

Diversity and clinical trials in the UK

February 2024



Clinical trials have a diversity blind spot

Clinical trials are critical to the development of medicines and devices to improve the health and wellbeing of people around the world. However, trials have historically failed to engage a diverse group of participants from different ethnic and racial backgrounds.

Creating more supportive environments for a diverse range of individuals to participate in clinical trials is a critical step in achieving health equity.

Getting a clear view of how people currently think about clinical trials can help us identify what steps need to be taken to make this a reality.

We conducted research to understand differences between white and ethnic minority adults in the UK when it comes to...

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**Awareness,
knowledge and
perception of
clinical trials**

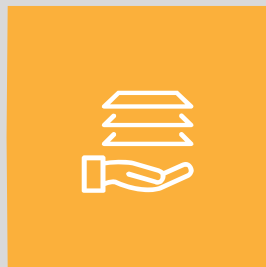
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**Clinical trial
participation**

3

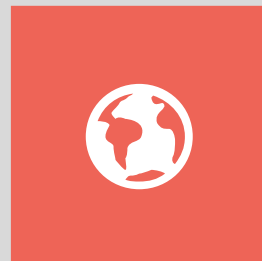
**Key barriers and
motivators to
participation**

We conducted a survey among a nationally representative sample of over 8,000 adults in the UK, 12% of whom were ethnic minorities



METHODOLOGY

8-min nationally representative survey run by [Ipsos KnowledgePanel](#) between 14-20 September 2023



