Under-served Communities Project

2023-2025

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WHAT IS AN UNDER-SERVED COMMUNITY?

"A GROUP THAT IS LESS WELL REPRESENTED IN RESEARCH THAN WOULD BE DESIRABLE FROM POPULATION PREVALENCE AND HEALTHCARE BURDEN"

NIHR | National Institute for Health and Care Research

www.nihr.ac.uk/about-us/our-key-priorities/under-served-communities.htm (1)

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Introduction

Welcome to Medway NHS Foundation Trust (MFT) and Medway Community Healthcare's (MCH) Research teams' report on a joint project undertaken during 2023-25 to understand and engage under-represented ethnicities.

Both MFT and MCH are funded by the Kent, Surrey and Sussex (KSS) Clinical Research Network (CRN) to support the delivery of the National Institute of Health and Care Research (NIHR) portfolio research studies.

In March 2023, the CRN KSS released a call for funding, inviting applications under their ***"Under-served Funding Programme."***

MFT and MCH Research teams decided to collaborate on a joint project due to having similar aspirations to work with the communities we both serve in the Medway and Swale area to engage them more in research.

This report details the related activities undertaken as part of the project, as well as the learnings taken by both organisations, recommendations for engagement and plans for continued Community working with the "Under-served Communities."

MFT and MCH Project Team

Left to right:

Julie Webster, Research Allied Health Professional (MCH)

Laura Adams, Patient and Public Engagement and Involvement (PPIE) Facilitator (MFT)

Chris Gedge, Head of Research (MCH)

Part 1

Background

In March 2023, CRN KSS released a funding call as part of their **"Under-served Communities"** programme to which MFT and MCH made a joint application.

Awards of up to £35,000 were available with the following eligibility criteria:

"Projects must:

1. *Be well-formed and ready to execute, ideally with commitment to collaboration/some evidence of existing relationship building, which may be between NHS Trusts as well as community or voluntary organisations.*

2. *Have a clear and well-considered project delivery plan and timeline.*

3. *Identify a distinct under-served community and provide evidence that the community is under-served in the context.*

Projects were also asked to consider the following:

-For which citizens will this funding enable better access to research?
-What types of impact could arise from your project and where?

An application was submitted and presented on 9th May 2023 to a panel made up of CRN Executive team members, Patient and Public Inclusion and Engagement (PPIE) Lead and CRN Research Champions (lay people).

Funding of £27,128 was confirmed in writing on 12th June 2023.

This funding was utilised to form the joint project team MCH (10 hours per week), and MFT (11 hours per week), as well as other non-pay costs including venue hire, hospitality costs, resources/material development and recognition payments.

Part 2

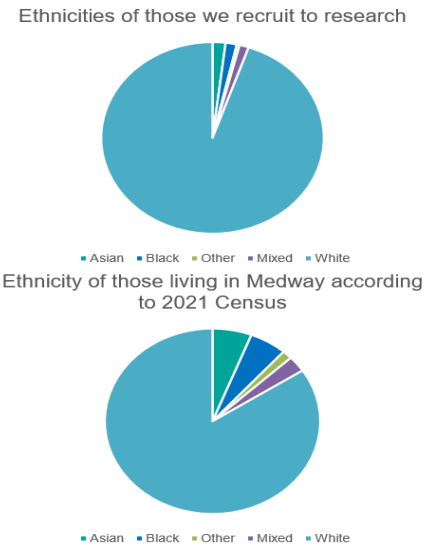
Our Activities…

Rationale for the identification of an under-served community

As part of developing the project, MFT looked at the ethnicity of their participants in research in the past 2 years (2022-23). Using the data platform, EDGE, they downloaded the ethnicity of all the recruits during this time. Those that were uploaded anonymously were excluded, as no data could be found.

