the first set of trials on non-ethnic minority individuals

“ Let is go through trials in the normal way in the normal timeframe, be open, answer questions as to why a vaccine is required for a disease that has a 99.98 survivability.

Male, 55-64 years, English

“ Advise the government to be honest about the risk factors of COVID. I follow all the NHS data. The Prime Minister said 'Many young people will die'. This is not true. Many elderly people have died. Many of them were being kept alive in 'Care' Homes being medicated and fed with an extremely poor quality of life. People have been deliberately frightened.

Female, 75 years and above, White

“ If the researchers can prove that they are not targeting BAME to be used as guinea pigs..., researchers have hard work to convince Africans living in Europe that vaccine trials are safe for everyone.

Female, 55-64 years, African

## Summary

### Main Findings

More females participated in the survey, but the representation of responses to the questions and the perception of COVID-19 vaccine trials were similar across both sexes. However, older age groups were more willing to participate in vaccine trials. Variation in willingness to participate was observed across the different demographic categories and vaccine trial willingness stages. These factors are worth taking into consideration when developing communication and publicity resources aimed at encouraging more people to participate in COVID-19 vaccine trials and other clinical trials. Key motivations reported, illustrated participants willingness to contribute to finding an effective solution for controlling COVID-19; however, several factors, as described in the suggested strategies to encourage participation, need to be considered to achieve an increase in active involvement.

### Strengths and Limitations

This study had limitations as the survey only reports a snapshot taken at one point in time. As the context of this particular survey is highly dynamic, and the landscape changing quickly, participant interests are also likely to change with time. Furthermore, the study focused only on the East Midlands; however, considering the representation and diversity of the participant demography, the results are most like generalizable to the wider UK population.

### Implications

Variation in willingness to participate across groups highlights priority areas that need to be addressed in COVID-19 vaccine trial research. Certain motivating factors were observed more among those with unclear preference or how were uninterested. Failure to consider this variation could lead to missed opportunities for vaccine trial involvement. Hence, publicity strategies and resources, including community engagement, reassurance, supporting safety-net and involvement of local healthcare service are required to increase participation in COVID-19 vaccine trials



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