

# DEMAND DIVERSITY

Exploring attitudes  
towards clinical  
research among  
people from  
different ethnic  
groups in the UK

# CURRENTLY, THERE IS POOR DIVERSITY IN CLINICAL RESEARCH POPULATIONS: WHITE PEOPLE MAKE UP THE MAJORITY OF PARTICIPANTS, WHILE ETHNIC MINORITIES ARE UNDERREPRESENTED.

This presents a scientific issue, given that the way people respond to treatments can relate directly to ethnicity. There is robust evidence from different clinical research that shows individuals from different ethnic groups experience variable responses to specific medicines. For example, beta blockers may be less effective in a subgroup of black vs white people for the management of congestive heart failure<sup>1,2</sup>. If clinical research populations fail to robustly assess a drug in different ethnicities, the efficacy and safety cannot claim to be optimal. The prevalence of certain conditions is also higher among different ethnic groups. For example, people from South Asian communities are up to six times more likely to have type 2 diabetes than white Europeans<sup>3</sup>.

**IF A STUDY HAS A POPULATION COMPRISING 70% WHITE PEOPLE, BUT THE TARGET TREATMENT POPULATION IS 70% BLACK PEOPLE, THEN THE STUDY POPULATION IS NOT REPRESENTATIVE, AND THE DATA ARE FLAWED.**

Diversity in clinical research is not a recent issue. It already has the attention of global regulatory bodies within healthcare and drug development. Indeed, there is increasing pressure for drug manufacturers to provide evidence of drug safety and effectiveness in diverse, representative populations. To stay ahead, the industry will therefore need to start driving initiatives forward sooner, rather than later.

To tackle the current lack of diversity, we need to understand the barriers to participation in clinical research, and how these may specifically relate to ethnicity. Consequently, the following research was conducted to gain a deeper understanding of people's views towards healthcare and clinical research.

## OBJECTIVES

### THE PURPOSE OF THIS WAS TO:

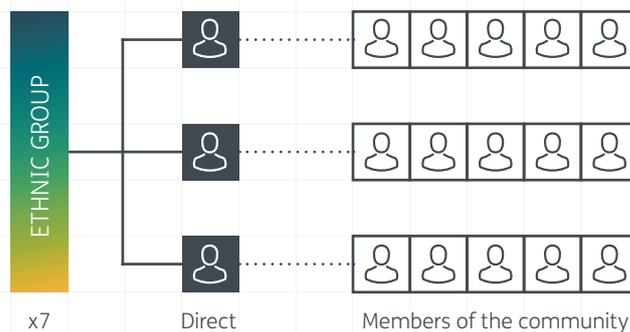
Explore attitudes towards clinical research with people from different ethnic groups

Understand the barriers and motivations to taking part in clinical research for different ethnic groups

Explore broader community influences on people's opinions on clinical research

## RESEARCH POPULATION

We spoke to 21 people directly, three from each different ethnic group: white British, Asian/Asian British (Indian, Pakistani and Chinese), black/black British (African and Caribbean), and Arabic. Each of these people spoke to five members of their ethnic community.



## DATA COLLECTION AND ANALYSIS

Interviews were conducted with the community representatives, which lasted approximately 90 minutes. These included people from different socioeconomic groups and UK locations covering the South, Midlands, and the North. Prior to their interview, each community representative completed a pre-task, designed to help them gather feedback on attitudes towards clinical research studies from the members of their ethnic community. Each interview was conducted using an online video call platform.

The interviews covered associations with clinical research studies, views on and experiences of clinical research, and motivations and barriers to participation.

The data were analysed by transcribing the interviews and performing a thematic analysis.

## RESULTS

The demographic characteristics of 21 community representatives and 105 community members are presented in Tables 1 and 2, respectively. The demographics were generally balanced across all ethnic groups.