Only **39%** of the participants had ethnicity data entered. Using the hospital systems, MFT completed some of the missing data; however, **15%** of the data was still missing. Using the available **85%** of the data, MFT then compared participants' ethnicity to the data from the **Census 2021**. The data showed MFT recruited **94.7%** participants of White ethnicity, which, compared to the census data for Medway, where **84.3%** of residents are White, showed an over recruitment from this community by **10.4%.**

In contrast, for the Asian population of Medway, MFT only recruited **1.9%** to their studies, whilst the Medway residents have a population of **5.9%,** a negative difference of **4%.** In those of Black ethnicity, MFT recruited **1.6%** of their participants with this ethnicity, and Medway residents make up **5.6%.** A negative difference of **4%.** Similar patterns were shown in the Other Ethnicity categories, including Arab, Roma and Gypsy or Irish Traveller, with a negative difference of **1%.** For those within the Mixed ethnicities, a negative difference of **1.4%** was shown between recruitment participants and the population of Medway.



MFT Research Participant Ethnicity Data 2022 and 2023.

It was clear from the data that MFT were not recruiting participants to research in a true representation of the demographic of Medway.

MCH were not collecting as detailed demographic data; however, they estimated that their research participants were also 95-98% of White ethnicity, which would indicate that they were not serving the other ethnic groups within Medway.

Data from the central NIHR Research champion survey (2) showed that **95%** of the Research Champions who completed the survey were of White ethnicity. Although only **22%** of all Research Champions completed the survey, and not all completed the ethnicity section; this still highlighted that the issue is widespread within the NIHR. Within MCH, there is one Research Champion who is of white ethnicity.

At the start of the project, it was unknown why there was such a large discrepancy in the recruitment of participants to research within these ethnicities. It was hypothesised that these people were not hearing about the research or that they had reasons for not taking part. The project aimed to help to understand the reasons and develop solutions together with the public.

There is a lot of evidence to show that there are ethnic disparities in healthcare. Data from **Ethnic disparities in the major causes of mortality and their risk factors – a rapid review (3)** shows that people from certain ethnic groups are at the highest risk of mortality due to specific conditions such as ischaemic heart disease, stroke, neonatal preterm birth and cirrhosis Hep C. The review also highlighted that people from some ethnic groups are more likely to live in areas of high deprivation, which is linked to poorer health outcomes.

If people from ethnicities at greater risk of the disease are not taking part in research, how do we know the research results will work for them?

The MFT maternity department had also started collecting data on the ethnicities of those who declined to take part in their studies. Triangulating all the data mentioned above, we decided to focus our project on Black African and Black Caribbean groups.

Top 5 ethnicities documented that declined

1	Black African
2	Pakistani
3	Any other Asian Background
4	Bangladeshi
5	Indian

MFT Maternity Department Research Participant Ethnicity Data April 2023 onwards.

Existing context: details of existing or developing collaborations and groundwork to date…

MFT had previously conducted an under-served project in lung disease research. This project highlighted ways of raising awareness around the research they do at the trust, which they could improve on. This work is ongoing and will hopefully improve awareness in other groups as well as people with lung disease. Processes used in the lung project were considered and utilised as part of this new project, as they worked well, including suitable communications, information, and running of focus groups.

During the lung disease research project, MFT improved their ties with MCH by looking at how they could work collaboratively on this area. Following on from this, both organisations decided that, as they served the same communities and there were additional benefits from collaborative working, they would work together on the project.

By working together, we aimed to avoid oversaturating these communities with too many people attempting to build relationships.
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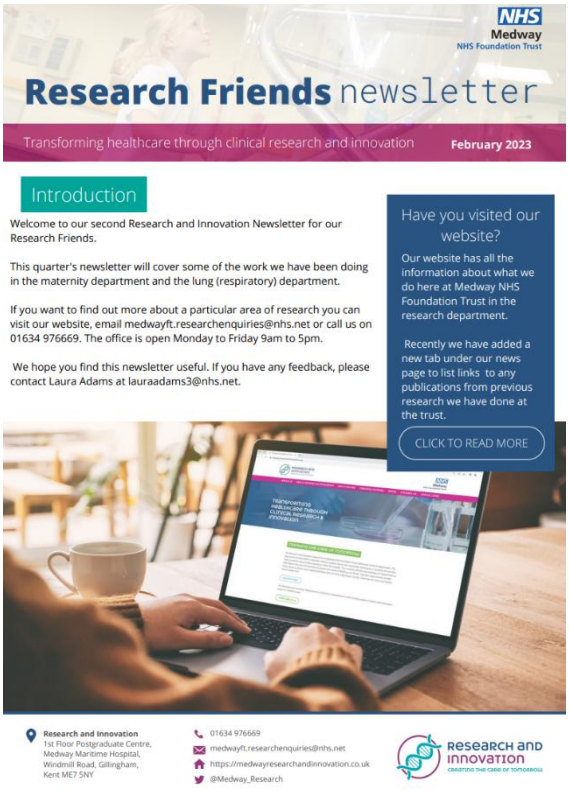
MFT have launched a “Research Friends” scheme where they invited members of the public to sign up to keep updated on what they do at the trust. At the start of the project, **28** people had signed up, but only one person stated they were from a non-white ethnicity. MFT hoped to improve this with the project, as they plan to work with their Research Friends when developing new research or planning the department strategy.



