Centric

Health Inequalities Programme

Participation in Health Research and Clinical Trials

Working with communities to better understand and address existing barriers to participation

October 2023

Executive Summary

Research

Currently, members of the Black, Asian, and Minority Ethnic (BAME) community are underrepresented in health research and clinical trials. To make research more inclusive and reflective of the local community they serve, King's College Hospital Foundation Trust (KCH) aims to better understand the barriers to participation and put in place actions to address them.

An initial plan was developed with Centric to engage with BAME and other seldom-heard residents of Lambeth, Southwark, and Bromley. The mixed methodological approach utilised quantitative and qualitative instruments. The primary objective was to gather data about the underrepresented and seldom-heard communities' perceptions, ideologies, suggestions, thoughts and challenges, and additionally to try and understand the root cause that is driving low participation in health research and clinical trials. This was achieved by delivering 3 case studies, 10 interviews and 30 surveys. Some of the key findings of the research included:

- There is a relationship between the lack of information and understanding of and distrust in COVID-19 vaccines and distrust of medical research and clinical trials.
- A lack of communication and awareness surrounding medical research and clinical trials causes distrust and lowers motivation to participate.
- The preferred way to communicate about research and clinical trials is through text messages, although it's highlighted that a range of other communication methods would also be beneficial.
- There is a need for health institutions to create more awareness of the process, benefits and compensation related to participation in research and trials to avoid misinformation dominating public perceptions.
- Participants stressed the importance of choice and making informed decisions, especially for the BAME community.
- Previous negative experiences and perceptions around vaccines influence decision-making about participating in health research and clinical trials.

This report provides an in-depth analysis of the data collected. It also highlights specific recommendations that will support KCH to increase the percentage of research participants from underrepresented groups, including:

- Raising awareness of research and trials via communications products both online and within KCH and local GP surgeries and via email/text messaging.
- Integrating information about upcoming research and trials in existing information being disseminated to patients.
- Co-designing communications products with communities to ensure they are accessible, relatable and engaging.
- Compensation, eligibility criteria, benefits and risks should be clearly outlined in communication products and in dialogue during a consultation.
- Training for staff on empathic and culturally competent approaches to engaging patients.
- Establishing an advisory group made up of representatives of the community.
- Rebuilding trust with patients and healthcare professionals via restorative practice.
- Collaboration with Voluntary and Community Sector (VCS) organisations representing target groups to co-design communications products and recruitment strategies for research and trials.

Summary of Recommendations

This report contains 9 recommendations for working with communities to better understand and address existing barriers to participation in health research and clinical trials. Further details and full explanations of each recommendation provided by Centric are linked below.

1. **Creating Awareness and Disseminating Knowledge**

2. **Communicating Results and Outputs**

3. **Research and Trial Advertisements via Trustworthy Channels**

4. **More Effective Methods of Community Engagement**

5. **Implementation of Rebuilding Trust Framework**

6. **Training for staff**

7. **Advisory Group**

8. **Targeted Approach**

9. **Working with Faith Groups and Community Organisations**

Contents

Preface

The KCH Strong Roots Global Reach Strategy states the Trust's commitment - *“to ensure that changes to our services and facilities are made in a person-centred way”* while *“any new services we establish will be co-designed alongside patients and members of the public to make sure they are fit for purpose”* and that *“we will build stronger links with our patient groups, volunteers and local community, working with them to improve King’s through co-production.”* [1]

Over the last 6 months, Centric has been working with KCH Foundation Trust to pilot a new Engagement and Innovation Model to acquire insights to increase research participation of BAME and underrepresented communities while addressing institutional mistrust, reducing health inequalities and improving the efficacy of service delivery within the Trust. To deliver the pilot, Centric has collaborated on the delivery of the following activities:

- Feedback on the Engagement and Innovation Model via our community research team.
- Recruitment of Community Champions to represent community views on Trust health inequalities working groups.
- Training for Trust staff and Community Champions.
- Co-design of community research objectives, plan and design.
- Delivery of community research on priority topics.
- Support the evaluation of the pilot.

This report details insights from the Health Research and Clinical Trials project. We conducted surveys, interviews and case studies with participants to provide different quantitative and qualitative engagement mediums for the communities of Lambeth, Southwark and Bromley. In this report, we will highlight the key themes from participants we engaged with to provide an overview of their perceptions regarding health research and clinical trials, consider the factors that influence and alleviate scepticism, and the barriers to participation in health research and clinical trials.

Health Research and Clinical Trials Elements

The Project Team

Muhammed Rauf
Project Director

Raquel Caires Januario
Project Manager

Danna Michelly Quinones
Senior Community Researcher

Sophie Johnson
Community Researcher

Ese Okuma
Community Researcher

Centric Approach

Centric Community Research is a Research Hub developed, owned, and operated by the communities of Lambeth and Southwark. Informed by a history of racism and discrimination against people of colour and our lived experience of racial inequities that we still face to this day, we aspire to empower diverse communities of colour across the urban landscape. Our communities and researchers are important to the work we do.

Why Centric

- Centric trains and upskill local community researchers with no previous experience in research methods, thereby creating capacity and capability for local communities.
- Centric is part of the communities we serve, which means we have access to in-depth insight and are trusted by a demographic who are weary of always being researched by outsiders.
- Our team has a diverse range of both lived and learned skills and expertise and a founding team of researchers from different cultural backgrounds, with over 8 languages spoken within the organisation.
- The programme is accessible in a short space of time and offers unique progression routes for community researchers over time. Community researchers progress into leadership roles such as project management and most recently hosting of our own Cen-X podcasts.

APC Model

APC gives us unique, sustainable and dynamic access across the urban locale. We socially broker between organisations and communities to co-design, co-produce and co-evaluate.

Accessibility

We specialise in delving into the heart of 'hard to reach' communities across the distrust nexus that traditional institutions struggle to access.

Positionality

We act as a conduit between institutions and underserved communities across all urban locales through our informal networks that are constantly expanding.

Credibility

We hold a valued, relevant and healing voice within the urban locale that allows our work to have a desired impact. Empowerment of various types of community leaders give us a consistent audience, sense of ethics and direction.

Engage, Connect, Activate

The activation of underserved communities through the community research model and equitable research practices is central to the mobilisation and social activism aspect of research. Centric has developed an internal process for this model. This process is central to the success of the community research model, ensuring communities actively participate, co-design and have a stake in the research process. [2]

Our Methodology

Centric partnered with King's College Hospital Foundation Trust to test and pilot the new Engagement and Innovation Model as part of the Trust's health inequalities programme, which is designed to bring community voices and lived experiences into the Research Health Inequalities working group.

Research in Health Inequalities and Clinical Trials consists of medical research used to learn more about improving positive health outcomes. Similarly, clinical trials are used to test the effectiveness of new medications, vaccines or medical procedures.

The Centric team co-designed the research project with the Research Health Inequalities working group to explore the following:

- To understand the barriers to being part of health research and clinical trials.
- To understand the best methods of engagement with patients about health research and clinical trials.
- To understand if there are methods of engagement outside of KCH that may be best to use for health research and clinical trials.

To do this, we set out an initial plan to engage with residents of Lambeth, Southwark and Bromley via the following methods:

- 30 Surveys
- 10 Interviews
- 3 Case Studies

Interview Methodology

Qualitative research methodology enables researchers to explore social and behavioural issues related to public health that are not achievable with quantitative methods. Several complex public health issues can be better understood by exploration using qualitative methodologies. [3]

The Centric research project team co-designed and created an interview guide, which was approved by the KCH health inequalities programme team and the Research Health Inequalities working group.

- The 10 interviewees were provided with an onboarding form to ensure they met the requirements as set out in the recruitment criteria.
- The community research team then conducted the semi-structured 1-1 interviews using the guide provided.
- The community research team collated and analysed the data received via the interview recordings.

Case Study Methodology

Case study methods are widely recognised in many social science studies, especially when in-depth explanations of social behaviour are sought.[4]

- The research team invited **3** participants to engage in the 1-1 interviews for the case studies. Participants were required to be over 18 and reside in Lambeth, Southwark or Bromley.
- The interviews provided an in-depth account, personal experience sharing and ideas for the engagement on the elements within the research.
- By breaking down the details of a case study, we can provide better support for our community researchers and gain a more thorough understanding of the interviewee's statements.
- This process helps create a clearer outline of the information we have gathered, which can be used to develop a more complete understanding of the subject matter.

Survey Methodology

Survey research is a specific type of field study that involves the collection of data from a sample of elements drawn from a well-defined population through the use of a questionnaire.[5] Surveying is one tool employed in research and behavioural sciences to assess the needs of the community and to garner a deeper understanding of existing issues and potential solutions.[6]

During the survey design phase, we collaborated with the Research Health Inequalities working group members. This led to the development of a survey that accommodates both the stakeholder objectives as well as the participant perspectives in terms of subject content and culturally sensitive language.

- Our survey involved using quantitative research methods that included numerically rated items, multiple-choice questions and open-ended questions. This approach allowed us to obtain a more comprehensive understanding of our respondents' opinions.
- We designed posters, QR codes and WhatsApp messages to make information more accessible to participants. Our community researchers also utilised their existing networks to engage with the community.
- We collated the data from all 30 responses received to form the basis of our analysis, conclusions and subsequent recommendations.

PARTICIPATION IN HEALTH RESEARCH & CLINICAL TRIALS TIMELINE

1 Feedback on Engagement Model

January 2023

Our community research team, comprised of Lambeth and Southwark residents, provided feedback to KCH on the Community Engagement and Innovation model, including recommendations.

2 Recruitment

February 2023

We recruited 5 Community Champions to work with KCH health inequalities programme working groups.

3 Training

March 2023

Training was provided on Centric's community research model for KCH staff and Community Champions.

4 Co-Design

April 2023

Centric co-designed the research plan and instruments with KCH staff in Health Research and Clinical Trial working group.

5 Research

Apr - Sep 2023

Community research was conducted with 43 participants from Lambeth, Southwark and Bromley.

Challenges, Limitations & Successes

Challenges

- Attitudes toward the topic of research - This did not always resonate well with participants due to existing scepticism and lack of knowledge.
- Optimising formats for engagement - There were delays due to the extensive but essential discussions about the appropriate language and format for engaging effectively with survey participants. Our ongoing, close collaboration with the KCH team helped us to align the research requirements with participant understanding and cultural sensitivities.
- Security measures - We assigned additional security measures to prevent bots from accessing our online survey to ensure all the responses were human and directly related to the outreach we had conducted in the community, as even community members can use bots to fill out surveys on their behalf.

Project Limitations

- Duration of the research - Given more time and resources, Centric would have been able to expand the scope of the research and the number of research participants engaged in the project. This may have provided a wider range of insights for the report.
- Participant payments - Due to budgetary restrictions, payments to participants were smaller than usual. Although this is not what drives research participation, this should be factored in when engaging communities in research, considering the current economic climate and cost of living crisis.

Successes

- Participant engagement - Successfully engaging and connecting with participants during the interviews and case studies, with them opening up on a sensitive topic area.
- Research and trial participation - Identifying key influencing factors to increase participation among underserved and BAME communities.
- Building a common understanding between KCH and the Centric team - This was part of the co-design process for the research instruments utilised throughout the project.
- Broader success of the model - Recruitment and retention of community champions on the Research Health Inequalities working group.

Centric

Health Inequalities Programme

Participation in Health Research and Clinical Trials

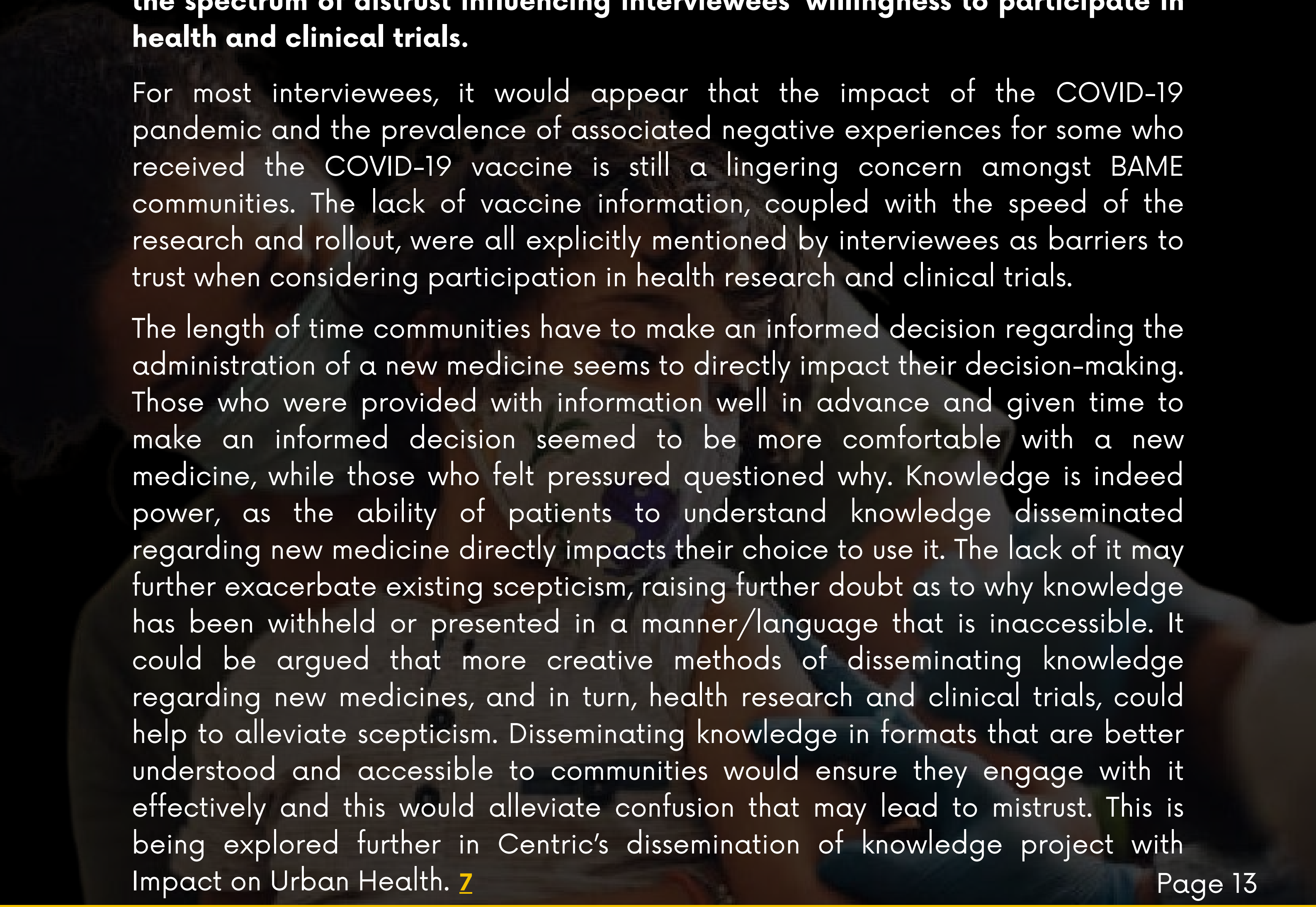
Interview Insights

1. Medical Scepticism
2. Communication
3. Lack of Awareness
4. Participation

Insight 1
Medical Scepticism

Patient distrust was highlighted by many interviewees as a prevalent theme post-COVID. This is based upon the inconsistent or lack of information surrounding vaccines for COVID-19 and the ingredients included in the vaccine. The resulting lack of clarity has exacerbated attitudes of distrust across Black, Asian and minority ethnic (BAME) communities regarding any new form of medical treatment. Our findings indicate that risks associated with new medicines were an important factor in the decision-making process for interviewees. The majority mentioned not receiving an information sheet about vaccines prior to appointments for their administration, while others reported receiving information shortly before the vaccine administration or even after receiving it. Some interviewees mentioned requesting further information directly from GPs so they could make an informed decision.