TARGET

General Public Age 16+ based in the UK



SAMPLE SIZE

N = 8,206



HEALTH HISTORY

59.6% had any medical condition*



GENDER

Male 48%
Female: 52%



RACE / ETHNICITY

**White: 88% / Asian: 8%
Black / African / Caribbean: 2%
Other Ethnicity: 2%



INTERNET ACCESS

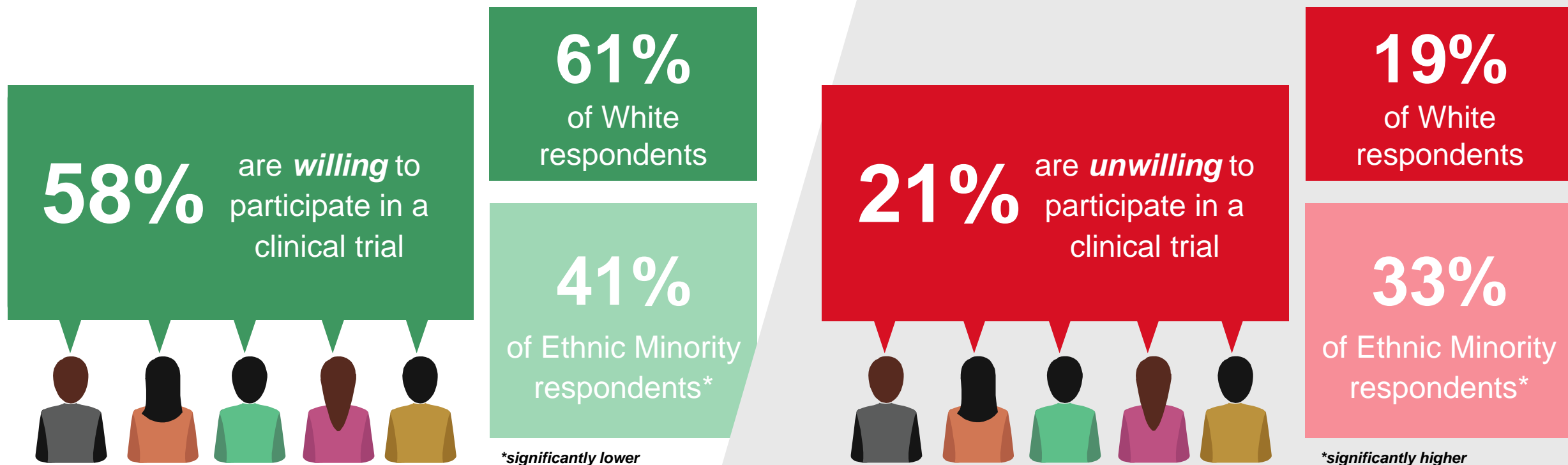
99% had access to internet***

*Primarily, Mental health 19%, Arthritis 13%, Asthma 12%, Hypertension 12%