MCH have an established Research Champion who was a participant in the Diabetes WELLbeing (DWELL) study. He then went on to become a DWELL Ambassador and work with MCH as a volunteer promoting research at various events and open days, as well as working within the Clinical Commissioning Group (CCG) and CRN on various advisory panels. MCH hope to increase their Research Champions, including within under-served groups. There will then be a truer reflection of the community they serve.

CRN KSS ran a project last financial year called “Research Ready Communities”(RRC). The CRN PPIE lead, Maddy Bell, ran the project within Medway, and we discussed with Maddy about working alongside these groups, as they may be able to share our findings and contribute to feedback, as well as take learnings from previous projects into this one.

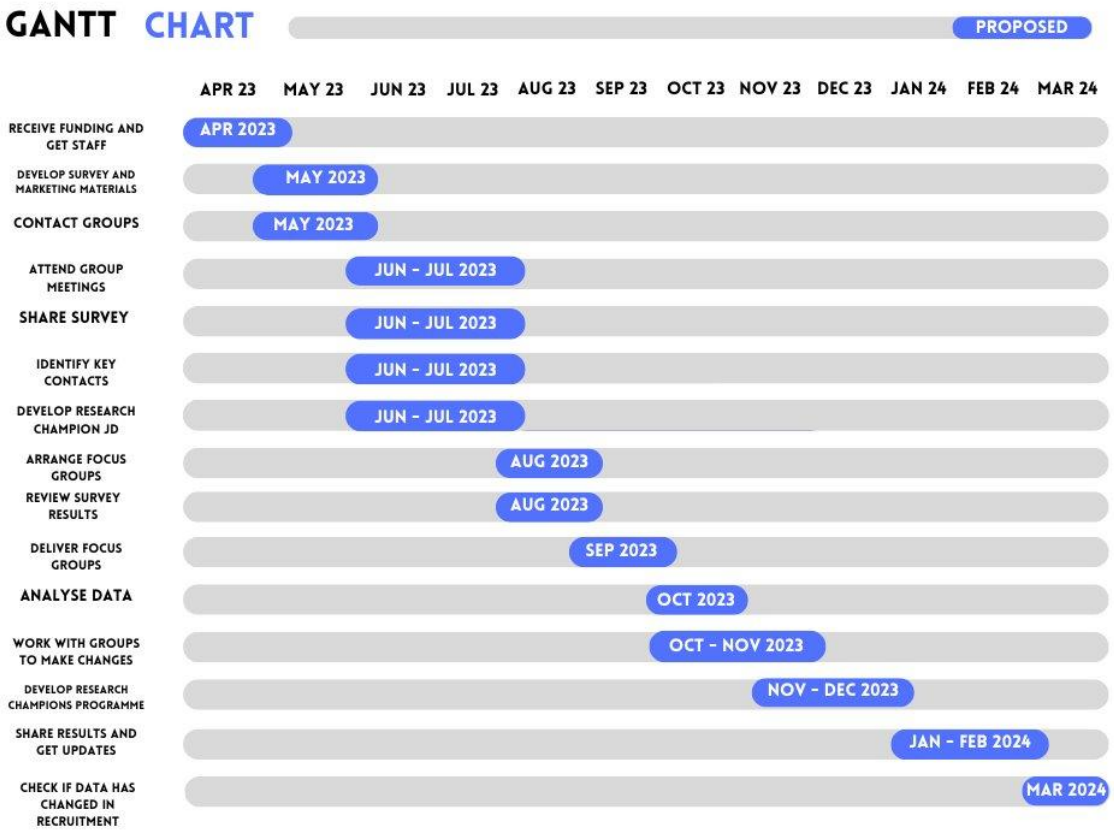
These groups will have already raised awareness of research, and this will result in valuable feedback on how we can make improvements. We made plans to link in with the project to work collaboratively. We also planned to link in with the central facilitator of the RRC project for advice and guidance on reaching out to these community groups, as they have vast experience in this area.