Childhood vaccines continue to generate widespread debate not included in this document. However, our findings here confirm that while some respondents understand the necessity, others maintain their disapproval of childhood vaccines. **We discovered further evidence that this scepticism is reflected in the spectrum of distrust influencing interviewees' willingness to participate in health and clinical trials.**



For most interviewees, it would appear that the impact of the COVID-19 pandemic and the prevalence of associated negative experiences for some who received the COVID-19 vaccine is still a lingering concern amongst BAME communities. The lack of vaccine information, coupled with the speed of the research and rollout, were all explicitly mentioned by interviewees as barriers to trust when considering participation in health research and clinical trials.

The length of time communities have to make an informed decision regarding the administration of a new medicine seems to directly impact their decision-making. Those who were provided with information well in advance and given time to make an informed decision seemed to be more comfortable with a new medicine, while those who felt pressured questioned why. Knowledge is indeed power, as the ability of patients to understand knowledge disseminated regarding new medicine directly impacts their choice to use it. The lack of it may further exacerbate existing scepticism, raising further doubt as to why knowledge has been withheld or presented in a manner/language that is inaccessible. It could be argued that more creative methods of disseminating knowledge regarding new medicines, and in turn, health research and clinical trials, could help to alleviate scepticism. Disseminating knowledge in formats that are better understood and accessible to communities would ensure they engage with it effectively and this would alleviate confusion that may lead to mistrust. This is being explored further in Centric's dissemination of knowledge project with Impact on Urban Health. [7]

Insight 1
Medical Scepticism
/continued

Some of the interviewees believe that prioritising a healthy lifestyle is more important than receiving vaccines or medical interventions. When they receive notifications urging them to seek medical treatment for a specific reason, they often feel pressured into making a decision without adequate time to consider the pros and cons. This rushed process can feel impersonal and overwhelming and, for some, would lead them to refrain from participation in research or trials if they had a similar experience when being invited to participate, despite any health benefits to themselves or the wider community.

Those who cited the use of traditional approaches mentioned the utilisation of herbal remedies, which was the focus of Centric's research with King's College London surrounding Health Activism. It was shown that the acknowledgement of the benefits of traditional remedies by healthcare professionals could be an important factor in improving relationships with patients, alleviating scepticism of new treatments and pharmaceutical prescriptions by accepting ideas put forward by the community and creating a dialogue rather than a one-way conversation. Improving the relationship with the patient allows them to become more accepting of guidance and information given for participation in health research and trials.

The power of choice appears to be a significant factor raised by interviewees contributing to the research, particularly for the BAME community. This could be due to past mistreatment of BAME communities in clinical trials or their desire to make what they feel are informed decisions regarding their bodies, regardless of the treatment being offered, whether it be vaccines, new medications or trials. An aspect of this sits within the delivery of how the information is presented, including potentially the tone and demeanour used by the professional presenting it. An insight from our Medical Scepticism project reflected one example where a patient was prescribed Prozac; when questioning the doctor why, they said, "because half of Lewisham is on it." Although the patient had a choice in this regard, the lack of alternatives offered, the information provided, and the disinterest in explaining further made her feel as though there was a lack of autonomy, resulting in her refraining from proceeding with the medicine. [8] Such examples show the importance of making a patient feel their decision is autonomous and options are available to them should they wish to proceed with new medicines. Furthermore, when engaging a patient on the topic of health research and clinical trials, the time available to them to explain the purpose, reiterating their autonomy in engaging in such processes and making them feel at ease with the option through tonality, body language and the offer of potential alternatives would be an important influence in their decision to proceed with participation. [9]

Interview Quotes

General scepticism and vaccine hesitancy were expressed by interviewees.

”They don't want our people talking about what's happening with these Covid vaccinations . . .”

“Like trying injections. Even for the COVID . . . they've been trying with old people and kids . . . But I wouldn't do it because you don't know what they put in the injection.”

“Vaccines . . . I believed [sic] that that is what probably started my MS off.”

“Targeting a specific community, I think that would increase my hesitancy.”

“I didn't see how ethnicity had a part to play in that – I could understand blood types or, you know, certain things like sickle cell, for example. “

“I think maintaining a healthy lifestyle is more important than having several vaccines . . . you should pick through choice.”

“But me personally – if I had a choice – then probably not.”

Vaccine hesitancy for children’s vaccines expressed by interviewees who are parents.

“At that time . . . There was a thing – that it might have caused autism. So I fought long and hard – as a parent, you're scared.”

“None of us in my family have had any of those childhood vaccines, and none of the children.”

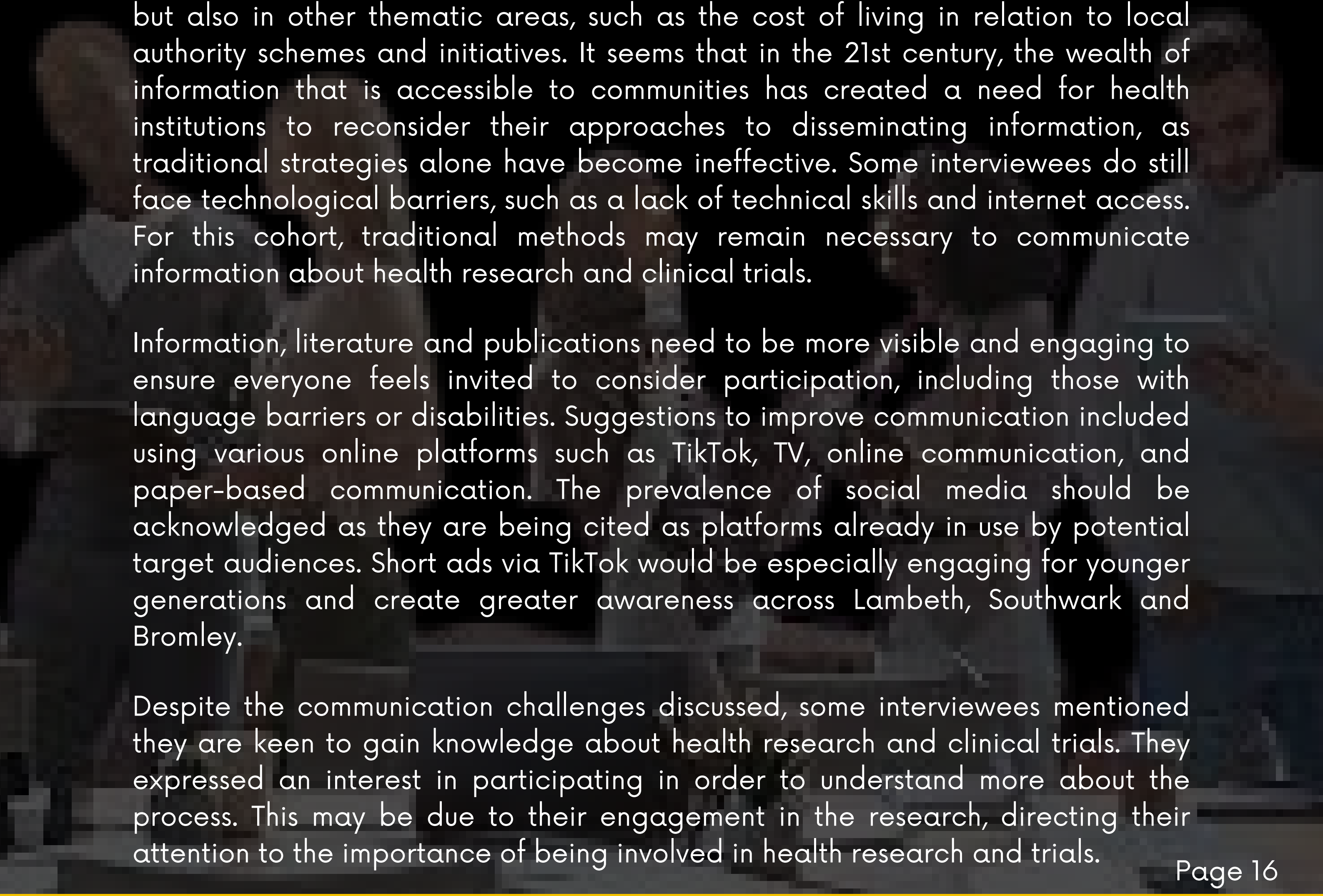
“From my mom's generation, my generation and then now to [the] grandchildren's . . . none of them have had it, and – all of us are quite a large family. [Only] my sister had whooping cough . . . we've escaped everything.”

“Although they say it's a choice . . . It's almost like they bully you into making a decision and it's definitely frowned upon – a lot of the times I've said my son hasn't had any of these vaccines and it's . . . almost like an interrogation.”

Insight 2
Communication

The majority of interviewees remain unsure of the reasons for clinical trials and have reservations due to inadequate information about health effects. There are ethical concerns when conducting trials on those with chronic illnesses, and some felt they may be ineligible due to vulnerable health or sensitivities: *"Transparency is essential, but I am uncertain about participating in trials given the risks involved."*

They have expressed concerns about a lack of communication and clear and transparent information, as many state that they have not seen any advertisements about how to become a participant. Additionally, English as a second language can create barriers as there may be difficulties for diverse communities with language or learning disabilities. It can be difficult for these individuals to participate without receiving accessible communication about what is being offered. This can also become a factor where medical jargon is used in communications, making it inaccessible for non-health professionals.



Communication challenges and lack of awareness are insights that have been prevalent in many of Centric's previous research projects on health inequalities, but also in other thematic areas, such as the cost of living in relation to local authority schemes and initiatives. It seems that in the 21st century, the wealth of information that is accessible to communities has created a need for health institutions to reconsider their approaches to disseminating information, as traditional strategies alone have become ineffective. Some interviewees do still face technological barriers, such as a lack of technical skills and internet access. For this cohort, traditional methods may remain necessary to communicate information about health research and clinical trials.

Information, literature and publications need to be more visible and engaging to ensure everyone feels invited to consider participation, including those with language barriers or disabilities. Suggestions to improve communication included using various online platforms such as TikTok, TV, online communication, and paper-based communication. The prevalence of social media should be acknowledged as they are being cited as platforms already in use by potential target audiences. Short ads via TikTok would be especially engaging for younger generations and create greater awareness across Lambeth, Southwark and Bromley.

Despite the communication challenges discussed, some interviewees mentioned they are keen to gain knowledge about health research and clinical trials. They expressed an interest in participating in order to understand more about the process. This may be due to their engagement in the research, directing their attention to the importance of being involved in health research and trials.

Interview Quotes

Communication

“More clarity - various cultures participate - so more knowledge . . . about how clinical trials work, what they're for, and . . . how it can help people.”

“Paper communications are always useful.”

“I'd say yes [sc. to participation] - if the information were available.“

“The way that information can be worded sometimes it's hard to understand. It's not as digestible. “

“No - didn't get anything like that. You were just basically told this is what you're having done and this is what it's for.”

“When it comes to clinical trials, people often complain that the results are not made public.”

“They want to know how their participation (data) will be used in the future.”

“It seems that the information is kept private.”

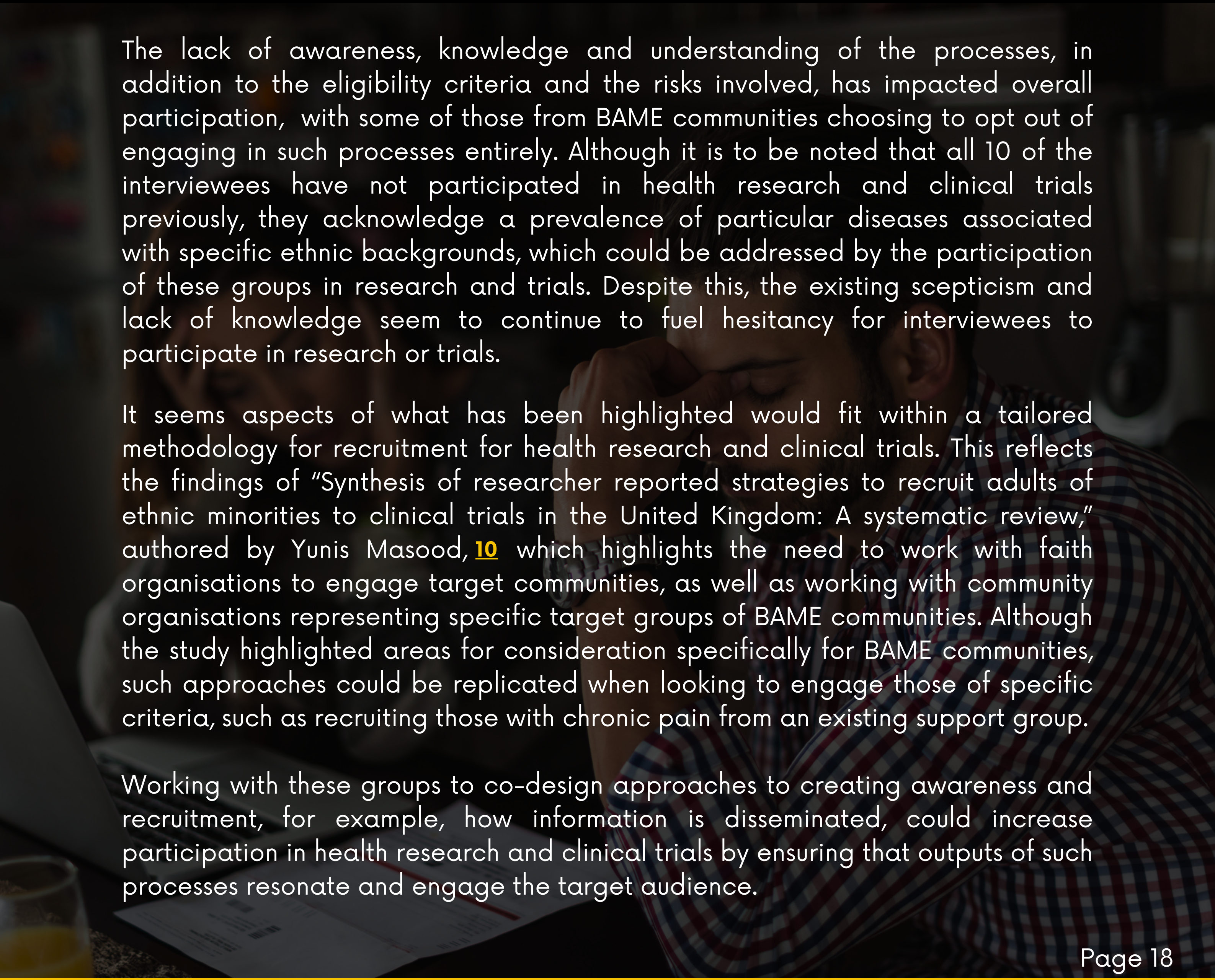
“The only time they let people know what they need is when they are looking for participants. Otherwise, the results are not shared.”