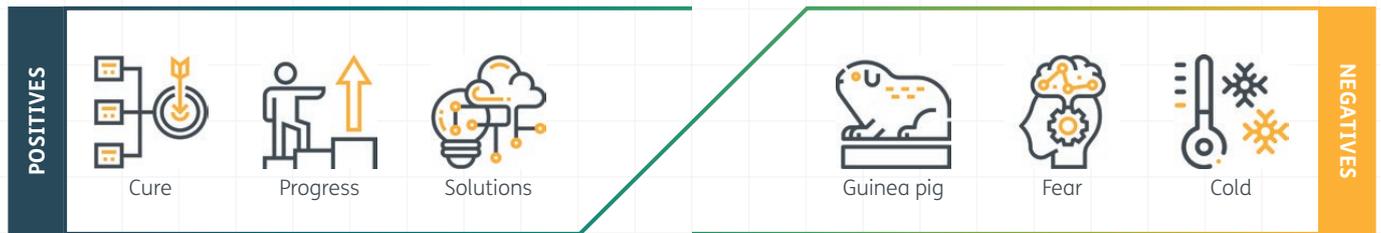
	Arabic	Black African	Black Caribbean	Indian	Pakistani	Chinese	White British
<b>TABLE 1. Demographic information for community representatives</b>							
n	3	3	3	3	3	3	3
Female, n (%)	2 (66.6)	2 (66.6)	2 (66.6)	2 (66.6)	2 (66.6)	1 (33.3)	1 (33.3)
Age, n (%)	18–24	0	1 (33.3)	0	0	0	1 (33.3)
	25–34	2 (66.6)	0	0	1 (33.3)	1 (33.3)	2 (66.6)
	35–44	1 (33.3)	0	3 (100)	1 (33.3)	1 (33.3)	0
	45–54	0	1 (33.3)	0	1 (33.3)	1 (33.3)	0
	55–64	0	1 (33.3)	0	0	0	0
	65+	0	0	0	0	0	0
Generation, n (%)	1 <sup>st</sup>	0	2 (66.6)	0	0	0	1 (33.3)
	2 <sup>nd</sup>	2 (66.6)	1 (33.3)	2 (66.6)	2 (66.6)	3 (100)	0
	3 <sup>rd</sup>	1 (33.3)	0	1 (33.3)	1 (33.3)	0	2 (66.6)
	>3 <sup>rd</sup>	0	0	0	0	0	0
English as 1 <sup>st</sup> or 2 <sup>nd</sup> language, n (%)	1 <sup>st</sup>	3 (100)	2 (66.6)	3 (100)	3 (100)	3 (100)	1 (33.3)
	2 <sup>nd</sup>	0	1 (33.3)	0	0	0	2 (66.6)
<b>TABLE 2. Demographic information for community members</b>							
n	15	15	15	15	17	17	15
Female, n (%)	9 (60.0)	9 (60.0)	10 (66.7)	9 (60.0)	8 (47.1)	9 (52.9)	8 (53.3)
Age, n (%)	18–24	3 (10.0)	2 (13.3)	1 (6.7)	2 (13.3)	6 (35.3)	6 (35.3)
	25–34	7 (46.6)	6 (40.0)	6 (40.0)	2 (13.3)	2 (11.8)	7 (41.2)
	35–44	4 (26.6)	4 (26.6)	4 (26.6)	1 (6.7)	5 (29.4)	0
	45–54	1 (6.7)	2 (13.3)	2 (13.3)	4 (26.6)	4 (23.5)	0
	55–64	0	1 (6.7)	2 (13.3)	5 (33.3)	0	4 (23.5)
	65+	0	0	0	1 (6.7)	0	0
Generation, n (%)	1 <sup>st</sup>	5 (33.3)	10 (66.7)	1 (6.7)	3 (20.0)	3 (17.6)	10 (58.8)
	2 <sup>nd</sup>	7 (46.6)	5 (33.3)	10 (66.7)	10 (66.7)	9 (52.9)	7 (41.2)
	3 <sup>rd</sup>	3 (20.0)	0	3 (20.0)	2 (13.3)	4 (23.5)	0
	>3 <sup>rd</sup>	0	0	1 (6.7)	0	1 (5.9)	0



Universally, the responses included a mix of emotional associations, with most associated words or phrases being neutral or negative. Positive word associations included cure, progress and solutions. In line with this, people had some awareness that studies could lead to medical advances and possibly treat a condition themselves or a family member had. The most common negative word associations were guinea pig, fear and cold. People were particularly concerned that investigative treatments would cause negative side effects and even death. Although people referred to the word hospital, several described the environment of clinical research as being confined in quarantine with references to white coats, rather than a regular hospital.

“IN MY MIND I’M PICTURING BEING ISOLATED OR IN QUARANTINE OR SOMETHING...”

MALE, 31, CHINESE.



“HOSPITALS... I JUST ASSOCIATE WITH DEATH, I DON’T LIKE THEM, SO I WOULDN’T WANT TO TAKE PART THERE.”