**White; including White minorities

***n=39 did not use internet, primarily White (n=32), in England (n=33), 55+ (n=36)

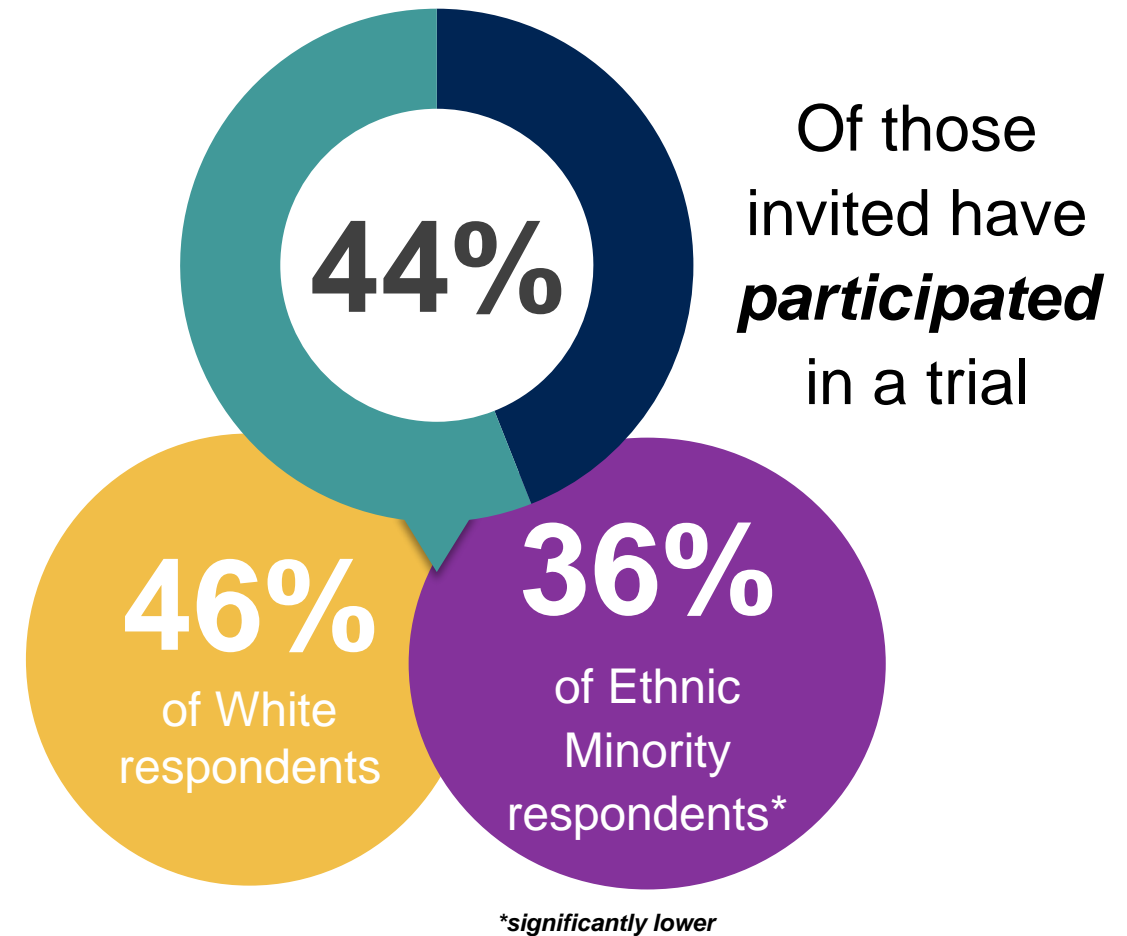
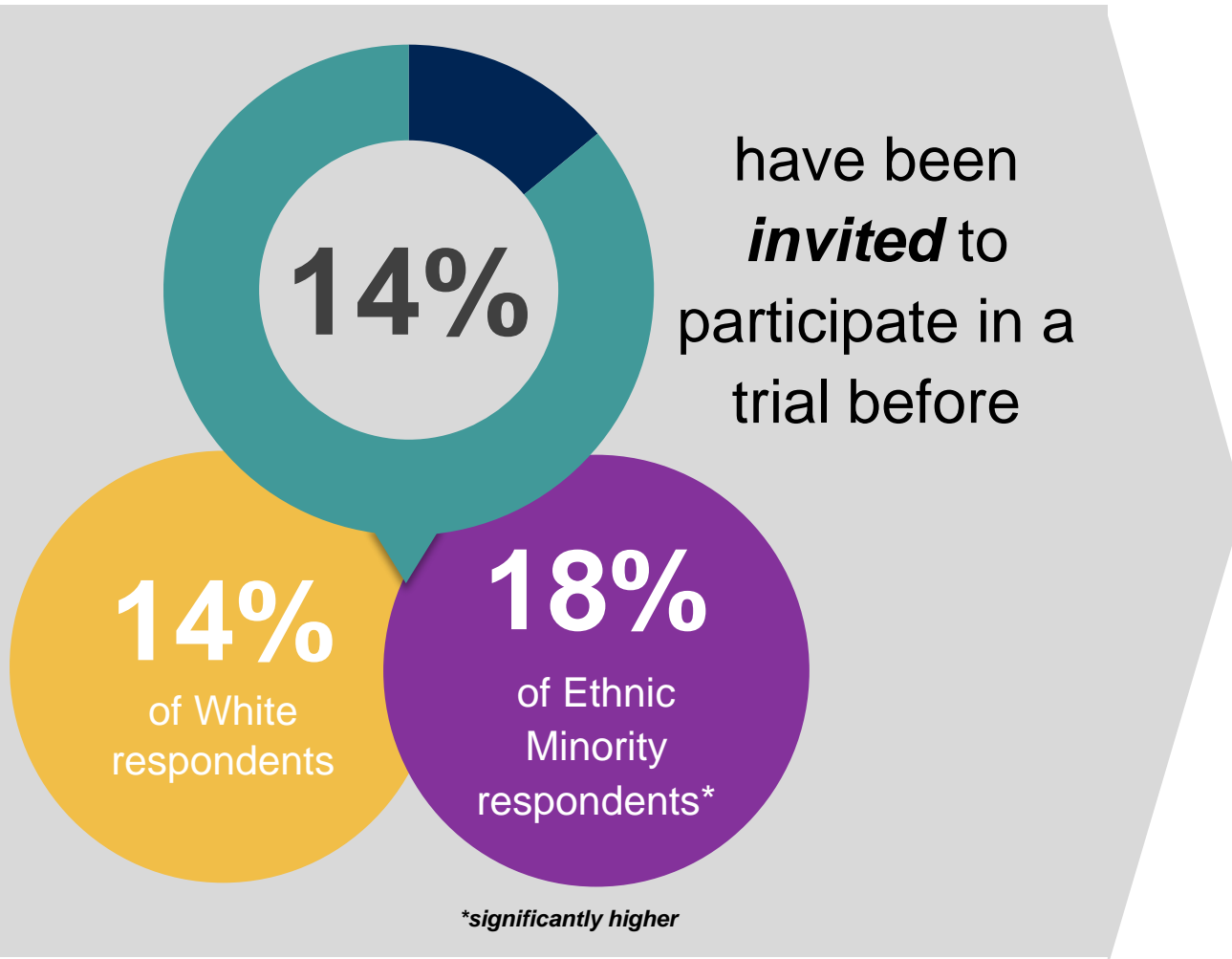
Willingness to participate in clinical trials is significantly lower among adults from ethnic minority backgrounds



Base: All respondents (n= 8206)

QA6: How willing or not would you be to participate in a clinical trial in the future? You can answer this question whether or not you have participated in a clinical trial before.