“I would like to be informed on . . . every trial or vaccine . . . as long as it's . . . ethically . . . managed, and . . . aims to produce . . solutions.”

Insight 3
Lack of Awareness

Throughout our interviews, we discovered that some participants were uncertain about the purpose of clinical trials. They were unable to cite the benefits of engaging in trials, demonstrating a lack of awareness and experience of such processes. This, therefore, suggests the need for more work to disseminate information about the benefits of participation in health research and clinical trials.

Interviewees expressed their concerns about participating due to their perceived health restrictions. They believed it was unsafe to support or partake in clinical trials or medical research because of the potential impact on their physical well-being. Moreover, they questioned the ethics of conducting a trial on a vulnerable or chronically ill patient. Some mentioned barriers, such as sensitivity to needs or aversion to the sight of blood, as factors making them ineligible for participation.

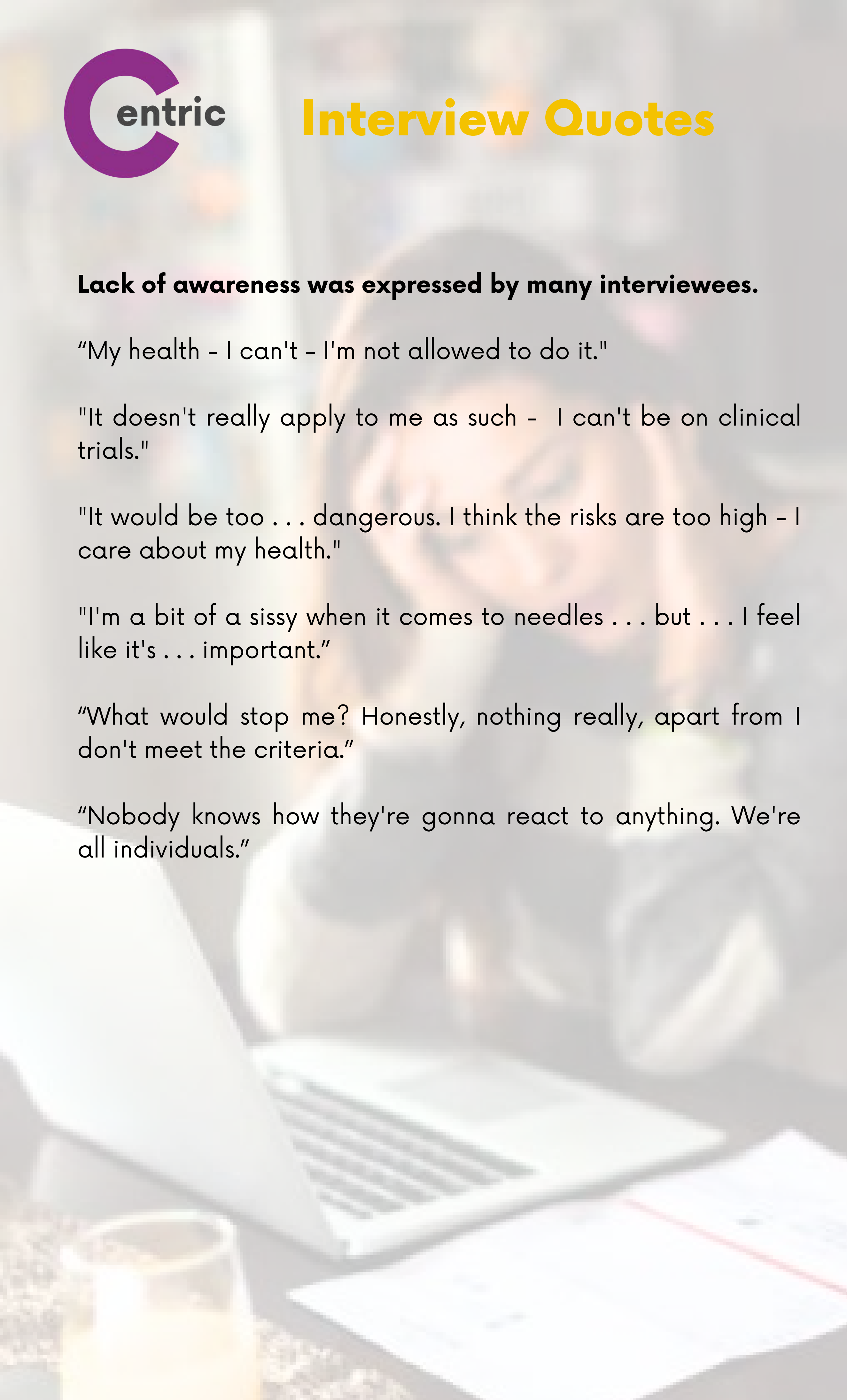


The lack of awareness, knowledge and understanding of the processes, in addition to the eligibility criteria and the risks involved, has impacted overall participation, with some of those from BAME communities choosing to opt out of engaging in such processes entirely. Although it is to be noted that all 10 of the interviewees have not participated in health research and clinical trials previously, they acknowledge a prevalence of particular diseases associated with specific ethnic backgrounds, which could be addressed by the participation of these groups in research and trials. Despite this, the existing scepticism and lack of knowledge seem to continue to fuel hesitancy for interviewees to participate in research or trials.

It seems aspects of what has been highlighted would fit within a tailored methodology for recruitment for health research and clinical trials. This reflects the findings of "Synthesis of researcher reported strategies to recruit adults of ethnic minorities to clinical trials in the United Kingdom: A systematic review," authored by Yunis Masood,[10] which highlights the need to work with faith organisations to engage target communities, as well as working with community organisations representing specific target groups of BAME communities. Although the study highlighted areas for consideration specifically for BAME communities, such approaches could be replicated when looking to engage those of specific criteria, such as recruiting those with chronic pain from an existing support group.

Working with these groups to co-design approaches to creating awareness and recruitment, for example, how information is disseminated, could increase participation in health research and clinical trials by ensuring that outputs of such processes resonate and engage the target audience.

Interview Quotes



Lack of awareness was expressed by many interviewees.

“My health - I can't - I'm not allowed to do it."

"It doesn't really apply to me as such - I can't be on clinical trials."

"It would be too . . . dangerous. I think the risks are too high - I care about my health."

"I'm a bit of a sissy when it comes to needles . . . but . . . I feel like it's . . . important.”

“What would stop me? Honestly, nothing really, apart from I don't meet the criteria.”

“Nobody knows how they're gonna react to anything. We're all individuals.”

Insight 4
Participation

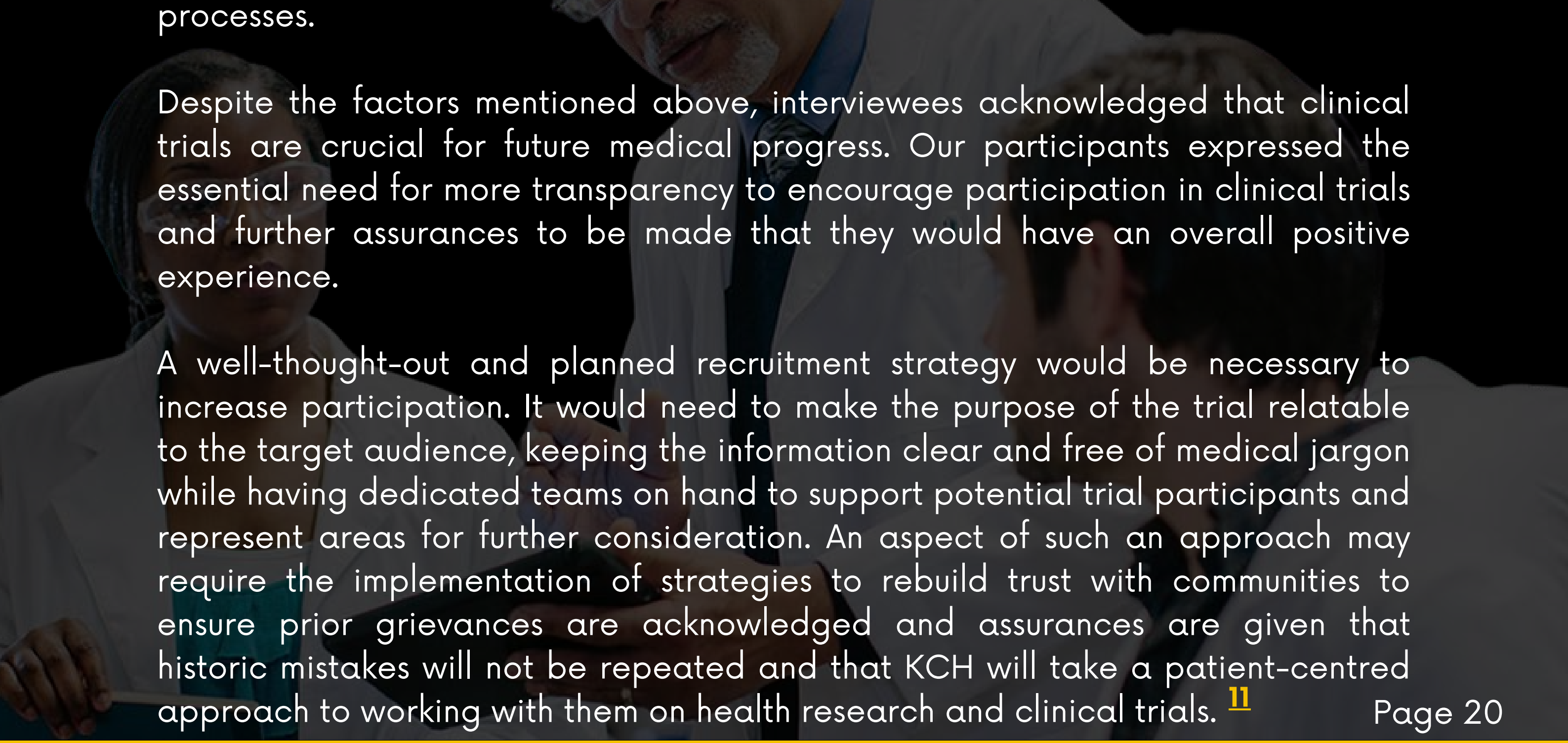
During the interviews for this research project, all 10 participants confirmed that they had no previous involvement in clinical trials. They expressed their hesitation to participate due to scepticism and lack of information, as cited previously. Due to the lack of information, participants from BAME communities ask the question, 'why me?' feeling as though they are being targeted. 1 participant likened this to outright discrimination. Although this may relate to previous negative experiences which feed into the formulation of such a perception, this further highlighted the need for more clarity on why the participation of BAME communities in trials and research is encouraged and how such processes will provide a positive experience and outcome.

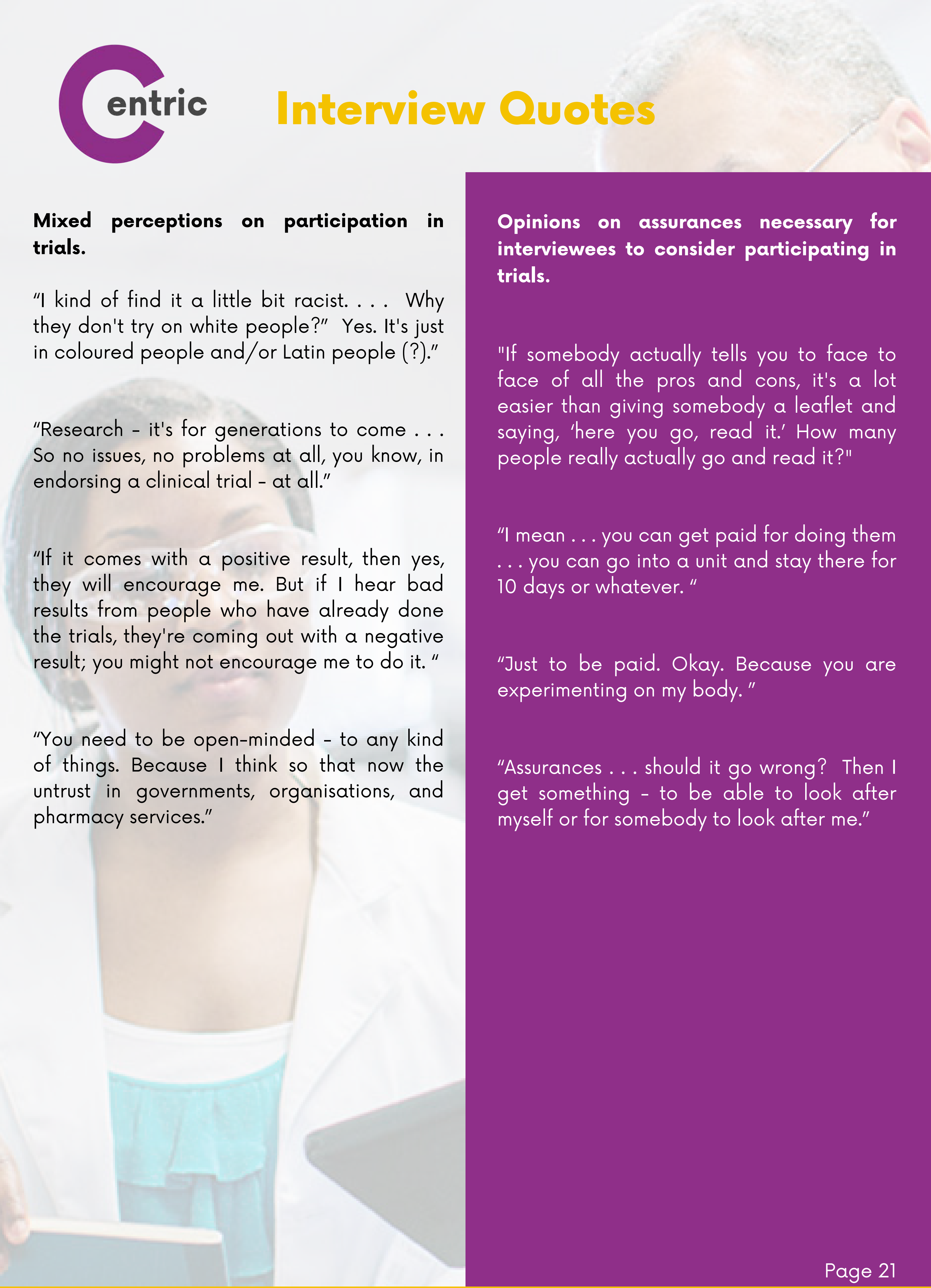
Participants articulated further discouraging factors, such as the lack of information highlighting the peripheral benefits of participation. This might take the form of assurances for future support in case something goes wrong (risks) and financial compensation for travel costs and loss of earnings during participation. Additionally, they would like to understand how data from their participation will be used and stored.