There is also a toolkit from the Applied Research Collaboration (ARC) East Midlands (4) on how to increase participation in research of Black, Asian, and Minority Ethnic Groups, which we planned to use as guidance for any engagement work we conducted.

Proposed activities and timeline…

The following Gantt chart and table detail the proposed activities and the initial timeline developed at the application stage of the project.

This formed the basis of the project plan and was monitored throughout the life of the project. There was some shift in the timeline due to various factors, including funding not being confirmed until June, a Pre-Election period and school holidays, but also due to some of the challenges involved with engaging various communities, which in itself was a reflection taken from the project.



Month	Proposed Activities
April 2023	• Review data to identify appropriate communities. • Meet with Healthwatch to discuss plan of action. • Develop a joint project Charter
May 2023	• Develop the survey, both paper and online. • Develop a flyer to hand out with a link to the online survey and advertise the project. • Develop a joint video with MCH and MFT staff to promote the project • Speak with trust/organisations' Diversity networks and attend their monthly meeting. • Organise with the MFT Community Engagement Officer opportunities to visit groups MFT already have contacts with. • Link in with Healthwatch Medway and make arrangements to attend their contact groups. • MCH to recruit into a post for the Under-served programme. • Identify suitable groups from different ethnic groups to begin work with. • Review recommendations from the RRC programme for the last financial year. • Link in with Medway Voluntary Action and RRC lead around planned events and attendance.
June 2023	• Attend group meetings to introduce research and the team. • Share the survey to obtain some initial feedback to formulate themes on areas of improvement. • Identify individuals who are keen to be contacts for their groups about research- Plan with these individuals their future attendance and discussions. Identify any areas of improvement needed in any materials being shared, i.e. any language barriers that will need to be overcome, such as a survey in an alternate language. • Share with groups for feedback or discuss at group meetings to meet their needs, as well as the trusts and CRN.

Month	Proposed Activities
July 2023	• Continue with June work and start to look at feedback from meetings and surveys. • Discuss with the groups' individuals about planning focus groups. Ideally, plan to have focus groups at their chosen location to increase attendance and comfort. • Discuss with groups' identified individuals about Research Champion roles and start the process of raising interest in the role.
August 2023	• Advertise focus groups and plan structure and content for focus groups-Ensure each focus group is specific for each ethnicity to ensure discussion and themes are consistent with the groups' individual requirements. • Continue to circulate the survey for more feedback for any follow-up focus groups.
September 2023	• Deliver focus groups. Ensure all up-to-date feedback is reviewed and discussed in focus groups. Return to the discussion around Research Champions (ongoing since the first introduction) and discuss applying for a role for each group. • Attend events with RRCs to gather feedback on highlighted issues.
October 2023	• Begin analysis of focus group discussions and plan improvements based on each group's feedback. • Return to group meetings with results of focus groups to work with the community to implement required changes.
November 2023	• If required, ensure any planned changes are shared with groups for final feedback before implementation. • Consider 6 monthly newsletter for MCH and MFT research to share with any Research Champions and the wider groups-Ensure newsletter is accessible for all. Work with identified individuals before circulating the newsletter to ensure relevant and appropriate. • Attend events with RRCs to gather feedback on highlighted issues.
December 2023	• Begin writing up the project and implement any changes. • Share work with the wider community and begin to attend other groups to share the work more widely. Involve any Research Champions in this work and, if they are happy to, ask them to share their journeys with the groups.