Similarly, although they are more likely to be invited, significantly fewer ethnic minority adults will take part in a clinical trial



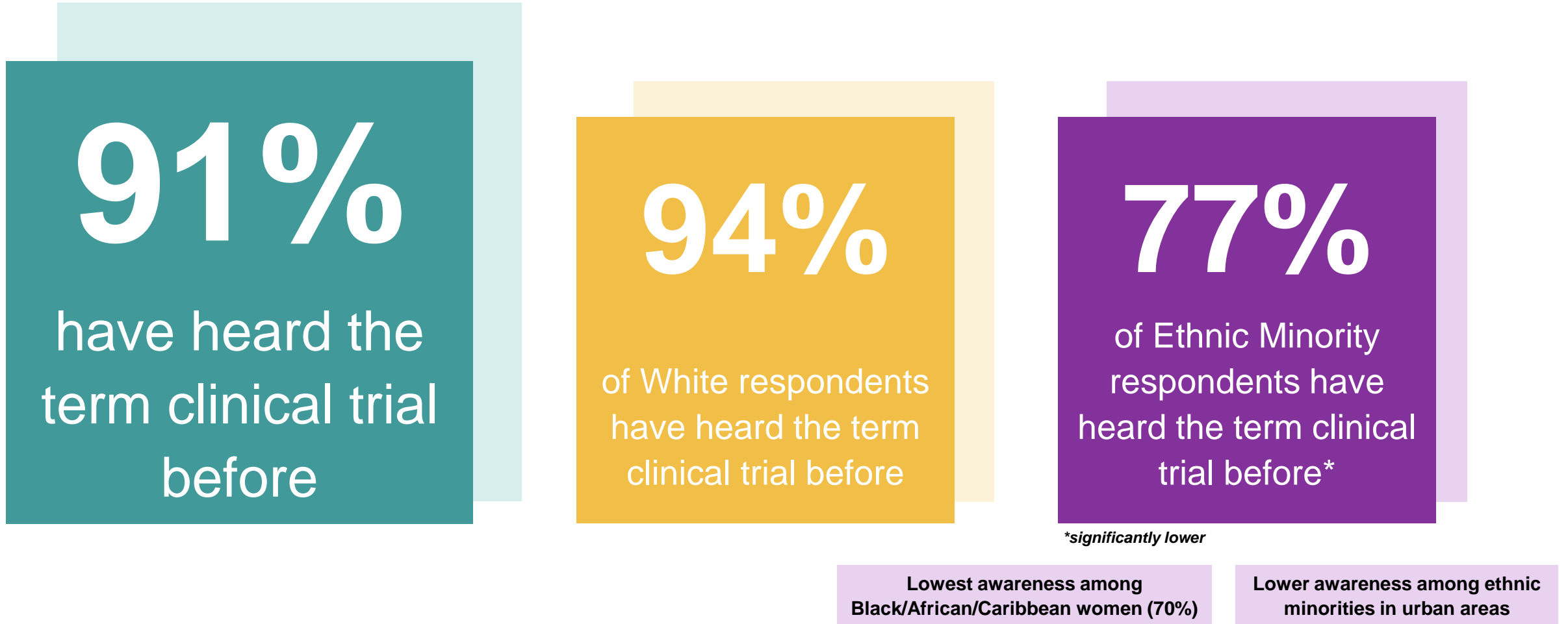
Base: All respondents (n= 8206), all invited to a trial (n=1189)

QA4: Have you ever been asked or invited to join a clinical trial to test a new drug, medical device, or surgical procedure by a healthcare provider? QA5: Have you ever participated in a clinical trial to test a new drug, medical device, or surgical procedure before?

What's behind the gap between willingness and participation?



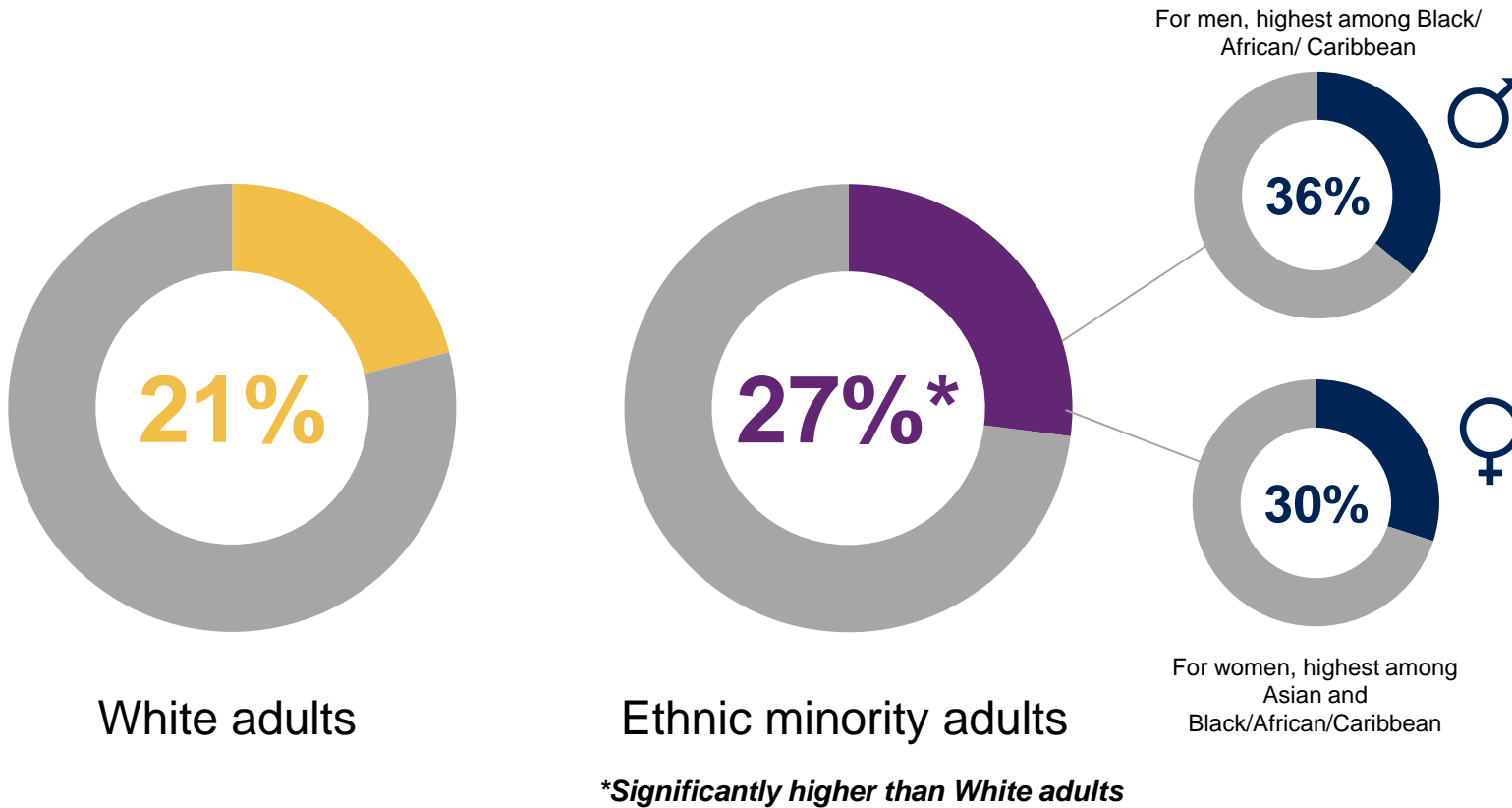
Knowledge may be a factor: 9 in 10 have heard of clinical trials, but this is significantly lower among ethnic minority adults