FEMALE, 37, WHITE BRITISH.

## VIEWS ON AND EXPERIENCES OF CLINICAL RESEARCH STUDIES

**Overall, people had a very limited understanding of clinical research studies, and this was evident within every ethnic group. There were no clear differences in people’s views that related to ethnicity or culture.**

The interviews established that people’s knowledge of clinical research generally comes from the media and TV/film. People had read negative stories in newspapers about things going wrong in clinical research and had heard adverts on the radio from companies trying to recruit participants. Many people also had negative perceptions of clinical research based on fictional portrayals in TV and film, which depict a cold, isolated and high-risk environment. One person mentioned conspiracy theories that cancer cures are deliberately not being found or made public.

“I ACTUALLY DON’T KNOW HOW CLINICAL RESEARCH STUDIES WORK. I THINK THERE’S HIGH TECH INVOLVED AND THAT MUST TAKE A REALLY LONG TIME AND A COMPLICATED PROCESS.” FEMALE, 28, CHINESE.

There was a common misconception that people thought they would be asked to take part in return for a financial reward.

Some people had a vague understanding of what clinical research studies involve and how they work. This knowledge was obtained from someone else who had taken part, or through education or work experience in the health sector.

“...THE MONEY OVER MY HEALTH, IT’S NOT WORTH IT. YOU CAN’T BUY YOUR HEALTH.” **FEMALE, 37, SOUTH, WHITE BRITISH.**

## MOTIVATIONS AND BARRIERS TO TAKING PART IN CLINICAL RESEARCH STUDIES

Most barriers to participation were similar throughout all ethnic groups (Figure 2).

Side effects were commonly reported as major concern for people considering taking part in a clinical research study. People felt they would be sacrificing their own personal health and physical wellbeing due to what was perceived as the ‘dangerous’ nature of investigative treatments.

“DON’T YOU THINK WE’VE GOT ENOUGH HEALTH PROBLEMS GOING ON, THE LAST THING WE WANT IS SIDE EFFECTS.” **FEMALE, 50, BRITISH PAKISTANI.**

Practical barriers were also universally reported, relating to taking time away from their lives and responsibilities:



Care of family members including children and elders



Work



Travel - location of study site

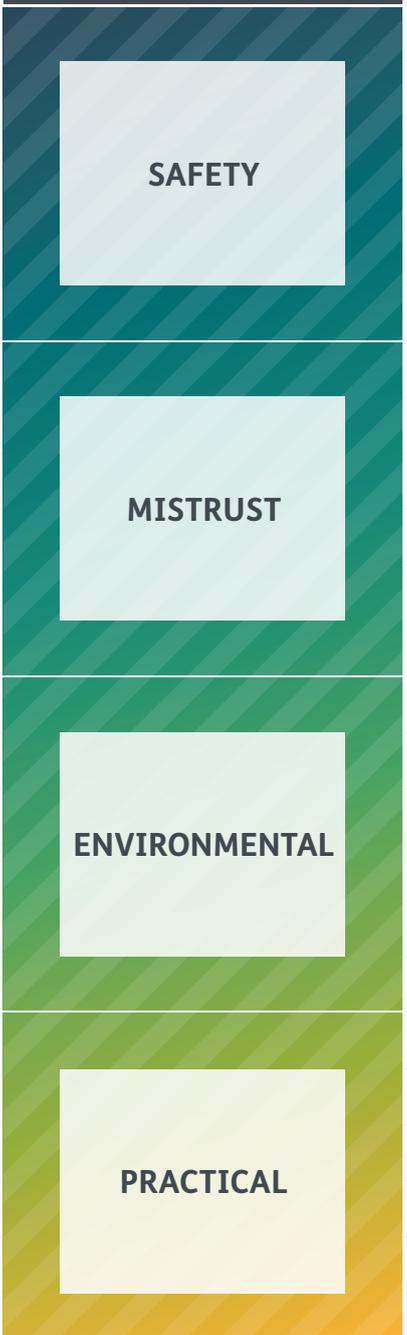


English not being a first language

“I’D HAVE TO KNOW THE PROS AND CONS. THE MAIN THING FOR ME IS SIDE EFFECTS: IF IT’S DETRIMENTAL TO MY HEALTH, I WOULDN’T DO IT.” **FEMALE, 52, BLACK BRITISH AFRICAN.**

Beyond these universal barriers, cultural and religious restrictions were also identified, which are presented in Table 3.