Month	Proposed Activities
January 2024	• Continue to attend wider groups to share outcomes and stories. • Attend Diversity Forum meeting at MFT to provide feedback on results. Ensure MFT and MCH share the project with their communities. • Share survey to gain updated feedback from groups and wider community- expecting minimal improvements as changes would be early on. Share the first newsletter.
February 2024	• Review ethnicity data of those recruited in past 12 months to research to see if any improvements have happened. Include any data findings in write up of the project, including any survey results. • Look at applying for the publication of the project and sharing it with the wider audience.
March 2024	• Discuss with Research Champions/Interested individuals about plans. • Arrange regular attendance at group meetings to keep informed and continue work on improvements as things change. • Attend the RRC event to share work.

Project deliverables and achievements…

Review of Research Ready Communities work- April 2023

During 2021-22, the NIHR piloted a community engagement model in 3 local areas across England. The pilot evaluation is available here:
Research Ready Communities Pilot evaluation 2021/22 | NIHR. (5)

This was reviewed as part of developing the idea for this project, as well as reviewing the training provided by Kadij Badri, Community Engagement Manager, NIHR, on “Community Ready Researcher”, delivered via the NIHR PPIE Community Forum. Below is an example of a tool for collecting community views that was considered:

Tools for collecting community views_v0.

Review of Maternity data- April 2023

As part of the project inception, MFT reviewed the research data from their Maternity Department, as it was the biggest recruiting department with over 4000 research participants per year. This helped in determining which communities may be appropriate to be approached.

The team had been documenting the ethnicity of those who declined since April 2023. The top 5 ethnicities that declined were as follows:

Top 5 ethnicities documented that declined

1	Black African
2	Pakistani
3	Any other Asian Background
4	Bangladeshi
5	Indian

Based on the census data and maternity decline data, as well as other research data within both organisations, the decision was made to focus the project on Black African and Black Caribbean groups.

Application Submission and Panel Meeting Charter- June 2023

Applications closed on 27th April 2023, and leads from MFT and MCH presented their project proposal to a panel consisting of Clinical Research Network Executives, Patient and Public Involvement Engagement Lead and a CRN Research Champion on **9th May 2023**.

The outcome of a successful application for funding for the project was confirmed on 12th June 2023.

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Project Charter- June 2023

A joint project charter was developed between MFT and MCH, giving more details on the project aims, objectives and scope. Senior buy-in and support was achieved from both organisations from the Heads of Research.

Project_charter_template- Underserved Cor

Literature Review- July 2023

MFT's Knowledge and Library services supported the completion of a literature search to give some baseline for reasons why people do not take part in research.

Databases searched: ***Medline, Emcare, HMIC, and NIHR.***
Terms used: ***research, participation, engagement, barriers, BME, BAME, minority ethnic, racial minorities, African, Asian, and under-served.***

The search returned the following results:

Barriers to participation in clinica

A short write-up of the article review can be found here:

write up of reading.docx

Initial Networking- Medway Diversity Forum July 2023

Julie Webster made initial contact with established links in a wide range of organisations, including the third sector, community groups and key individuals in Medway. These included Gillingham Street Angels, A Better Medway Champions Network, Pasta Rasta Restaurant, the Nigerian Association, Medway Afro Caribbean Association (MACA) and Medway Diversity Forum.

Whilst all people spoken to could see the benefits of the project, there was a feeling of saturation and fatigue expressed due to the number of times certain communities are approached to complete surveys and give up their time to answer questions. Comments made included ***"other people have already asked us questions***", ***"nothing ever changes"*** and ***"we never hear the results".*** Despite these feelings, people agreed to help and to promote through their networks.

Networking- Healthwatch Medway August 2023

Introduction to project.docx

Introduction to project.pptx

Conversations were held with colleagues from Healthwatch who agreed to share our survey and also signposted us to other organisations, including Medway Voluntary Action and the groups already mentioned above, who we were already talking about.

Networking- Medway Health Determinants Research Collaboration and Public Advisory Group- July-August 2023

As part of Chris Gedge's involvement in the development of Medway Council's Health Determinants Research Collaboration (HDRC), an opportunity was presented to have discussions about this project.

It was identified that Medway Council had already undertaken some community engagement work. (as part of the HDRC programme), and this involved work around the Joint Health and Wellbeing strategy. Medway Voluntary Action was supporting a Community Health Catalyst programme with Under-served Communities, and also a Time Credits scheme.