Base: All respondents (n= 8206)

QA2: Have you ever heard the term 'clinical trial' before?

1 in 4 ethnic minority adults feel they do not know enough about research or clinical trials to participate



Age also plays an important role in knowledge across groups



Knowledge among Black/African/Caribbean adults is consistently lower among adults between 16-44 compared to 45-54 year-olds



Knowledge among Black/African/Caribbean, Asian, and Other ethnic minority groups is lowest among 65-74 year-olds

Fear and mistrust also appear to play a large role in preventing ethnic minority adults in the UK from participating in clinical trials



**Fear of risks
and side
effects**



**Lack of trust
in pharma**

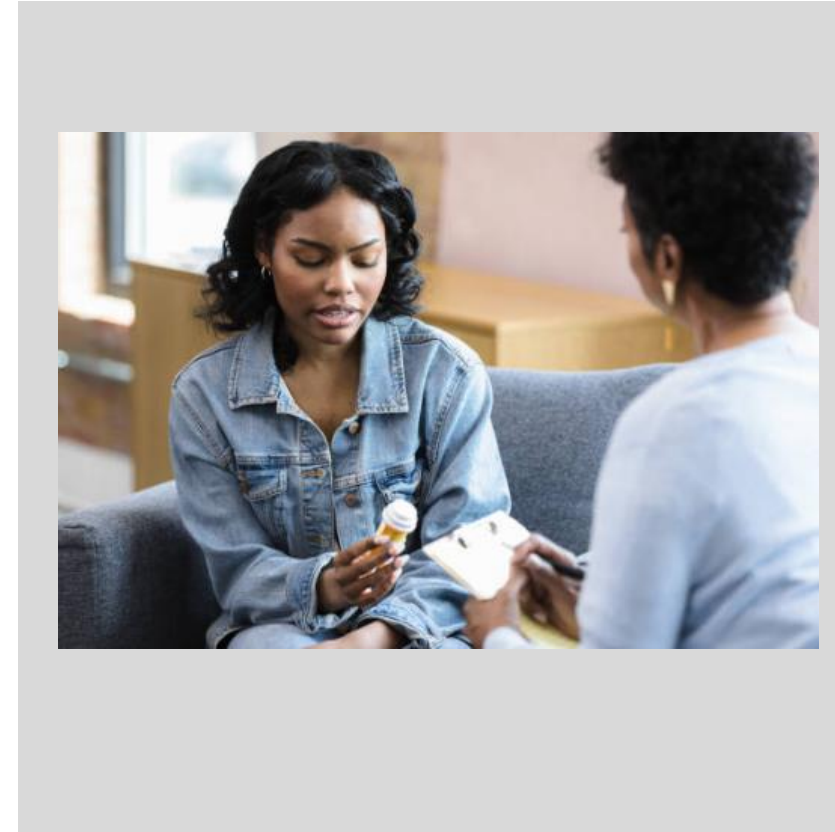


**Lack of trust in
the healthcare
system**

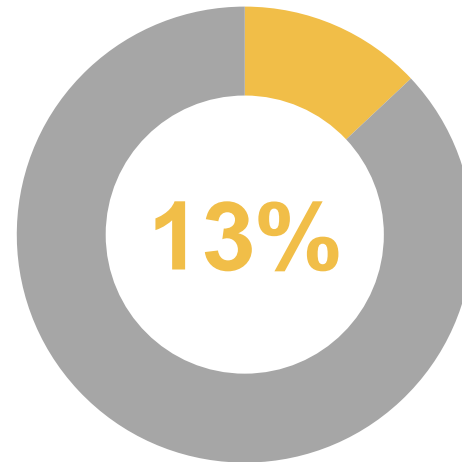


**Discomfort
with research**

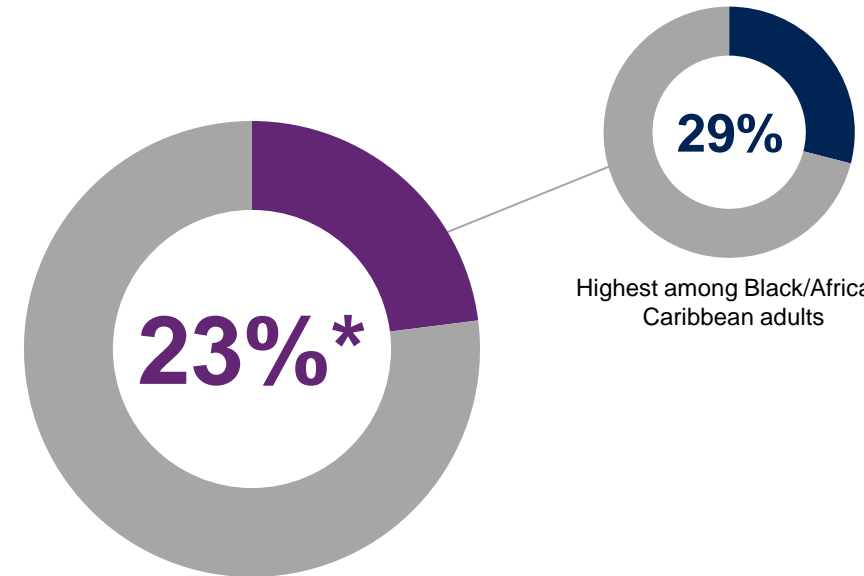
While fear of side effects and risk of participation is the largest barrier to participation, it is significantly higher among ethnic minority adults



Nearly 1 in 4 ethnic minority adults do not trust pharmaceutical companies to test treatments and devices on them



White adults



Ethnic minority adults

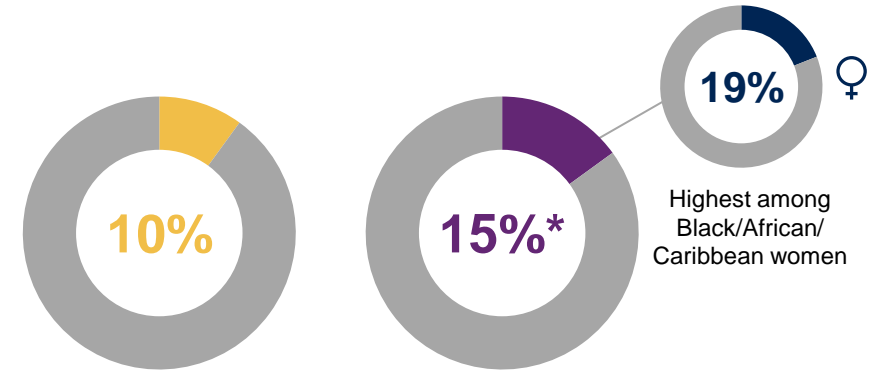
**Significantly higher than White adults*

Base: All respondents (n= 8206) QB2: Which of the following reasons, if any, would make it difficult for you to participate in a clinical trial? You can answer this regardless of whether you have participated in a clinical trial before.

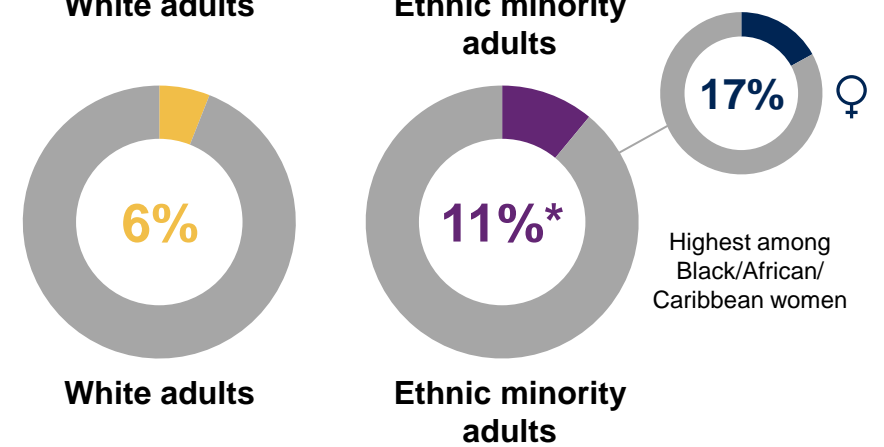
Ethnic minority adults were significantly more likely to report lack of trust in the health system as a barrier to participation