There were also accounts of past events, such as the negative vaccine experiences, which influence current decision-making not only about receiving vaccines but also about participating in any type of health research or clinical trial. Such experiences may represent a lack of care and, in turn, trust for health professionals who would be involved in health research and clinical trials, therefore inclining many in BAME communities not to engage in such processes.

Despite the factors mentioned above, interviewees acknowledged that clinical trials are crucial for future medical progress. Our participants expressed the essential need for more transparency to encourage participation in clinical trials and further assurances to be made that they would have an overall positive experience.

A well-thought-out and planned recruitment strategy would be necessary to increase participation. It would need to make the purpose of the trial relatable to the target audience, keeping the information clear and free of medical jargon while having dedicated teams on hand to support potential trial participants and represent areas for further consideration. An aspect of such an approach may require the implementation of strategies to rebuild trust with communities to ensure prior grievances are acknowledged and assurances are given that historic mistakes will not be repeated and that KCH will take a patient-centred approach to working with them on health research and clinical trials. [11]





Interview Quotes

Mixed perceptions on participation in trials.

“I kind of find it a little bit racist. . . . Why they don't try on white people?” Yes. It's just in coloured people and/or Latin people (?).”

“Research - it's for generations to come . . . So no issues, no problems at all, you know, in endorsing a clinical trial - at all.”

“If it comes with a positive result, then yes, they will encourage me. But if I hear bad results from people who have already done the trials, they're coming out with a negative result; you might not encourage me to do it. “

“You need to be open-minded - to any kind of things. Because I think so that now the untrust in governments, organisations, and pharmacy services.”

Opinions on assurances necessary for interviewees to consider participating in trials.

"If somebody actually tells you to face to face of all the pros and cons, it's a lot easier than giving somebody a leaflet and saying, ‘here you go, read it.’ How many people really actually go and read it?"

“I mean . . . you can get paid for doing them . . . you can go into a unit and stay there for 10 days or whatever. “

“Just to be paid. Okay. Because you are experimenting on my body. ”

“Assurances . . . should it go wrong? Then I get something - to be able to look after myself or for somebody to look after me.”

Centric

Health Inequalities Programme

Participation in Health Research and Clinical Trials

Case Studies

1 - Ana*
2 - Bina*
3 - Cataya*

*Please note that interviewee names have been changed to preserve anonymity.

Ana

Insights

Scepticism and Hesitancy

Ana was surprised to learn about clinical trial opportunities at the Trust as she had not received any prior information. Furthermore, she assumed that she may not be eligible because of her pre-existing health conditions. Due to the perceived risks associated with participation and the historical information she has seen or heard about long-term side effects related to new medicines, Ana is sceptical about participating in clinical trials. She also expressed hesitancy for the vaccination of her children due to claims associating certain vaccines with the risks of autism or ADHD. The need for more clarity and assurances for parents and patients prior to consenting to vaccines also highlights the requirement for more transparent communication with the wider community regarding the aims of medical research and clinical trials.

Open to Participation

Despite her cautious perspectives, Ana did express an interest in participation. However, she would require reassurances regarding the precise terms, such as compensation for her time and full disclosure of any risks associated from the outset. Ana explicitly mentioned that her willingness to participate would also depend on confirming her eligibility and receiving confirmation that she would receive ongoing follow-up care in the event of any complications or adverse outcomes.

Lack of Awareness

Ana's choice not to vaccinate her own children, who are now adults, was based on perceived concerns about links to autism at the time rather than medical advice or reassurances. Although she received written information about her recent COVID-19 vaccine, Ana was not given information sheets at previous vaccine appointments and risks were not highlighted. Moreover, her belief that one of her own vaccines may have contributed to her multiple sclerosis is further evidence of the need for comprehensive medical guidance.

Background

- Female, 45-54 years
- White Portuguese
- Christian
- Hetero / Straight
- Divorced, mother
- Has a dog

- Recently moved to Bromley
- Has a physical disability
- Has MS and other related conditions
- Works part-time
- King's College Hospital provides her main specialist care

Lack of Awareness Continued

Ana has yet to see any advertisement or communication about available clinical trials via any channels, including social media, GP surgeries, KCH or directly from health professionals with whom she has engaged.

Ana expressed her appreciation for the Trust's efforts towards her care but believes there is room for improvement in communication between its staff and herself. She mentioned it would be beneficial to receive direct communication regarding health research and clinical trials, considering she may be open to participation.

Scepticism and Hesitancy

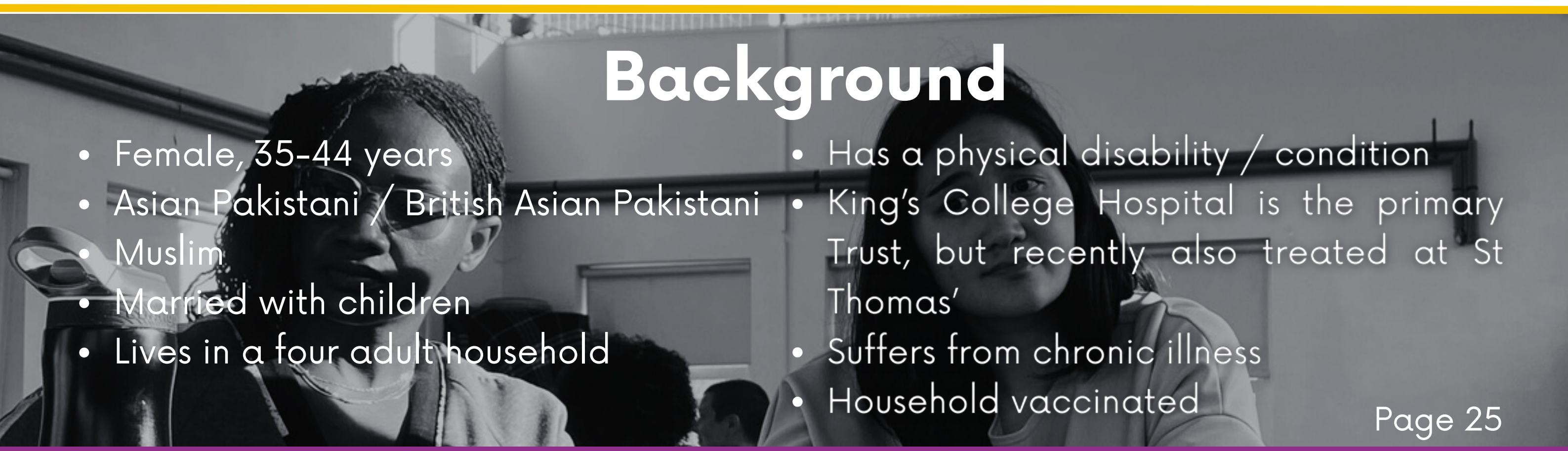
Bina mentioned that she has not taken part in clinical trials due to concerns about her health and uncertainty about the process. She feels that not knowing the potential outcomes and lack of long-term support are factors that impact her trust. Bina cited health concerns as a reason for hesitating to participate in clinical trials, fearing that participation risks could worsen her health. Communicating with healthcare professionals about other health conditions has been difficult, exacerbating scepticism towards health research and clinical trials and how the process would be better than what she is currently experiencing.

Lack of Knowledge

She lacks knowledge regarding available clinical research and trials, which is of particular interest as her mother has successfully engaged in a trial, yet she is unaware of what she may be eligible for, despite her ongoing engagement with healthcare services. Bina, however, remains cautious about the effectiveness and safety of vaccines, new medicines, and trials due to her lack of knowledge.

Participation in Research and Benefits

Bina's mother has engaged in health research about mental health and was grateful for the chance to share her thoughts and experiences. It was highlighted in this example the importance of a reliable source of information (via a doctor she has seen previously) regarding the research, which in turn leads to participation. It was also mentioned that the experience was better than the normal care they received, with direct contact for communication, wider options for testing and an overall better patient experience. It was mentioned in this case that it felt as though her mother was receiving private care due to the improved quality of the service throughout, which is still ongoing. In order to encourage community participation in trials, she suggested increasing advertising efforts, particularly through GP surgeries and social media posts. While she has seen some advertisements before, she believes more could be done to raise awareness.



Background

- Female, 35-44 years
- Asian Pakistani / British Asian Pakistani
- Muslim
- Married with children
- Lives in a four adult household
- Has a physical disability / condition
- King's College Hospital is the primary Trust, but recently also treated at St Thomas'
- Suffers from chronic illness
- Household vaccinated

Cultural and Parental Influence

Culture had an impact on her choices during her childhood. She had no say in whether or not she received vaccines, as those decisions were made by her parents. However, she remembers not being fully informed about what was being put into her. As for travel vaccines, she never questioned them and followed the advice of her GP. She acknowledges that although she had no power to choose back then, she now aims to make her own informed decisions. It is clear that cultural and parental attitudes act as a guideline in determining whether certain practices are appropriate and acceptable. If their parents trust healthcare professionals' advice, then the child is likely to follow suit, as long as they do not have negative experiences which may cause them to question the advice they are receiving.

Healthcare Provision in Country of Origin

Bina highlighted that the limited healthcare options in her country of origin impacted her opinion of the NHS. This is because there is no free health provisions in her own country. She appreciated the ongoing care she received from the NHS services, which would have been costly in her home country. However, she felt that she had to be quite vigilant as she is conscious of whether medicines contain ingredients like pork, which is prohibited as she is Muslim, and therefore she does her due diligence prior to accepting new medications. This shows that it would be beneficial to provide assurances about trial medicines' suitability for those with particular religious beliefs that would increase the likelihood of participation.

Scepticism and Vaccine Hesitancy

Cataya cited that insufficient information is available for people to participate in clinical trials and vaccines. However, she received the BCG vaccine at King's College Hospital and had the Hepatitis B vaccine when working in adult care. Although she is not against clinical trials, she is sceptical about the speed at which vaccines were developed for COVID-19 and the potential side effects that were communicated via social media, which may have been a result of the vaccine not having been rigorously tested prior to release. Catya is not opposed to clinical trials but has concerns about the development timeline and patterns for creating a safe vaccine.

Historical Mistreatment

Cataya has reservations about clinical trials due to past catastrophes in the Americas. For example, a vaccine trial on the Black community in the Caribbean resulted in the spread of HIV. However, she may consider participating in clinical trials if she or a family member was diagnosed with a critical health condition like cancer. If she were diagnosed with a critical condition, she would consider participating in a trial if the medication has undergone a thorough investigation and is deemed safe for use. However, it is noted that this is in the circumstances of critical health issues.

Lack of Knowledge and Awareness

The lack of awareness about health research and clinical trials has heightened existing distrust and hesitancy, particularly regarding the COVID-19 vaccine trials. Cataya expressed hesitancy but highlighted her lack of understanding regarding trials, their purpose, benefits and the process of participation.

Cataya feels health institutions should create more awareness of clinical trials and their benefits so she and the community can receive the right information to make an informed choice; she notes there is a wealth of misinformation available, which causes doubt. Therefore, she would benefit from being able to question the information provided to her by a professional in a non-judgemental manner.

Background

- Female, 35-44 years
- Black / Black British Caribbean
- Christian
- Hetero / Straight
- Unemployed single parent
- Lives in Camberwell
- Household: One adult, one child
- Does not have a disability / condition

Autonomy on Vaccination

When it comes to children's vaccines, Cataya believes that there should be no barriers, but parents should have the choice to opt out. Her first reason for not wanting to give her son a vaccine is due to information she read online that 1 in 4 Black children develop autism because of vaccines. Her second reason is that none of her family members have ever received a vaccine. Cataya feels that there is a lot of interrogation by health professionals (not specified which) when parents choose not to vaccinate their children. She wants the autonomy to choose which vaccines her son will receive and feels there is a lack of opportunity to legitimately question why particular vaccines are necessary, their contents and the potential side effects prior to making an informed decision. This shows that clear information about side effects, benefits and long-term impact is important when patients are considering participation in a trial.

Due to 3 generations of her family not taking the vaccine, she is reluctant to proceed with vaccinations just because they are being recommended or part of standard procedures. If 3 generations of her family have lived healthy lives without vaccinations, she questions why it is now necessary for her and her children. Cataya mentioned there is a feeling of being pressured to have the vaccines by healthcare professionals and a lack of opportunity for open and honest dialogue regarding their benefits. This shows patients would benefit from an open dialogue with a doctor regarding the information on clinical trials being proposed to them, which may increase the likelihood of participation if the appropriate assurances are made regarding side effects and impact on long-term health.

She does note that education about vaccines and their perceived benefits and risks could be better communicated so people like her can make informed decisions. This further emphasises the need for accessible information disseminated to patients via multiple communication channels and in consultations with doctors, which would increase the likelihood of participation and reduce misinformation creating false perceptions of the safeness of trials.

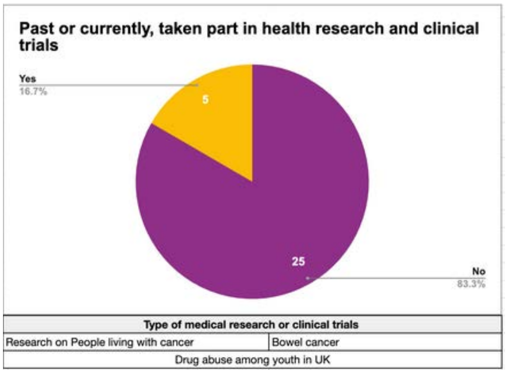
Health Inequalities Programme

Participation in Health Research and Clinical Trials

Survey Insights

Health Research and Clinical Trials in General

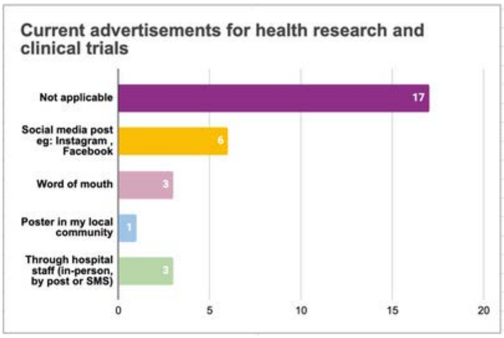
Respondents are largely unfamiliar with medical research and clinical trials. (Graph A)
The majority of our respondents (83%) have no prior or current experience of taking part in health research or clinical trials. Those who indicated experience had been involved in health research or clinical trials relating to cancer and drug abuse among youth in the UK.