Researchers from the University of Kent and Medway Council had also undertaken some social network analysis. They engaged the voluntary sector and the general public to get views on engaging in the HDRC, and views on health inequalities and health priorities for communities.

Conversations with the Public Advisory Group Lay members also identified that several community and faith leaders had been approached about engagement in research and health programmes.

It was important for us to understand who had been engaged already, so as not to overburden them with our requests for them to be involved, but also if any lessons had already been identified from their engagements.

Survey Development - August 2023 onwards

A survey was developed using the COM-B methodology (02.09.19_COM-B_and_changing_behaviour_.pdf (social-change.co.uk) (6) as part of the project and formed the basis of gathering initial information to enable improved understanding around engaging under-represented ethnicities in research.

During September, the survey was piloted and consulted on with some of the individuals contacted during the initial engagements. These were members of the public and included an elderly Afro-Caribbean gentleman with English as his second language, and limited awareness of research. Some members of the research teams also tested the survey and gave feedback.

As a result of this feedback, the survey was amended and scheduled to be launched as part of a social media campaign beginning in October 2023. Paper versions of the survey were also made available. The survey remained open throughout the life of the project and was monitored for updated responses regularly.

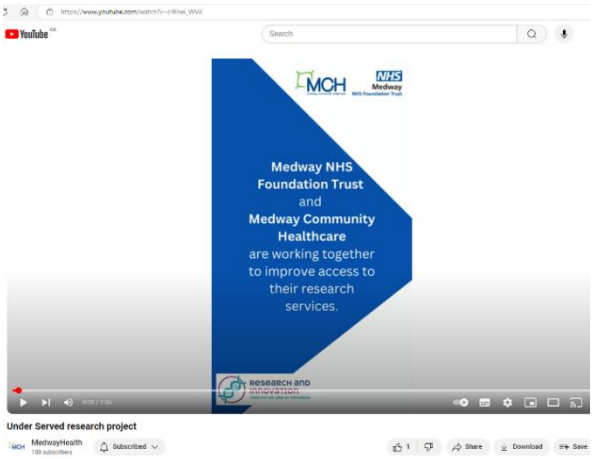
Survey Final.docx

`Video and Social Media Campaign- September 2023 onwards

To support the rollout of the survey, a planned social media campaign was developed with support by the Communications teams within both MFT and MCH.

This included the development of a poster with a QR code, but also a video highlighting the importance of the project and getting people's views. The video contained words from staff members from both organisations and was published on YouTube and can be found below:

YouTube link: Under Served research project (youtube.com)



Social media posts were developed and scheduled to run from October to December to enable time for data to be collected.

This included a mixture of Facebook, X (formerly Twitter) and LinkedIn.

Details can be found here:

Social Media posts.docx

Survey Results…. December 2023

The survey had a total of 41 responses from 21st September to 1st August 2024. Not all responses had a full data set, as some individuals chose not to answer some of the questions. We deliberately decided to make some of the questions “non-mandatory” to be more inclusive and not put additional pressure on respondents.

An initial review of the data was undertaken at the end of December 2023, and it was this initial data that was then utilised as part of the focus group development.

The full SurveyMonkey results set can be found here:

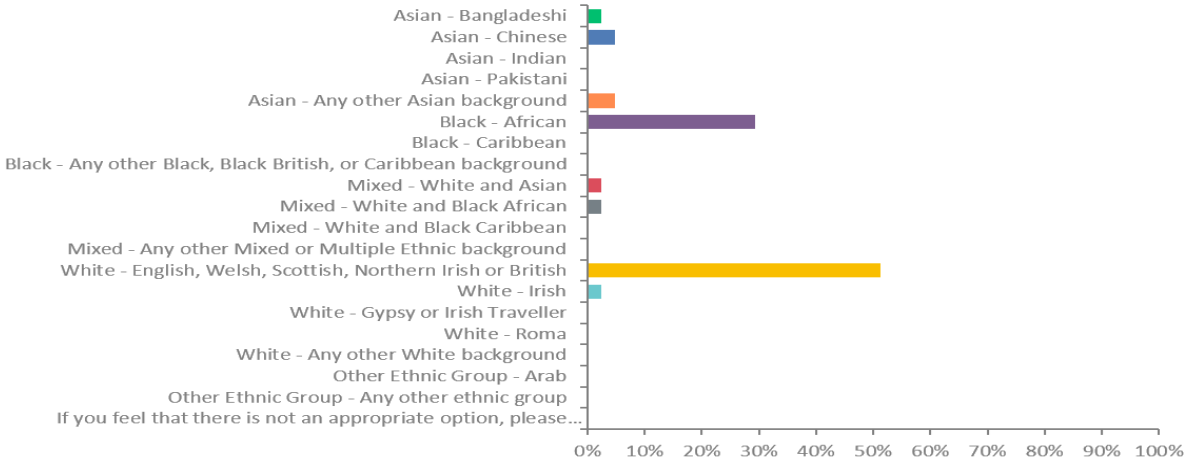
Full Dataset -.pptx

Key findings:

Several questions were asked as part of the survey, but some of the key findings are highlighted below.

Question: What would you class as your ethnicity?

Answered: 41 Skipped: 0



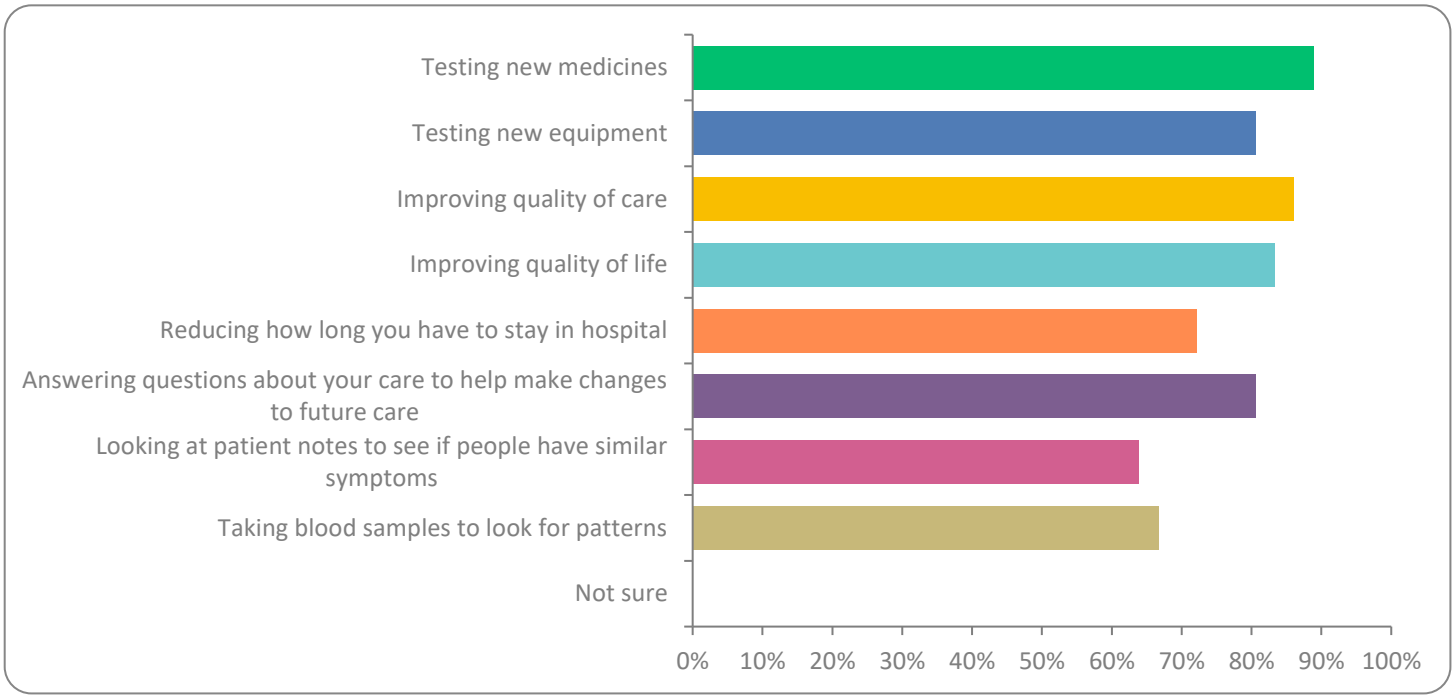
Powered by SurveyMonkey

Of those that responded, **51.22%** considered themselves to be White-English, Welsh, Scottish, Northern Irish or British. **29.7%** Black African; **4.88%** Asian- any other Asian background; **4.88%** Asian-Chinese; Asian- Bangladeshi, and Mixed- White and Asian, Mixed- White and Black African, and White-Irish were all **2.44%.**