**FIGURE 2.** Universal barriers to participation in clinical research studies



**TABLE 3.** Religious and cultural barriers to healthcare and participation in clinical research studies

<b>Indian</b>	Older women may need a chaperone for reassurance and guidance	Some prefer traditional or homeopathic remedies		
<b>Pakistani</b>	Islam: - Ingredients - Giving part of the body	Men may fear impact on social status (if people think they are being paid and it appears they are in financial difficulty)	Women may face more judgement for participating instead of being at home	
<b>Arabic</b>	Islam: - Ingredients - Giving part of the body	Deep mistrust for some	Women may have less autonomy over what they do with their time and body, and may need a chaperone	Some prefer traditional or homeopathic remedies
<b>Black Caribbean</b>	Feelings of exploitation and dehumanisation	Deep mistrust for some	Conspiracy theories and fears about deliberate harm	Some prefer traditional or homeopathic remedies
<b>Black African</b>	Some feelings of exploitation and dehumanisation	Some mistrust	Some older generation people prefer traditional or homeopathic remedies	
<b>Chinese</b>	Heightened awareness and concern about how data are used	Some prefer traditional or homeopathic remedies		
<b>White British</b>	No culturally specific barriers reported			



Overall, there is one clear difference; white British people reported no culturally specific barriers, whereas every other ethnic group did.

The position of women was highlighted by people within the Indian community, who explained that older women may need a chaperone for reassurance and guidance. In the Pakistani and Arabic groups, it was stated that women may be judged for choosing to take part in a study and spend time away from the home, and that women have less autonomy compared with men.

The preference for traditional, herbal or homeopathic medicine was mentioned as a barrier among most groups: Indian, Arabic, black Caribbean, black African and Chinese.

“WE HAVE NATURAL HERBS INSTEAD OF SOMETHING MADE IN A LAB. YOU DON’T KNOW WHAT THESE SCIENTISTS ARE DOING BEHIND CLOSED DOORS.” **MALE, 44, BLACK BRITISH CARIBBEAN.**

Across all ethnic groups except white British, cultural and religious barriers were more likely to be present for older generations and those with more traditional values. These people were also more likely to strongly believe that God will provide and that faith is needed more than medicine, which also creates a barrier. The less traditional, younger participants also recognised this theme.

The sense of mistrust against ‘the system’ and clinical research can be very deep among certain cultures, particularly black African and Caribbean communities. People in these groups were very concerned about being exploited and dehumanised in clinical research, potentially as a result of the way certain ethnic groups have been treated throughout history. This treatment has left a lasting effect on people’s perceptions of clinical research. One example of this is the Tuskegee syphilis study, which was mentioned by one community representative and has become a well-known case of racist and unethical experimentation. Further, although fear of invasiveness was a universal concern, this was elevated in some ethnic groups, presenting as a sense of being exploited, degraded and dehumanized.

“THAT WOULD BE VERY DEGRADING... MY COMMUNITY WOULD NOT RESPECT THAT.”

**MALE, 21,  
BRITISH ASIAN PAKISTANI.**

“A LOT OF OUR COMMUNITY AREN’T INTERESTED – WE’RE NOT GUINEA PIGS.”

**FEMALE, 37,  
BLACK BRITISH CARIBBEAN.**

Among Pakistani and Arabic Muslims, it was noted that giving part of the body is not permitted. There were also more suspicions among these groups and black people about the ingredients of medicines than in other groups. Some expressed fears of attempts to kill or stunt the development of a group. These views were particularly prevalent among people from black and Arabic communities.

“A LOT OF THE ARAB COMMUNITY WOULD MAKE COMMENTS ABOUT IT BEING A CONSPIRACY... SIMILAR TO BLACK AFRICAN COMMUNITIES. THAT THEY WANT TO USE OUR BODIES AND KILL US...” **MALE, 30, ARABIC.**

“THE OLDER GENERATIONS ARE LIKELY TO SAY NO BECAUSE THEY STICK WITH TRIED AND TESTED METHODS THAT THEY’VE ALWAYS KNOWN, WHEREAS THE YOUNGER GENERATIONS WHO HAVE LIVED HERE AND BEEN BROUGHT UP HERE, ARE MORE OPEN TO IT AND TRYING NEW THINGS.”