Type of medical research or clinical trials	
Research on People living with cancer	Bowel cancer
Drug abuse among youth in UK	

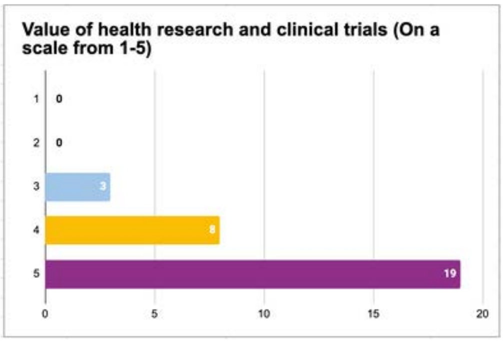
A

A small minority of respondents have seen advertising or information about health research or clinical trials through hospitals. (Graph B)
Only 10% of our respondents had seen or received information about health research or clinical trials through hospital communication channels. A further 20% indicated that they had seen advertisements through social media platforms like Instagram or Facebook; however, a 57% majority had not seen or received any such information. This would indicate an increase in advertisements and how they are designed would create more awareness of health research and clinical trials.



B

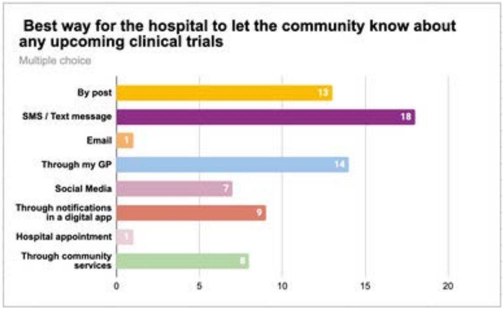
The respondents value health research and clinical trials. (Graph C)
90% of our respondents acknowledged the value of medical research and clinical trials with 63% indicating the maximum value score.



C

Most respondents are happier to receive SMS/text updates about any upcoming clinical trials. (Graph D)
60% of our respondents indicated that SMS/text messaging is an even more popular choice than post or GP communication when receiving updates about any upcoming clinical trials.

(The 47% preference for GP communication aligns with participant viewpoints expressed in our companion research project about managing the Vital 5).



D

Medical Research and Clinical Trials in General /continued

Financial reward, support, together with personal health status information, are the 3 most influencing factors affecting participation. (Table E)

A significant majority (77%) of our respondents indicated that their decision to participate in health research and clinical trials is most likely to be influenced by the opportunity to receive information about their own health status. While financial reward and support for participation ranked second, at 67%, clear communication about the health research and clinical trials goals scored 63%.

It is notable that both positive and negative past experiences were acknowledged as deciding factors (47-50%), whereas current health status and the opportunity to help improve future community health scored slightly higher (57%).

E

How **much** would the following factors affect your **decision** to participate in health research and clinical trials?	Very much	Somewhat	Not at all
Personal or religious beliefs	**13**	10	7
My medical status	**17**	9	4
Hospital invitation by email or post	8	10	**12**
GP invitation by email or post	6	**12**	**12**
Clear communication about the goal of the clinical trial	**19**	5	6
Trustworthy dialogue with researchers	**16**	7	7
Financial reward for my participation	**20**	5	5
Financial support for my time or travel expenses	**20**	6	4
Access to the outcome of the research results	**16**	9	5
Public awareness of the clinical trial	13	**14**	3
Receiving information about my own health status	**23**	3	4
Past experience/s (positive)	**14**	9	7
Past experience/s (negative)	**15**	6	9
The opportunity to help improve the future health of my community	**17**	7	6
The opportunity to be part of clinical innovation	**12**	10	8

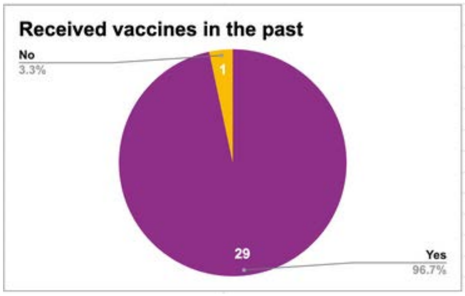
Interestingly, invitations from hospitals or GPs via email or post were considered the least influential deciding factors for our respondents (40%).

Furthermore, linking the health research or clinical trials to positive health outcomes in the respondent's community would be a highly influential factor, in addition to highlighting a clear goal as to what the intended outcome of the trial is.

(Shaded cells denote the most frequent response)

Most respondents have received vaccines in the past. (Graph F)
Only one respondent indicated they had not received vaccines in the past.

F



Most have received a number of vaccines as adults and children. (Table H)
97% of respondents have received vaccines in the past, and most indicated that they had received childhood vaccines. Additionally, they had also ensured that their own children received such vaccines. However, the adult flu vaccine was the most commonly declined vaccine (25%). This may be due to the recent introduction of the COVID-19 vaccine and the associated debate or confusion regarding the potential side effects. Therefore, perceptions may have changed recently due to vaccines from respondents only taking those they deem necessary. Therefore, participation in health research and clinical trials could be encouraged through education about the importance of their participation and the impact of the long-term efficacy of medicines in their communities.

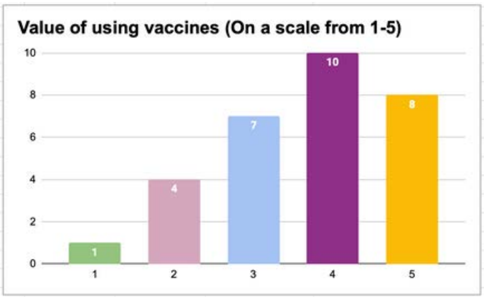
H

Which vaccines have you **taken or declined** in the past?	**Childhood vaccines (e.g Polio, BCG etc)**	**Childhood vaccines for my child(ren)**	**Travel vaccines**	**Adult flu vaccines**	**Other vaccines**
Taken	**28**	**20**	**18**	**16**	**13**
Not sure	2	4	4	2	8
Declined	0	2	0	6	2
Not applicable	0	4	8	6	7

Other Vaccines mentioned		
Covid Vaccine I refused due to fact I was pregnant at time	Covid	Measles vaccine
Tetanus	Whooping cough vaccine	Fever vaccine
	cervical cancer	

Most respondents value the use of vaccines. (Graph G)
60% of our respondents rated the value of vaccines at 4/5 or higher. This may suggest some hesitancy in the 40% who expressed a more neutral or negative response regarding the perceived value of vaccines for overall health. This, in turn, could indicate a reduced likelihood of interest in participation in health research and clinical trials - especially those relating to vaccines.

G

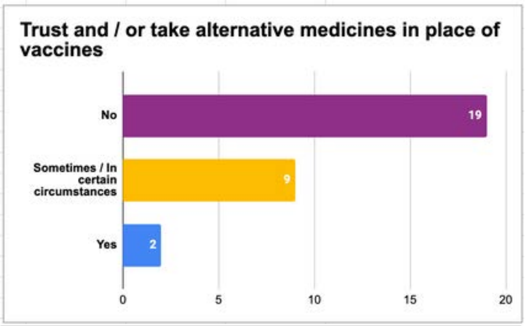


(Shaded cells denote the most frequent response)

Most respondents do not trust/take alternative medicines to vaccines. (Graph I)
Our findings indicate that only 37% of our respondents would trust or use alternative medicines in place of vaccines in either general or specific circumstances. Two respondents explicitly confirmed that they trust and use alternative medicines instead of vaccines, opting for a more natural approach. Alternatives mentioned were natural herbal remedies, such as those traditionally used in BAME communities for generations, such as Black Seed Oil.

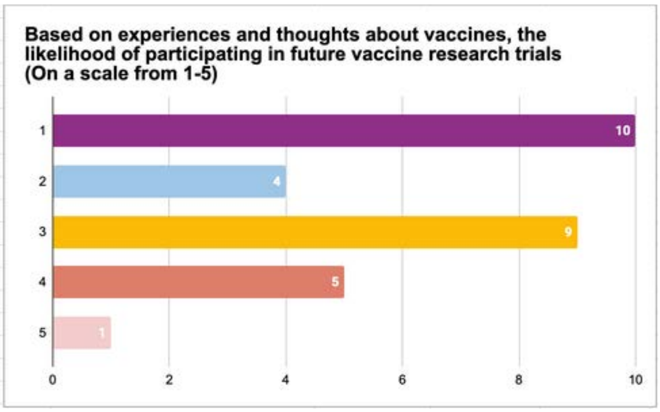
The natural approach may be linked to medical scepticism, as highlighted in the interview insights. Some people prefer a natural approach that they perceive to be healthier and safer for their bodies rather than taking a vaccine that may contain unknown ingredients that could be harmful or cause side effects. Individuals who take such an approach would be highly unlikely to participate in health research and clinical trials.

I



Alternative medicines	
Herbal medicines	Natural/herbal/traditional remedies
Paracetamol, cold/flu syrup	

J

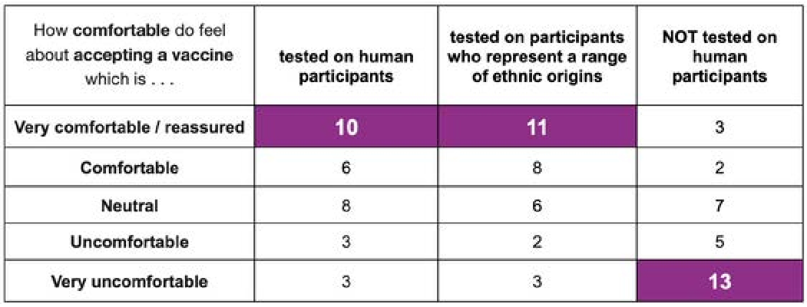


Almost half of our respondents indicate they are unlikely to participate in future vaccine research trials (Graph J)
Based on respondent experiences and thoughts about vaccines, the strongest responses indicating the likelihood of participating in future vaccine trials rated as either most unlikely (33%) or unsure (30%). Only 1 respondent expressed a strong likelihood of participating in future vaccine research trials.

Respondents are most comfortable accepting vaccines tested on a range of ethnicities. (Table K)

Respondents expressed a clear aversion (60%) to accepting any vaccine not previously tested on humans, including 43% who felt 'very uncomfortable' about this prospect. Conversely, 63% of respondents felt comfortable or very comfortable about accepting vaccines tested on a range of ethnicities. This preference was marginally higher than that for the more general category of vaccines tested on human participants (57%). A persistent 17-20% of our respondents maintained their aversion to any vaccine tested on humans, suggesting a distinct unlikelihood of willingness to participate in clinical trials for this field. This highlighted the need for higher participation of diverse ethnic groups, which should also be communicated publically to encourage further participation.

K

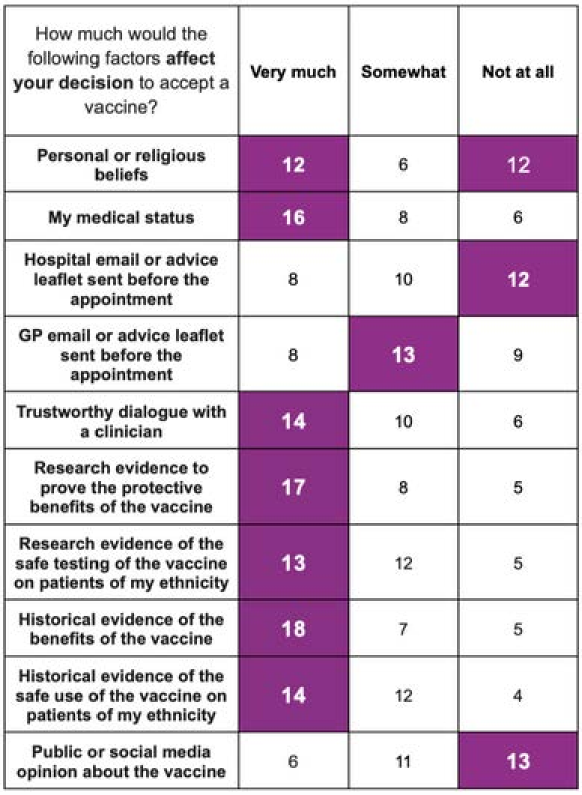


How comfortable do feel about accepting a vaccine which is . . .	tested on human participants	tested on participants who represent a range of ethnic origins	NOT tested on human participants
Very comfortable / reassured	**10**	**11**	3
Comfortable	6	8	2
Neutral	8	6	7
Uncomfortable	3	2	5
Very uncomfortable	3	3	**13**

Historical and research evidence of benefits and safe testing are the most persuasive factors impacting vaccine acceptance. (Table L)

Respondents showed a clear inclination towards basing their decision to accept a vaccine on both historical evidence of its success (60%) and research evidence of its protective benefits (57%). These factors, however, were slightly less pronounced when criteria were modified by the inclusion of safe use on patients of the same ethnicity. It is also notable that both medical status (53%) and trustworthy dialogue with a clinician (47%) also featured as strong influencing factors. Respondents indicated that religious beliefs were equally likely and unlikely to impact their decision about vaccine acceptance, while public opinion and social media were indicated strongly as the least persuasive factor.

L



How much would the following factors affect your decision to accept a vaccine?	Very much	Somewhat	Not at all
Personal or religious beliefs	**12**	6	**12**
My medical status	**16**	8	6
Hospital email or advice leaflet sent before the appointment	8	10	**12**
GP email or advice leaflet sent before the appointment	8	**13**	9
Trustworthy dialogue with a clinician	**14**	10	6
Research evidence to prove the protective benefits of the vaccine	**17**	8	5
Research evidence of the safe testing of the vaccine on patients of my ethnicity	**13**	12	5
Historical evidence of the benefits of the vaccine	**18**	7	5
Historical evidence of the safe use of the vaccine on patients of my ethnicity	**14**	12	4
Public or social media opinion about the vaccine	6	11	**13**

(Shaded cells denote the most frequent response)

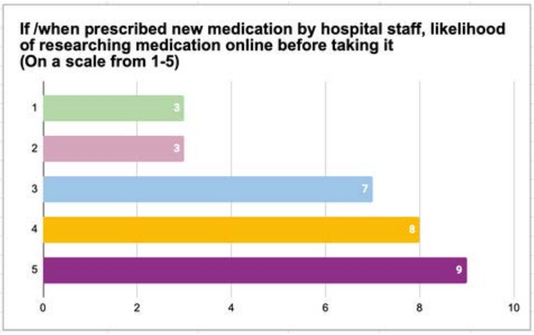
Overall, these findings suggest the need to disseminate trustworthy information effectively to engage target communities about the key outcomes of research, perhaps utilising creative outputs rather than less accessible written reports and articles that may be inaccessible. Such information could be referred to in correspondence via GPs or within formal advertisements from GPs/KCH, prior to appointments where patients can be engaged in further and trustworthy dialogue. Those with existing relationships, such as GPs may also be best placed to encourage participation.