I do not feel comfortable spending time in hospitals or health care settings

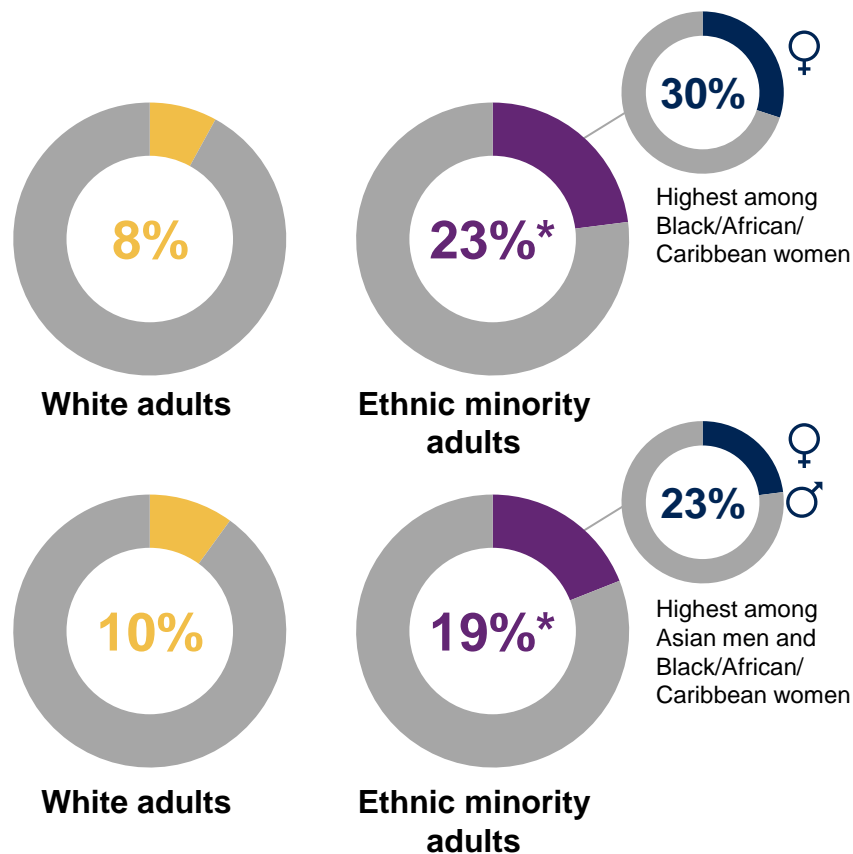


I do not feel that staff will listen to me if I have problems



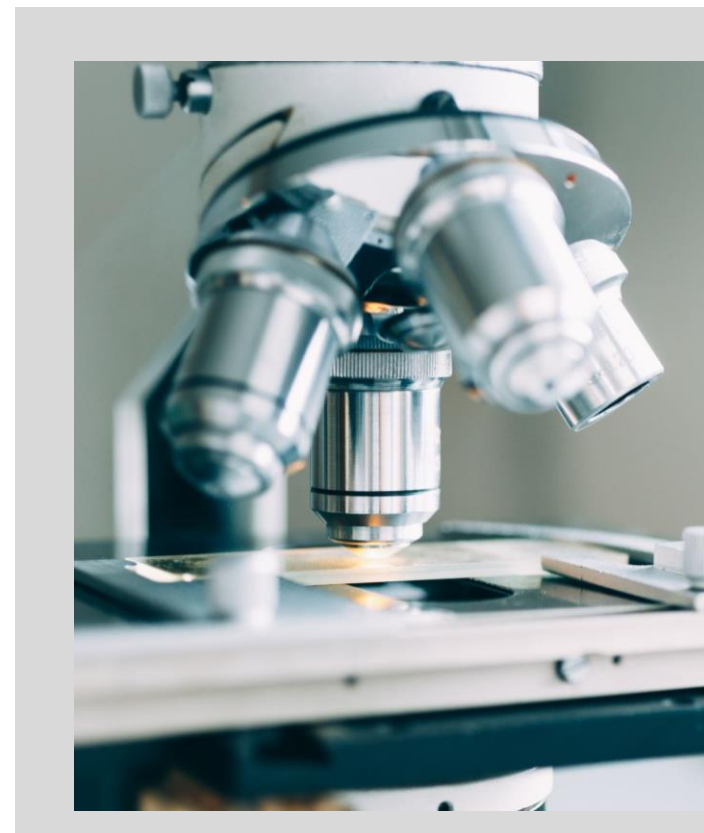
**Significantly higher than White adults*

Ethnic minority adults were also significantly more likely to report discomfort or lack of trust in clinical trials and research as barriers to participation



I do not feel comfortable being studied

I have heard of clinical trials that have been conducted unjustly in the past



**Significantly higher than White adults*

Location and cost of participation in a trial are also a barrier for some



47% overall would find the location of the clinical trial to be a barrier



Highest for white adults overall (49%)

Significantly high for Asian adults aged 65-74

In England, significantly high for adults in rural areas

Higher income respondents across all ethnicities are more concerned about location

Less concern for younger adults

No notable difference by ethnicity and age



No notable difference by ethnicity and income



Highest for Asian men (32%) compared to their female counterparts (20%)



28% overall are concerned about cost of participation

How can we increase diverse clinical trial participation in the UK?