**FEMALE, 43, INDIAN.**

This research has unearthed insights from people in the UK who have cultural and religious barriers to taking part in clinical research. We found that people in the UK have a limited understanding of clinical research, and perceptions are generally neutral or negative, relating to concerns about risks and side effects. Additionally, many non-white people have strong concerns about being exploited and have additional cultural and religious barriers to clinical research compared with non-religious white people. Importantly, some of these barriers were unique to certain groups, such as fears of exploitation among the black African and black Caribbean communities. The words research and trials were commonly associated with the word clinical, but this is probably because the participants knew that the premise of the research was clinical research studies. Being paid to take part in clinical research studies was repeatedly mentioned by participants, suggesting that they thought people mostly only took part for the financial reward rather than to benefit their own health or the health of others.

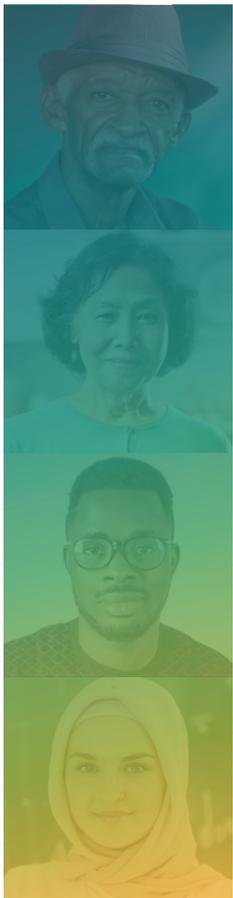
Our research aligns with previous studies, which have also found that patients' attitudes towards clinical research are shaped by their cultural and religious values, beliefs, practices and traditions<sup>4,5</sup>. This specifically relates to religious guidance in medicine, spanning elements such as gender roles, fasting and the role of God,<sup>6</sup> as well as cultural values, whereby some people are more likely to view modern medicine as secondary to traditional remedies<sup>7,8</sup>. These are important factors to consider, as they may lead to people choosing not to take part in a clinical study, if it does not consider or adapt to their religion or cultural values. Although we found that more non-white people expressed views that God determines health outcomes rather than medicine, white people with extremely strong religious values were not included in the interview cohort. We also demonstrate further evidence that the historical treatment of certain ethnic groups still impacts people's views of clinical research<sup>9-11</sup>. Other studies have found that even today, ethnic minority patients feel they are treated according to stereotypes<sup>12,13</sup>.

In the context of patient recruitment to clinical research, people from all ethnic groups have many of the same concerns when it comes to joining a study, so these still need to be addressed. These include factors such as understanding benefits vs risks and the time required to take part. However, it is more important than ever to be mindful of two core barriers faced by ethnic minorities:

- **Restrictions driven by religious or cultural values**
  - This includes treatment ingredients, autonomy and social judgement
- **Mistrust relating to religion and culture**
  - As an industry, it is clear that work is needed to build trust among everyone. But based on historical events and cultural differences, specific focus is needed to build trust among people of non-white ethnicities.

Although this research revealed important insights, further studies are needed to dive deeper into whether these barriers have prevented people from taking part in clinical research. We would recommend that studies are conducted among people who have had the opportunity to participate in a clinical research but have not, alongside those who have participated. In addition, it would be beneficial to gain a better understanding of how opinions on clinical research are formed, and how these opinions could be influenced. These insights would be vital before initiating a campaign to increase awareness and knowledge of clinical research.

# AN EDUCATION PROCESS IS NEEDED AMONG THOSE WORKING IN CLINICAL RESEARCH AS WELL AS THE GENERAL PUBLIC AND PATIENTS. WE ALL NEED TO FULLY UNDERSTAND THE CURRENT ISSUES AND BARRIERS BEFORE THEY CAN BE ADDRESSED.



Many people will not be aware that ethnic minorities are underrepresented in clinical research so this needs to be explained to the general public, alongside why this is an important issue to address. This education process must go beyond recruitment campaigns for individual clinical research and include a broader strategy, which aims to increase awareness and educate people on the importance and benefits of clinical research generally. The strategy should use insights to understand how the process should be tailored to different ethnic groups. For a large educational campaign to be successful, there is a need for community advocacy and the involvement of religious leaders. This way, the approach will be community based and self-directed. People need to feel empowered that their point of view is listened to and understood. Ultimately, the education process will build trust and understanding, so that people can make an informed decision about taking part in clinical studies.

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# DEMAND DIVERSITY

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