New Medication

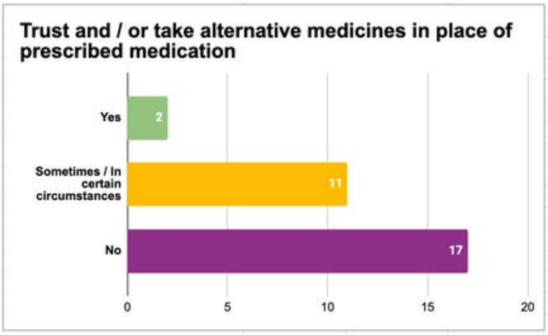
Respondents would research new medication prescribed by hospital staff before taking it. (Graph M)

Our research showed that 57% of respondents are likely or highly likely to research newly prescribed medications before taking them. This may suggest a lack of adequate information provided to patients at the point of prescription or alternatively the need for further reassurance due to existing scepticism already expressed around health institutions and pharmaceutical companies. However, 20% of respondents indicated a low inclination towards researching new medication as prescribed by hospital staff, suggesting some level of trust for medical professionals.

M



N



Respondents' lack of trust in alternative medicines. (Graph N)

When considering alternatives to prescribed medications, 57% of respondents indicated a clear disinclination, suggesting a willingness to accept and proceed with pharmaceutical options offered by medical professionals. However, 37% expressed potential trust and acceptance for alternative medicines in certain circumstances, although it is unclear whether this would apply more to serious or long-term health conditions rather than short-term remedies.

Persuasive factors for accepting new medications. (Table O)

Our findings revealed that respondents indicated 60% confidence in hospital advice, research evidence of benefits and safe testing on patients of the same ethnicity when deciding to take new medications. GP advice for the same consideration ranked slightly higher at 63%. However, personal, religious, public and social media opinions were indicated as the lesser influencing factors, showing the importance of direct communications and guidance from KCH and GPs to increase the likelihood of trial participation.

O

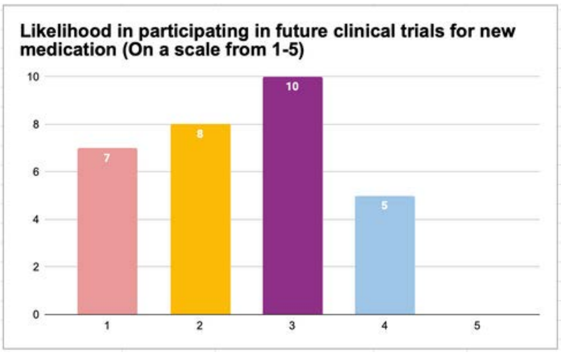
How much would the following factors affect your decision to take new medication?	Very much	Somewhat	Not at all
Personal or religious beliefs	10	5	**15**
Hospital advice or information leaflet	**18**	9	3
GP advice	**19**	7	4
Research evidence to prove the benefits of the medication	**18**	7	5
Research evidence of the safe testing of the medication on patients of my ethnicity	**18**	8	4
Public or social media opinion about the new medication	6	11	**13**
Other factors	6	11	**13**

(Shaded cells denote the most frequent response)

New Medication

/continued

Respondents expressed a low willingness to participate in future clinical trials. (Graph P)
A minority of respondents (17%) expressed any likelihood of participating in future clinical trials for new medication, whilst 50% of respondents indicated a low or very low likelihood of participation. One third of participants expressed a neutral perspective, indicating an overall hesitancy in participating in future clinical trials for new medication. Given the right communications and circumstances, a portion of survey respondents may be inclined to participate in clinical trials.



P

Respondents are most comfortable about accepting new medications tested on human participants, including those who represent a range of ethnic backgrounds. (Table Q)
Respondents indicated they were most comfortable (43%) with new medications tested on humans, including 40% who were also reassured by testing on participants who represent a range of ethnic origins. Conversely, medications not tested on humans caused the highest levels of discomfort or concern for two thirds of respondents.

These findings are comparable with earlier responses submitted for a similar question about the levels of trust for vaccines tested on human participants, including those who represent a range of ethnic origins **(Table K)**. Overall, respondents expressed a core level of trust in health research and clinical trials based on inclusivity in terms of ethnic backgrounds. Greater interest in participation in health research and clinical trials may, therefore, be promoted by utilising this trend in communications related to further health research and clinical trials, improving the efficacy and acceptance of such medications in these communities.

Q

How **comfortable** do feel about accepting **new medication** which is . . .	**tested on human participants**	**tested on participants who represent a range of ethnic origins**	**NOT tested on human participants.**
Very comfortable / reassured	**13**	**12**	2
Comfortable	8	8	5
Neutral	6	5	3
Uncomfortable	2	3	6
Very uncomfortable	1	1	**14**

(Shaded cells denote the most frequent response)

Historical Medical Research and Clinical Trials

Respondents support the value of medical research and clinical trials. (Table R)

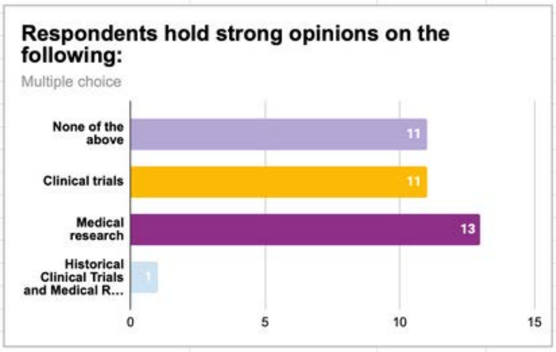
Support for the value of medical research came top at 43%, with support for the value of clinical trials second at 37%, in the opinion of our respondents. However, 37% also indicated no strong opinions about the value of historical or current clinical trials or medical research.

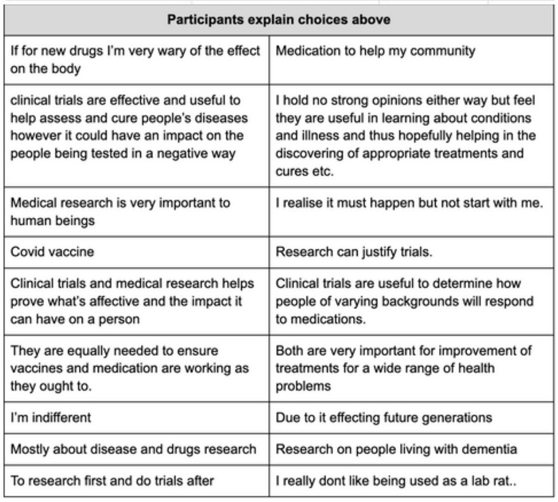
A selection of further comments from respondents confirmed a wide range of views and varying levels of community awareness about the need for clinical trials and medical research.

Current knowledge or impression respondents have of historical clinical trials. (Table S)

When asked to agree or disagree with certain value statements about historical clinical trials, over two thirds of respondents expressed the belief that clinical trials are essential to the success of modern medicine and have helped to prevent or cure diseases, save lives and develop better medicines. However, respondents indicated less certainty of knowledge when asked about any benefits (financial or otherwise) which may have been afforded to participants or whether clinical trial results were made available to the public.

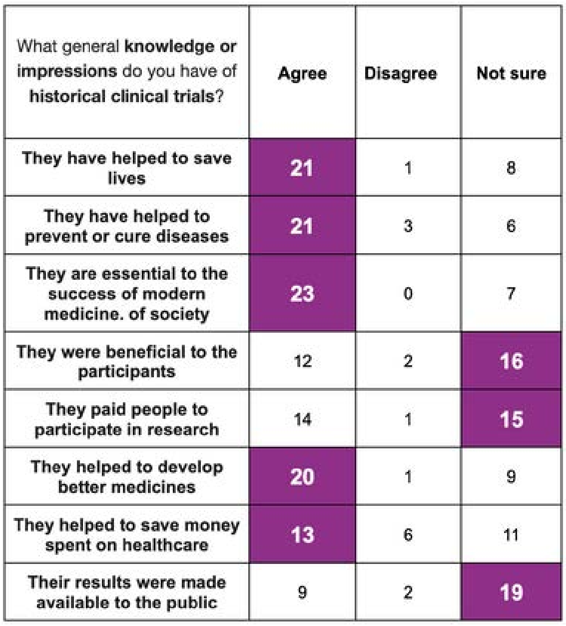
These findings highlighted key gaps in respondents' knowledge or perception of clinical trials and the need to articulate findings to the public.





Participants explain choices above	
If for new drugs I'm very wary of the effect on the body	Medication to help my community
clinical trials are effective and useful to help assess and cure people's diseases however it could have an impact on the people being tested in a negative way	I hold no strong opinions either way but feel they are useful in learning about conditions and illness and thus hopefully helping in the discovering of appropriate treatments and cures etc.
Medical research is very important to human beings	I realise it must happen but not start with me.
Covid vaccine	Research can justify trials.
Clinical trials and medical research helps prove what's affective and the impact it can have on a person	Clinical trials are useful to determine how people of varying backgrounds will respond to medications.
They are equally needed to ensure vaccines and medication are working as they ought to.	Both are very important for improvement of treatments for a wide range of health problems
I'm indifferent	Due to it effecting future generations
Mostly about disease and drugs research	Research on people living with dementia
To research first and do trials after	I really dont like being used as a lab rat..

R



What general **knowledge or impressions** do you have of **historical clinical trials?**	Agree	Disagree	Not sure
They have helped to save lives	21	1	8
They have helped to prevent or cure diseases	21	3	6
They are essential to the success of modern medicine. of society	23	0	7
They were beneficial to the participants	12	2	16
They paid people to participate in research	14	1	15
They helped to develop better medicines	20	1	9
They helped to save money spent on healthcare	13	6	11
Their results were made available to the public	9	2	19

S

(Shaded cells denote the most frequent response)

Lack of inclination to consider participation in clinical trials. (Table T)
The majority of participants remained either neutral (33-47%), or uncomfortable (27-46%) about participation, suggesting an overall unwillingness to take part in clinical trials.

It is interesting to note that vaccine specific clinical trials caused the most discomfort (46%), while clinical trials for new medical procedures generated the most potential interest (33%). This presents an opportunity to potentially encourage participation regarding new medical procedures, especially where it may related to an existing health issue they have, as highlighted in Bina's case study.

In comparison with earlier data exploring willingness to accept vaccines or new medication tested on human participants from a range of ethnic backgrounds **(Table K and Table Q)**, these findings reveal a core resistance or indifference to clinical trials in general. This may confirm the hesitancy towards clinical trials, which is reflected in our earlier interview findings on medical scepticism. (Insight 1)

T

Based on your thoughts and opinions, how **comfortable** do you **feel about participating in clinical trials** for..	**A new vaccine**	**A new medication**	**A new medical procedure**
Very comfortable / reassured	**4**	**4**	**5**
Comfortable	**2**	**4**	**5**
Neutral	**10**	**14**	**11**
Uncomfortable	**7**	**5**	**6**
Very uncomfortable	**7**	**3**	**3**

(Shaded cells denote the most frequent response)

Report Conclusion

It is clear that the COVID-19 pandemic and vaccine continued to exacerbate the distrust that is prevalent among BAME communities in South London. This was a theme that was prevalent throughout the quantitative and qualitative research during this project. This was highlighted by the interviewees who shared their attitudes toward vaccines and new medicines. It seems that due to the impact of and controversy about the COVID-19 pandemic, awareness and distrust of new vaccines and treatments has heightened. In the survey responses, one respondent simply left an explanation of "COVID Vaccine" when asked about why they have a strong opinion about clinical trials.

Historical negative experiences have also heavily impacted their willingness to participate in health research and clinical trials, with interviewees citing historical abuses of Black communities in the US and the Caribbean, influencing their attitudes of mistrust, scepticism and vaccine hesitancy. This was compounded by examples given in the case studies with claims that particular vaccines could be responsible for the development of autism and ADHD in young children. It is important to note that there has been no reconciliation for the past grievances of BAME communities, which may be continuing to impact their participation in health research and clinical trials. Therefore, some of our recommendations include concepts such as restorative and reflective practice - just one example of a wider rebuilding trust framework for KCH to consider. This would be important to increase the participation of BAME communities in health research and clinical trials.

Lack of awareness of such processes, perhaps due to the previous scepticism, was highlighted as a barrier to participation. Interviewees and case study participants both cited this as an issue, unable to identify the specific benefits of being involved in such processes other than being aware they are necessary processes for the development of new medicines. Furthermore, eligibility was an area of confusion, where many expressed their ineligibility to engage in such processes due to poor health or long-term health conditions, which they believed would exclude them from participation.

The lack of awareness seems to correlate closely with communication channels to: 1. Advertise health research and clinical trials and 2. Inform the populace of South London of the benefits of being involved in such processes along with associated risks, compensation and provisions for ongoing support.

Furthermore, where there was awareness of health research and clinical trials, interviewees cited a lack of transparent and accessible information. They related this to their experiences of the recent administration of vaccines, where they received information late or even after receiving the vaccine.

Report Conclusion

/continued

The question was raised as to why information about the vaccines and, in turn, health research and clinical trials is inaccessible and not given well in advance of a decision having to be made. This issue appears to reinforce the disincentives around their willingness to participate.

The timing and accessibility of information also fed into the feeling of a lack of autonomy mentioned by interviewees. Receiving information regarding health research and clinical trials in advance would be conducive to increasing their willingness to participate, giving them time to assess the information (assuming it is accessible) to make an informed decision. This is where communication is highlighted as an important factor. Interviewees and case study participants would value the opportunity to have an open and non-judgemental conversation with a health professional prior to agreeing to proceed. As an example, in Cataya's case study she said she felt pressured into vaccinating her child and the unable to question the necessity for her child to receive a particular vaccine. Her questioning is understandable, as she mentioned 3 generations of her family have not received any vaccinations and are in good health.

Regarding creating awareness of health research and clinical trials, survey respondents indicated SMS and email as the best communication method. However, it is important to note that due to the scepticism highlighted in the interviews and case studies, such an approach should be co-designed with the same communities from whom increased participation is sought. This would ensure it is culturally sensitive and conducive to increasing participation rather than heightening scepticism or provoking questions such as 'Why me?' from patients who are being targeted by the correspondence. This is further discussed in the recommendations section.