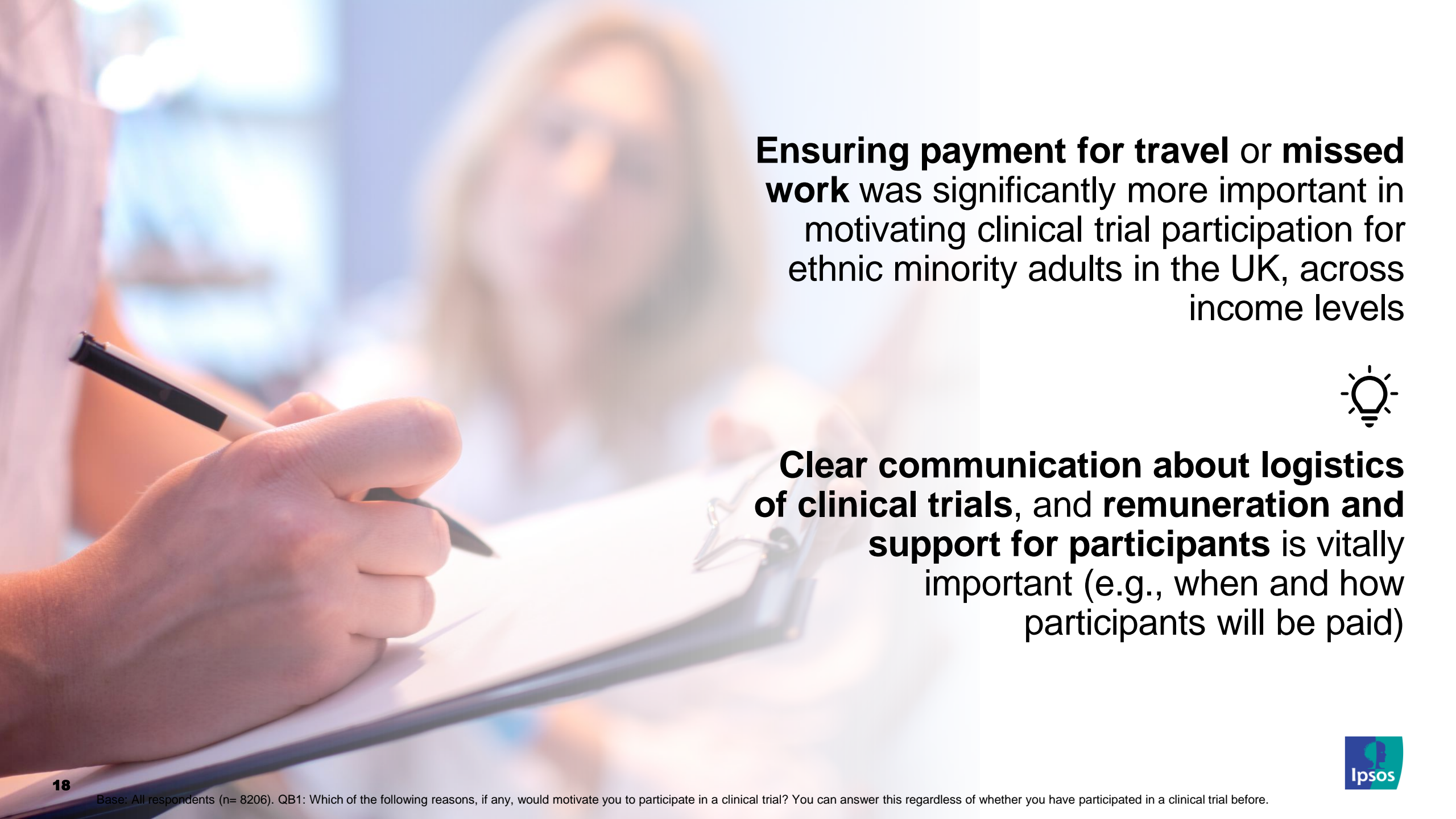


The potential of clinical trials to improve one's own health and the health of others were the two greatest motivators across all respondents



Emphasising the benefit of clinical trials on both a personal and community level should be included in communications and messaging





Ensuring payment for travel or missed work was significantly more important in motivating clinical trial participation for ethnic minority adults in the UK, across income levels



Clear communication about logistics of clinical trials, and remuneration and support for participants is vitally important (e.g., when and how participants will be paid)

Communication channels should be tailored by age



Face-to-face discussions with an HCP is the most preferred communication method for ethnic minority adults by all ages, particularly for those age 35+



Websites and email from HCPs are preferred methods of communication about trials for ethnic minority adults between 16-34



Ethnic minority adults 25+ also like receiving leaflets and brochures, which can be easily handed out in an HCP's office and link to other resources like a website



Black/African/Caribbean young adults aged 16-24 and 55+ would also like group education sessions; these could be held in healthcare settings or community spaces

Base: All respondents (n= 8206)

Leveraging referring physicians as trusted sources of information may be key to overcoming emotional barriers



What if I get side effects from the trial?

Make explicit what the trade-offs and benefits of participation are

Reframe risk in a simple way (e.g., 1 in 100 experience headache)

Emphasise that ensuring their safety in the trial will be a key priority

The thought of being studied makes me uncomfortable

Explain study processes clearly in jargon-free language to reduce uncertainty and fear

Approach conversations with empathy to address anxiety, fear, stress

Position participation as contributing to the greater good

Doctors have minimised my complaints before when I've been sick

Explain processes for monitoring and providing regular feedback throughout trials

Show examples of others from the community who participated in clinical trials

Provide connections to support groups or peer mentors

Sharing real-life patient experiences can help demystify clinical trial participation and make it seem more accessible

1 in 4 Black/ African/ Caribbean adults would find **being able to speak with someone else about their experience in a trial** to be motivating, significantly higher than any other group



Provide opportunities for past participants to **share testimonials**, including forums or Q&A sessions

Engage peer educators/ advocates who can **provide 1-1 support** to potential participants

Promote transparency and allow for participants' broader support systems to be involved throughout the process

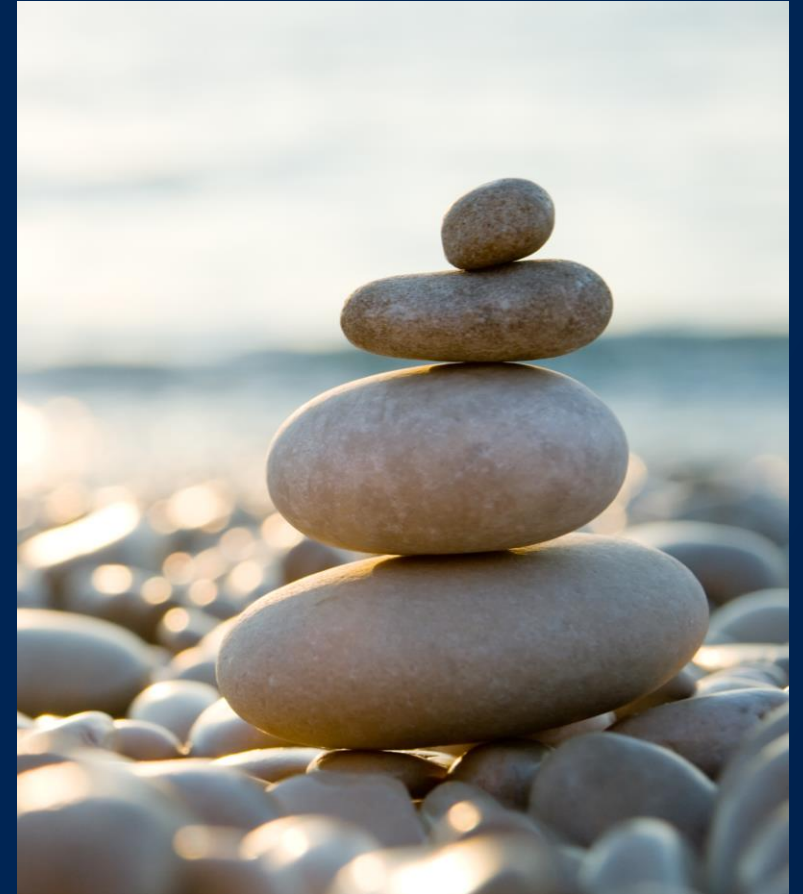
- Allow for a **family member or friend** to be involved from **early discussions to the decision-making process**
- Use **patient navigators** to help understand process such as help with **transport and lodging**, and provide **ongoing emotional support**
- Keep **referring physicians engaged** and **updated** throughout the trial if the patient desires



Increasing engagement will have a reciprocal effect on trust

7 in 10 adults in the UK across ethnicities agree that encouraging more diverse clinical trial participation *can increase trust in the healthcare and pharmaceutical industries*

To combat perceptions of historical injustice, clinical trials should be designed using a community-informed approach, with transparent and routine feedback mechanisms



Base: All respondents (n= 8206)

QB3: Below is a list of statements about diversity and clinical trials. Please consider whether you agree or disagree with these statements.