Despite the areas for improvement highlighted above, there was interest among participants in the surveys, interviews and case studies about the topic of participation in health research and clinical trials, perhaps encouraged through their engagement in the research exercise. Moreover, this could also be a resulting factor in their acknowledgement of the value of health research and clinical trials in the development of new medicines. Increasing participation among BAME communities in health research and clinical trials would require effective communication of the benefits, process, eligibility criteria and compensation. Furthermore, the importance of their involvement in such processes, assurances of safety and ongoing support post-conclusion of the process would instil confidence in potential participants. Based on the insights garnered throughout this research project, Centric has developed a series of recommendations to increase participation in health research and clinical trials, detailed in the following pages.

Centric

Health Inequalities Programme

Participation in Health Research and Clinical Trials

Recommendations

1. Creating Awareness and Disseminating Knowledge

We recommend that KCH creates awareness of and disseminates knowledge about health research and clinical trials via the following methods:

- Posters, leaflets, and messaging across KCH and at local GPs (to be used in conjunction with other methods).
- Including information on research and trials in consultations, especially with clinicians or doctors who have an existing relationship with patients, as highlighted in Bina's case study.
- Including an opt-in facility in patient forms and communications.
- Direct text and email communications to eligible patients.
- Notifications via the "My Chart" application.
- Placing communication products in locations that target communities frequently, such as universities, faith groups and community centres.

a. Nimble Knowledge Production

We also recommend the development of nimble knowledge production (knowledge that is easily accessible and engaging to the viewer) via creative outputs to disseminate knowledge in a format conducive to communities through videos and illustrations. An aspect of this would require working with creative partners who understand and are entrenched within the communities that the outputs are aimed at targeting. This is likely to ensure that the resulting outputs resonate with and are relatable to the target audience. KCH should also consider utilising the principles from Centric's Trauma-informed design literature where appropriate.[12]

b. Content for Communications Products

Information that is disseminated via these methods should communicate the following:

- Purpose of the research/trial.
- Eligibility criteria and reason why (for example, why BAME participants may be required).
- Explanation of the benefits and risks of participating in the trial.
- Explanation of the long-term goals and expected outcomes, also to clarify that they will be notified of such outcomes.
- Evidence/outcomes of previous research/trials.
- Access to a hotline to speak to a member of staff regarding questions and queries they may have, which can also act as a referral channel for participation.
- FAQs section.
- Including QR codes in materials that link to further resources.
- Case study of successful participants from prior health research or clinical trials.

c. Co-Design of Communications Products

Communication products highlighted above should be co-designed with communities to ensure they are conducive to the intended outcomes. The design/content of such communications is paramount and highly sensitive, given the existing scepticism, and a trial of such an approach should be accompanied by an evaluation to measure the impact and responses to content, for adjustments to be made where necessary.

2. Communicating Results and Outputs

We recommend that KCH considers how creative and more accessible forms of communication can be used to disseminate health research and clinical trial results and evidence to the communities of Lambeth, Southwark and Bromley. This is important, as highlighted by the survey respondents. This is a key influencing factor for them to consider participation. Yet currently, academic journals and papers are one form of dissemination that remains inaccessible in terms of language, and paywalls have been established, which create a barrier to obtaining this knowledge. KCH should consider how it can better communicate findings via platforms and methods that communities are already engaging with and how this may be included in communication products cited in recommendation 1.

3. Research and Trial Advertisements via Trustworthy Channels

We recommend advertising information regarding health research and clinical trials via all communication channels, especially social media. However, an important consideration in this is via an avenue that is trusted by target communities. This would vary depending on the community. However, it would include:

- NHS England
- KCH
- UK Government and Local Authority
- Organisations with existing relationships with communities, like Centric and faith organisations
- GP surgeries
- Better Health Instagram

4. More Effective Methods of Community Engagement

We recommend the implementation of more effective methods of engagement, highlighted in the literature previously developed here - 7 Rules for Highly Effective Community Engagement.[13] It is worth KCH considering how each of the 7 rules could be implemented to increase participation in research and clinical trials. Additionally, KCH should also consider how to implement the community outreach components of the recently published King's Model.[14]

5. Implementation of Rebuilding Trust Framework
We recommend the implementation of the framework to rebuild trust with the communities of Lambeth, Southwark and Bromley, cited here. The approach below is one example of how this could be put into practice.

a. Restorative Practice
We recommend the use of restorative practice with patients to facilitate open dialogue, which will provide a foundation upon which trust can be built. Only through the acknowledgement of challenges and concerns patients have faced can more open and equitable relationships be built. Restorative practices are quite new for healthcare, and the notion arrived from the criminal justice sector. There is a need for open and honest communication between patients and families on the one hand and experienced healthcare professionals on the other hand. Not only does this create an environment where empathy can thrive, of which our previous medical scepticism research has revealed a huge deficit, but is also a disruptive approach to directly dealing with medical liability and patient grievance for marginalised communities. [15]

Restorative values include:
- Active participation
- Respectful listening and communication
- Truthfulness
- Accountability
- Empowerment and equal concern

A restorative inquiry involves looking at:
- Who has been hurt, and what are their needs? (past focus)
- Who is responsible for the harm, and what are their obligations? (present focus)
- How can harms be repaired and relationships improved?
- How can we prevent it from happening again? (future focus)

A restorative practice approach within healthcare can offer healthcare professionals and patients an opportunity to reflect on their own experiences of either harm or poor treatment. This also helps to facilitate change in future practice and instills greater empathy in healthcare professionals. Innovative and fresh dialogue can be undertaken in a non-defensive, non-aggressive environment in which healthcare professionals understand what it is like to experience harm, and patients and families also understand the complex dynamics of healthcare settings that govern the performance of healthcare professionals in their daily practice that may lead to harm.

6. Training for Staff

We recommend that KCH finds an appropriate provider who represents and understands BAME communities to provide training for staff on empathic and culturally competent approaches to engaging patients. This would improve relationships with patients and increase the likelihood of them adhering to the information provided to encourage their participation in research and clinical trials.

7. Advisory Group

We recommend that KCH establish a patient advisory group consisting of community champions, patients and local community groups who can represent their respective communities to provide ongoing support, feedback and recommendations. The group could advise KCH on the following:

- Design, content, and placement/dissemination of communications products.
- Review and advise on recruitment and ongoing processes for health research and clinical trials to ensure they are conducive and culturally appropriate to the communities from whom increased participation would be beneficial. This may include recommendations on appropriate compensation for participation.
- Advise on strategies and approaches to build trust and improve the experiences of patients overall, which would support attempts to encourage participation in research and trials.

Centric is already managing a Patient Advisory Group for Lambeth Together, consisting of 8 chronic pain patients who meet quarterly to provide ongoing feedback on primary and secondary care provisions, as well as recommendations to improve patient experiences in healthcare settings.

8. Targeted Approach

We recommend identifying and targeting patients who could benefit from being involved in a trial/research. An example was provided in Bina's case study, where her mother directly benefited from the research and received better quality of care via more options for medical testing, communication, and improved patient outcomes. She was notified of the research directly by a healthcare professional during a consultation. Therefore, identifying the correlation between the requirements of new health research and trials with patients who are attending the hospital would be beneficial, and the healthcare professional engaging with the patient can open a dialogue with them during the appointment and explain how they may benefit from participating in such a process.

9. Working with Faith Groups and Community Organisations

We recommend that KCH considers working with faith groups and community organisations to co-design and develop the following:

- Gain a better understanding of the cultural and religious nuances and barriers that may be driving lower participation rates in BAME communities.
- Design and write content for communications products that will be disseminated to the communities they represent.
- Placement and dissemination of communications products.
- Co-design of recruitment strategies for health research and clinical trials.
- Develop channels for recruitment for target communties.

Working with these organisations to develop these strategies while educating them on the benefits of participation may also create new avenues for recruitment. What is important here is developing relationships based on shared equity, ensuring there is appropriate reciprocity with partners to ensure the relationship is not extractive, as this would be counter-productive to increasing participation by exacerbating current scepticism. KCH may want to consider what other benefits (other than financial) can be offered to make the partnership equitable and develop long-lasting relationships that build trust with these organisations and, in turn, the communities they represent.

Health Inequalities Programme

Participation in Health Research and Clinical Trials

End Notes

- Acknowledgements
- CR Reflections
- References

Acknowledgements

Centric would like to acknowledge the support and cooperation of the King's College Hospital team - especially Simon O'Donoghue - for their keen attention to the co-design and commissioning of this research project.

CR Reflection

“As someone who studied Biomedical Science, I've always been interested in the subject. Hearing directly from participants about their experiences and the potential of this research has been enlightening.”

“However, there is still a lot of work to be done in conducting health research. It's a multifaceted process, and I hope that the research that has been conducted can contribute to improving it.”

“By interviewing community members, I've improved my ability to understand their lived experiences and thoughts regarding health research and clinical trials. It's important to hear from those who are often unheard in these matters.”

“Moving forward, I hope to see more dialogue and communication between the community and decision-makers regarding health research and clinical trials. The insights gained should be used to create a more sustainable and community-focused model.”

Sophie, Community Researcher

CR Reflection

“I was interested in learning about what it's like to work on a project at King’s College Hospital, both for research purposes and to understand the aim of clinical trials in finding new medicine and curing existing diseases. Additionally, my personal experience with the loss of a family friend to leukaemia motivated me to understand people's experiences with clinical trials.”

“I have gained familiarity with the type of information the medical sector needs to improve people's lives, the importance of engaging with the community to collect data, collaborating with team members, and understanding the views of marginalised communities on clinical trials and health inequalities. I am also interested in improving my techniques for interviewing marginalised communities, analysing data, and using other methods to conduct interviews.”

“Moving forward, I would like to see changes implemented based on the data collected to make informed decisions that build community trust. Specifically, I would like to see more community engagement in research, increased awareness in schools and within the community about the importance of health research and clinical trials, and greater transparency about the risks and benefits of participating in these studies.”

Ese, Community Researcher

References

1. King’s Engagement and Innovation Model 2022
2. Centric - Engage, Connect & Activate
3. Isaacs, A.N., 2014. An overview of qualitative research methodology for public health researchers.
4. Zainal, Z. (2017). Case Study As a Research Method.
5. Visser, P. S., Krosnick, J. A., & Lavrakas, P. J. (2000). Survey research. In H. T. Reis & C. M. Judd (Eds.), Handbook of research methods in social and personality psychology (pp. 223–252).
6. Tepper, Stephanie J., et al. 2022
7. Dissemination of Knowledge: Empirical Expansions
8. Medical Scepticism
9. Health Activism in Brixton - Real Talk
10. Kadam, R. A., Borde, S. U., Madas, S. A., Salvi, S. S., & Limaye, S. S. (2016). Challenges in recruitment and retention of clinical trial subjects.
11. Ross, S., Grant, A., Counsell, C., Gillespie, W., Russell, I., & Prescott, R. (1999). Barriers to Participation in Randomised Controlled Trials: A Systematic Review
12. Centric - Trauma Informed Design Literature
13. The Seven Rules for Highly Effective Community Engagement: Reimagining Engagement for a Better Society
14. Ray Chaudhuri, K., Podlewska, A., Hui Lau, Y., Gonde, C., McIntosh, A., Qamar, M., O'Donoghue, S., Larcombe, K., Adeeko, M., Gupta, A., Bajwah, S., Lafond, S., Awogbemila, O., Van Coller, R., Murtagh, A., & Ocloo, J. (2023) Addressing the gap for racially diverse research involvement: The King's Model for minority ethnic research participant recruitment.
15. Wailling J, Kooijman A, Hughes J, O'Hara JK (2022) Humanizing harm: Using a restorative approach to heal and learn from adverse events (4), 1192-1199

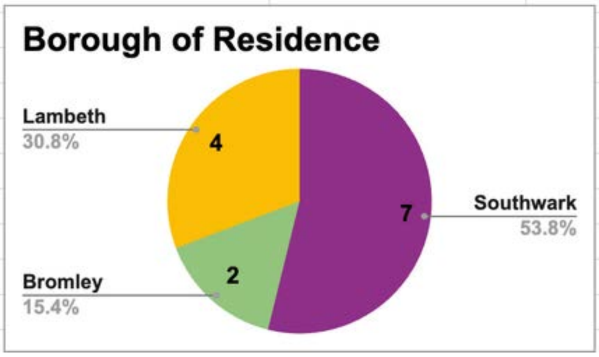
Centric

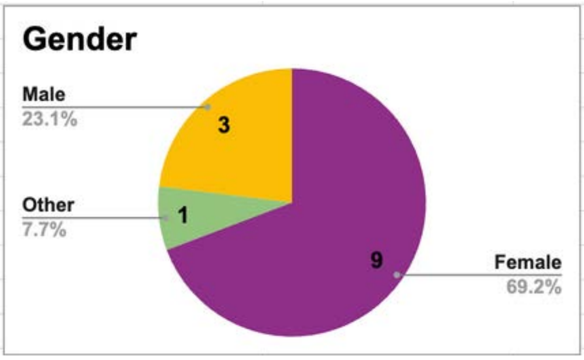
Participation in Health Research and Clinical Trials

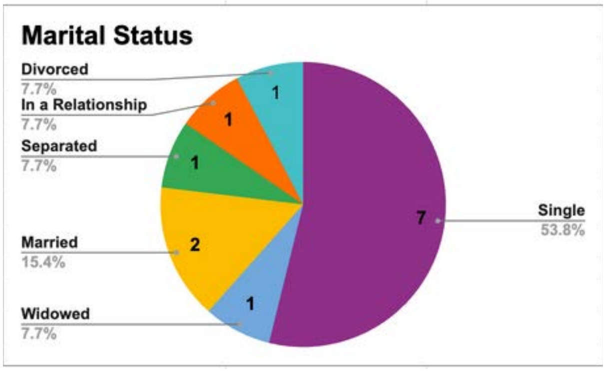
Appendices

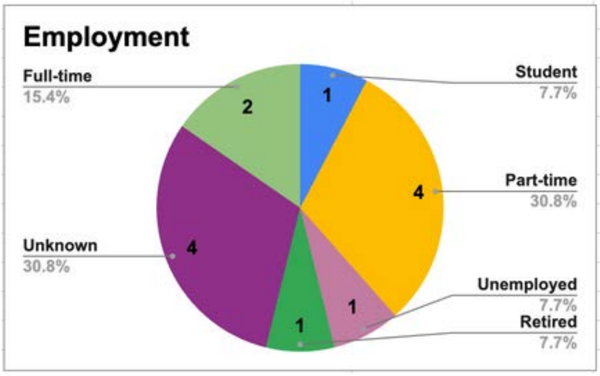
Interview Demographics

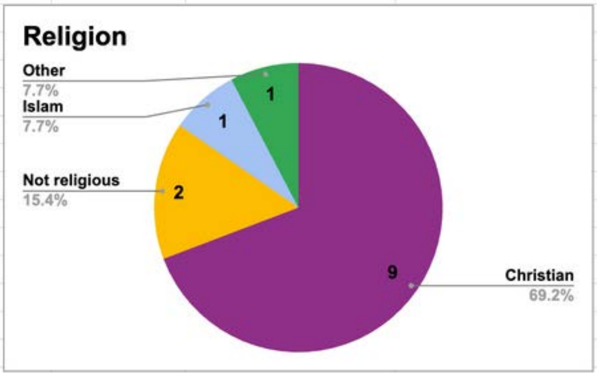
We recruited across different ethnicities with a focus on the inclusion of those from underserved communities.

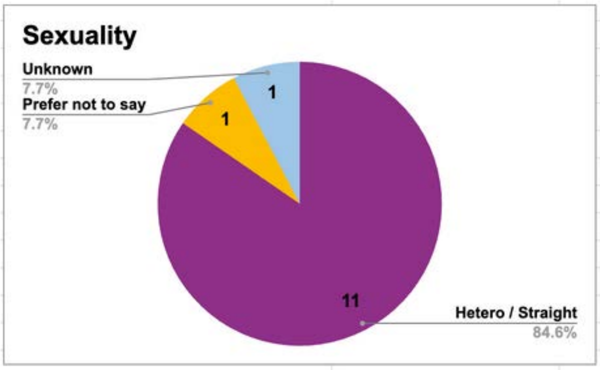


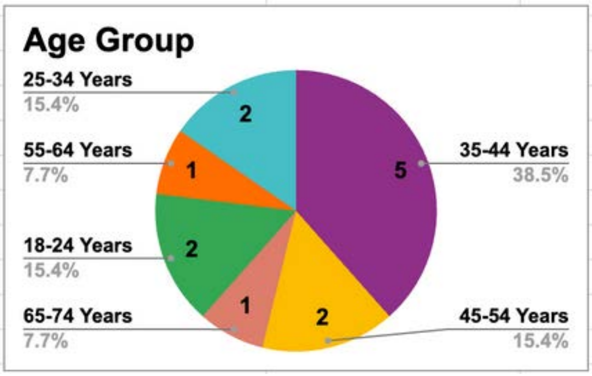






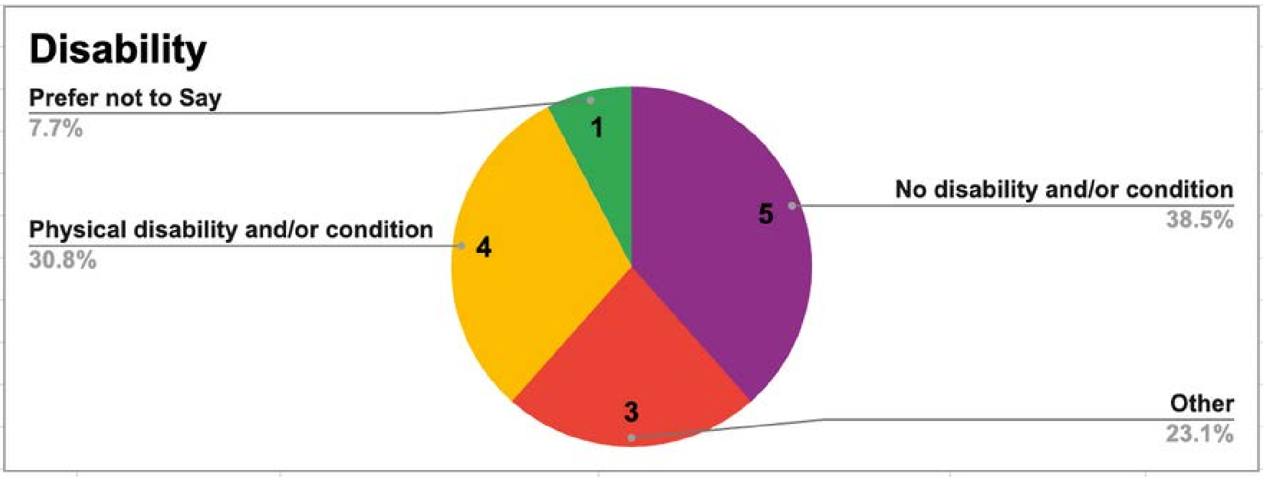


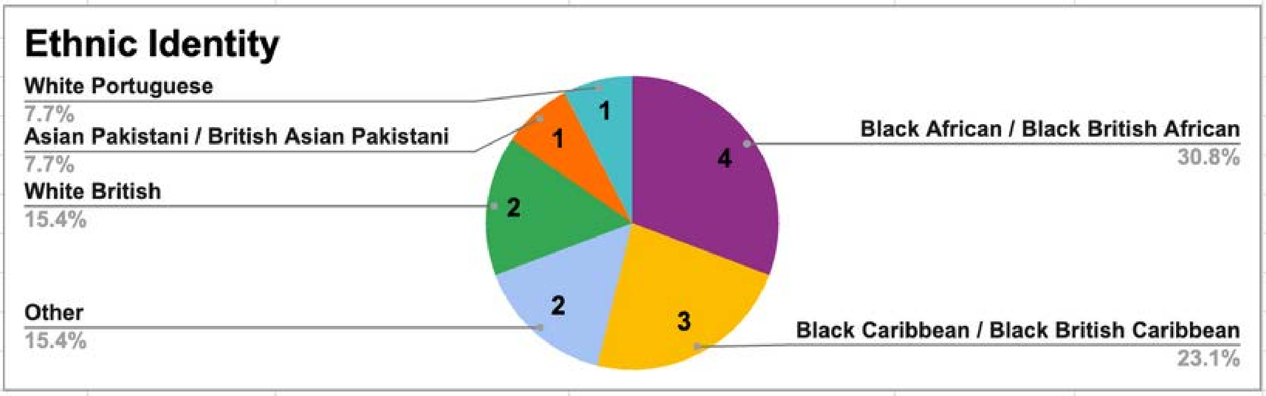




Interview Demographics

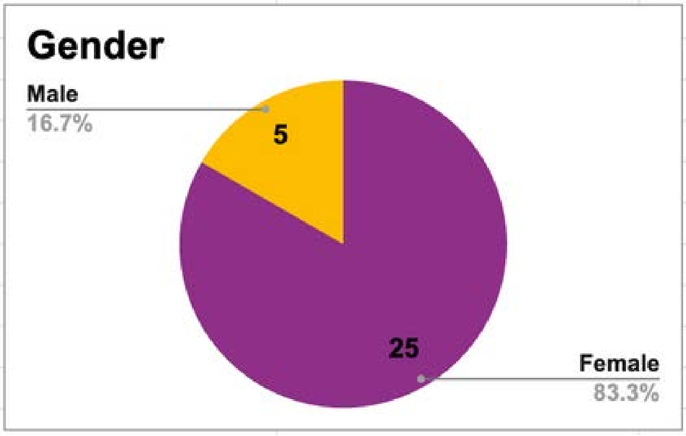
/continued

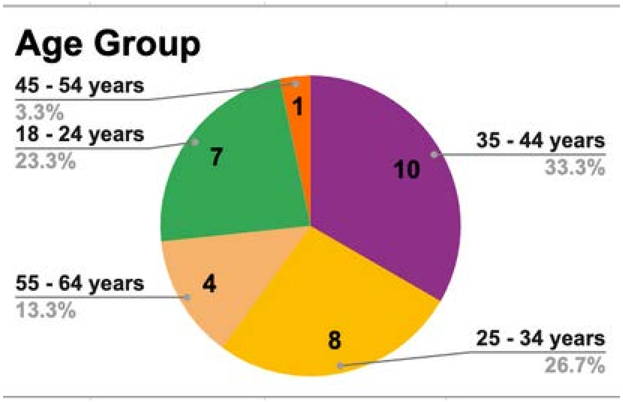


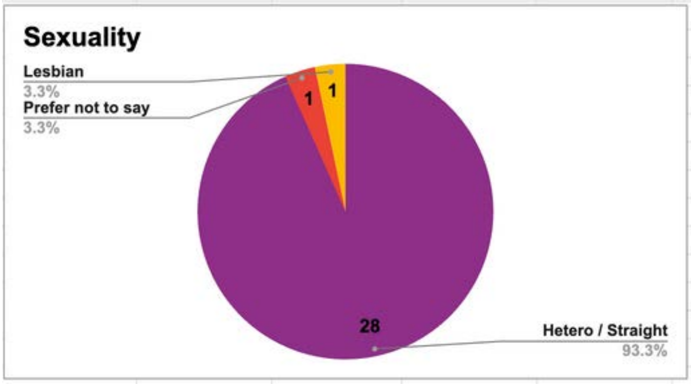


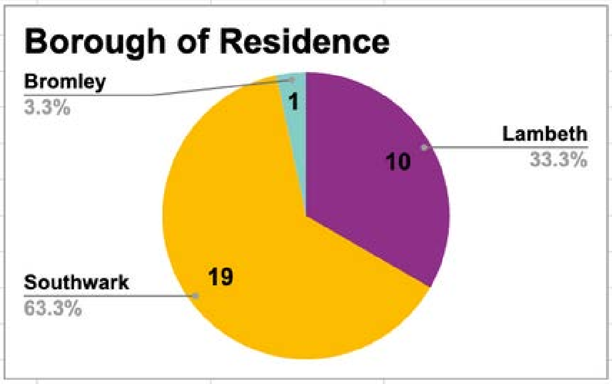
Survey Demographics
/continued

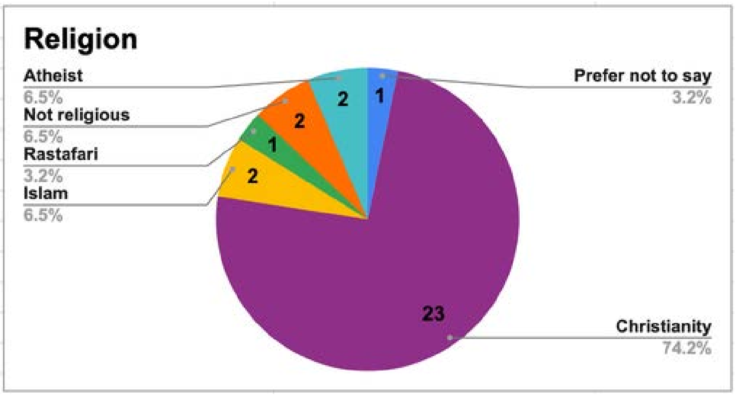
We recruited across different ethnicities with a focus on the inclusion of those from underserved communities.





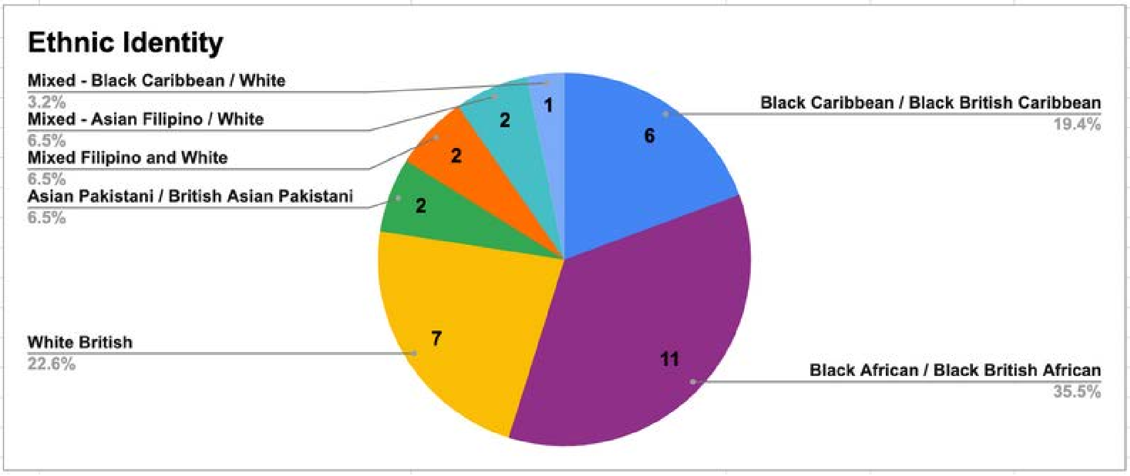


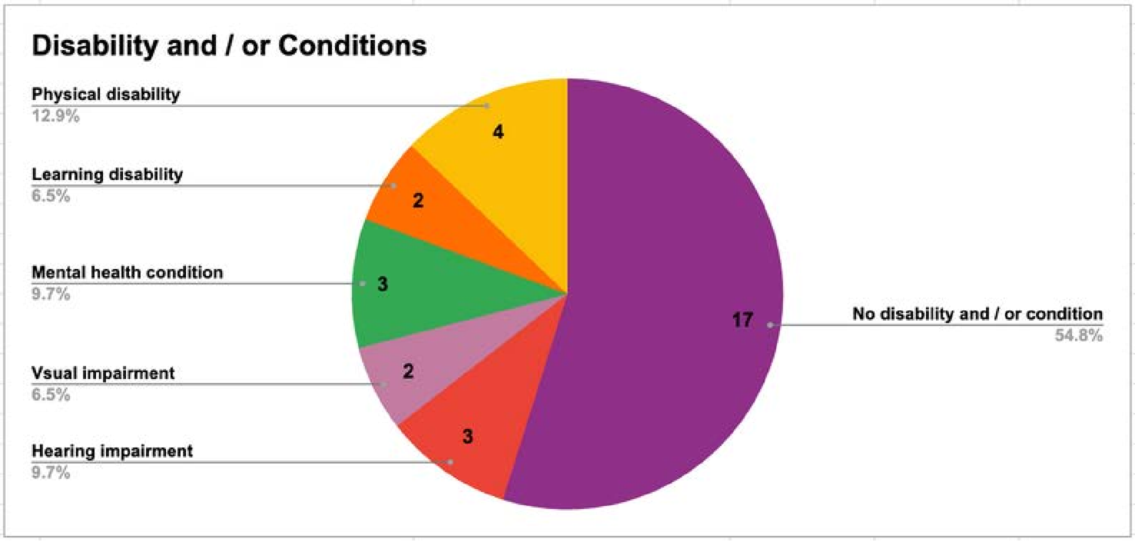




Survey Demographics

/continued


Ethnic Identity


Disability and / or Conditions

For More Information:

Email us: welcome@centric.org.uk

Visit us: www.centric.org.uk

Connect with us: www.linkedin.com/company/centric-community-research

Follow us: @centricmoments (FB, Instagram, TikTok, Twitter & YouTube)

Thank You For Your Attention!

This report was compiled by Centric on behalf of and in partnership with King's College Hospital Foundation Trust.