Charting the course to health equity together

Although patient-centred clinical trial design is now a growing practice, our study shows that efforts to recruit diverse participants can be still be greatly improved.

Conducting research to give voice to future clinical trial participants is an important part of determining what changes need to be made, but it is only a piece of the puzzle.

It is up to the research, healthcare, and life sciences industries to work together to design more innovative and inclusive strategies for clinical trial engagement in the future.

THANK YOU

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Appendix

Technical note

Recruitment to the panel

Panellists are recruited via a random probability un-clustered address-based sampling method. This means that every household in the UK has a known chance of being selected to join the panel. Letters are sent to selected addresses in the UK (using the Postcode Address File) inviting them to become members of the panel. Invited members can sign up to the panel by completing a short online questionnaire or returning a paper form. Up to 2 members of the household can sign up to the panel. Members of the panel who are digitally excluded can register either by post or telephone, and are given a tablet, an email address and basic internet access which allows them to complete surveys online.

Completing the survey

The survey was designed using a 'mobile-first' approach, which took into consideration the look, feel and usability of a questionnaire on a mobile device. This included a thorough review of the questionnaire length to ensure it would not over-burden respondents from focusing on a small screen for a lengthy period, avoiding the use of grid-style questions (instead using question loops which are more mobile friendly) and making questions 'finger-friendly' so they're easy to respond to. The questionnaire was also compatible with screen reader software to help those requiring further accessibility.

Sample

This study was conducted on the KnowledgePanel between 14th – 20th September 2023. The KnowledgePanel is a random probability survey panel. Therefore, the KnowledgePanel does not use a quota approach when conducting surveys. Instead invited samples are stratified when conducting waves to account for any profile skews within the panel.

The sample was stratified by country and education.

A total of 16,138 panellists in the UK (16+) were selected and invited to take part in the survey. Of these, 8,206 respondents completed the survey.

Weighting

To ensure the survey results are as representative of the population as possible, the below weighting spec was applied to the data in line with the target population profile. Up to 3 people per household were allowed to complete this survey. To account for this and varying household sizes, we employed a design weight to correct for unequal probabilities of selection of household members. Calibration weights have also been applied using the latest population statistics relevant to the surveyed population to correct for imbalances in the achieved sample. England and Wales, Scotland, and Northern Ireland were each weighted separately, while an additional weight has been created for the United Kingdom to account for any over or under-sampling within each of these countries.

Calibration weights were applied in two stages:

1. The first set of variables (using ONS 2019 mid-year population estimates as the weighting targets): An interlocked variable of gender by age, and region.
2. The second set were (using ONS 2019 mid-year population estimates and the ONS Annual Population Survey as the weighting targets): education, ethnicity, index of multiple deprivation (quintiles), and number of adults in the household. Ethnicity and number of adults in the household were not applied to Northern Ireland.

Weighting profile: England and Wales

Age and Gender				
	Male	Female	In another way	PNTS
16-24	6.7%	6.3%	0.1%	0.1%
25-34	8.3%	8.2%	0.1%	0.0%
35-44	7.7%	7.8%	0.1%	0.1%
45-54	8.2%	8.4%	0.0%	0.0%
55-64	7.3%	7.5%	0.0%	0.1%
65-74	5.9%	6.4%	0.0%	0.1%
75+	4.5%	6.0%	0.0%	0.0%

Region	
North East	4.6%
North West	12.4%
Yorkshire and The Humber	9.3%
East Midlands	8.2%
West Midlands	9.9%
East of England	10.5%
London	14.8%
South East	15.4%
South West	9.6%
Wales	5.4%

Ethnicity	
White	85.7%
Non-white	13.0%
Don't know/prefer not to say	1.3%

Number of adults in household	
One	18.2%
Two or more	81.8%

Education	
Degree level or above	30.0%
Below degree level	68.9%
Prefer not to say/Not stated	1.2%

IMD Quintiles	
1	20.0%
2	20.0%
3	20.0%
4	20.0%
5	20.0%

Weighting Profile: Scotland

Age and Gender				
	Male	Female	In another way	PNTS
16-24	14.6%	14.5%	0.2%	0.1%
25-34	7.2%	7.5%	0.1%	0.0%
35-44	8.1%	8.6%	0.0%	0.2%
45-54	7.8%	8.3%	0.0%	0.0%
55-64	6.1%	6.6%	0.0%	0.0%
65-74	4.2%	6.0%	0.0%	0.0%
75+	14.6%	14.5%	0.2%	0.1%

Region	
Central Scotland	12.1%
Glasgow	13.1%
Highlands and Islands	8.3%
Lothian	14.6%
Mid Scotland and Fife	12.3%
North East Scotland	14.1%
South Scotland	12.6%
West Scotland	12.9%

Ethnicity	
White	94.5%
Non-white	4.7%
Don't know/prefer not to say	0.8%

Number of adults in household	
One	21.7%
Two or more	78.3%

Education	
Degree level or above	27.5%
Below degree level	70.5%
Prefer not to say/Not stated	2.0%

IMD Quintiles	
1	20.0%
2	20.0%
3	20.0%
4	20.0%
5	20.0%

Weighting Profile: Northern Ireland

Age and Gender				
	Male	Female	In another way	PNTS
16-44	23.1%	23.1%	0.3%	0.0%
45-54	8.4%	8.8%	0.0%	0.0%
55-64	7.6%	7.8%	0.0%	0.0%
65+	9.5%	11.4%	0.0%	0.0%

Region	
Belfast	15.5%
East	24.5%
North	15.7%
Outer Belfast	21.8%
West and South	22.5%

Education	
Degree level or above	27.5%
Below degree level	70.5%
Prefer not to say/Not stated	2.0%

IMD Quintiles	
1	20.0%
2	20.0%
3	19.9%
4	20.0%
5	20.1%