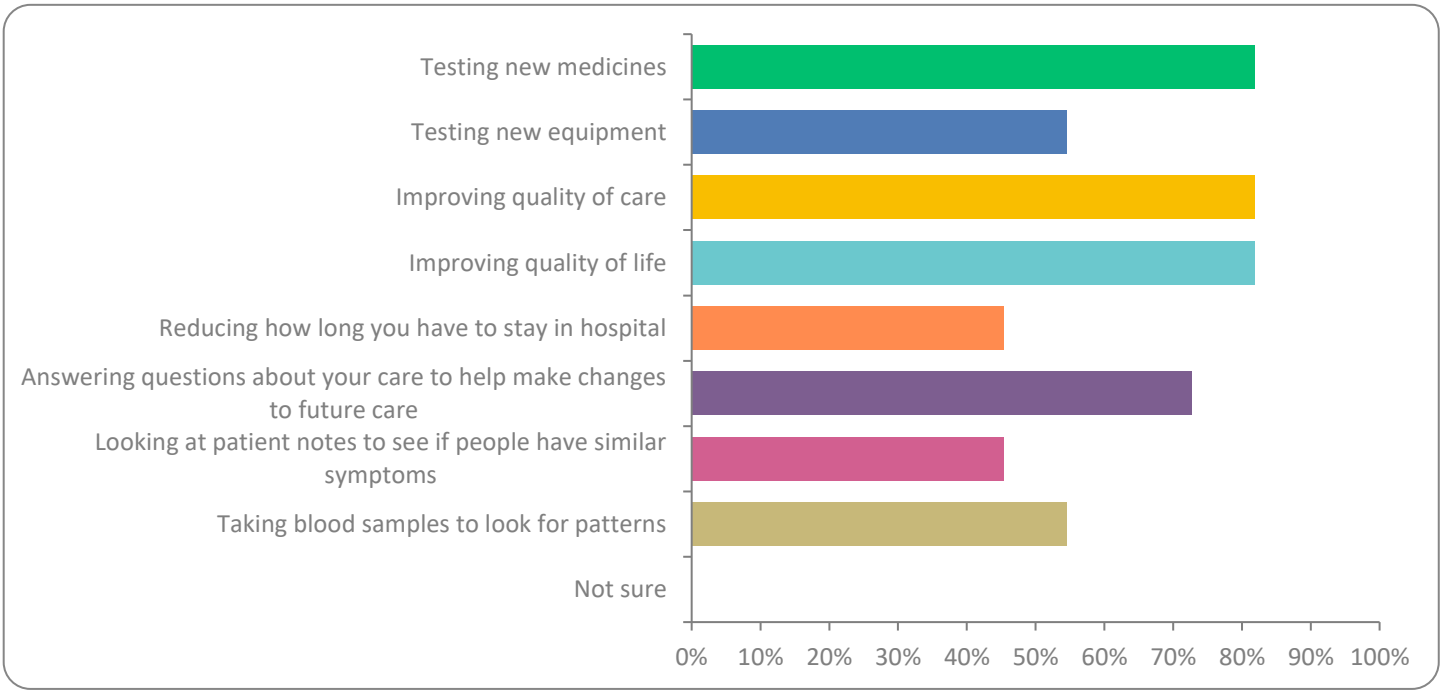
Interestingly, none of the respondents were of Black-Caribbean ethnicity, which was one of the ethnicities we had identified early on in the project as wanting to work with. We did filter some of the questions to review the responses of those people who stated Black African and Mixed White or Black African as their ethnicity to better understand their perspectives.

Question: What do you think is involved in research in the NHS?

Full data set:



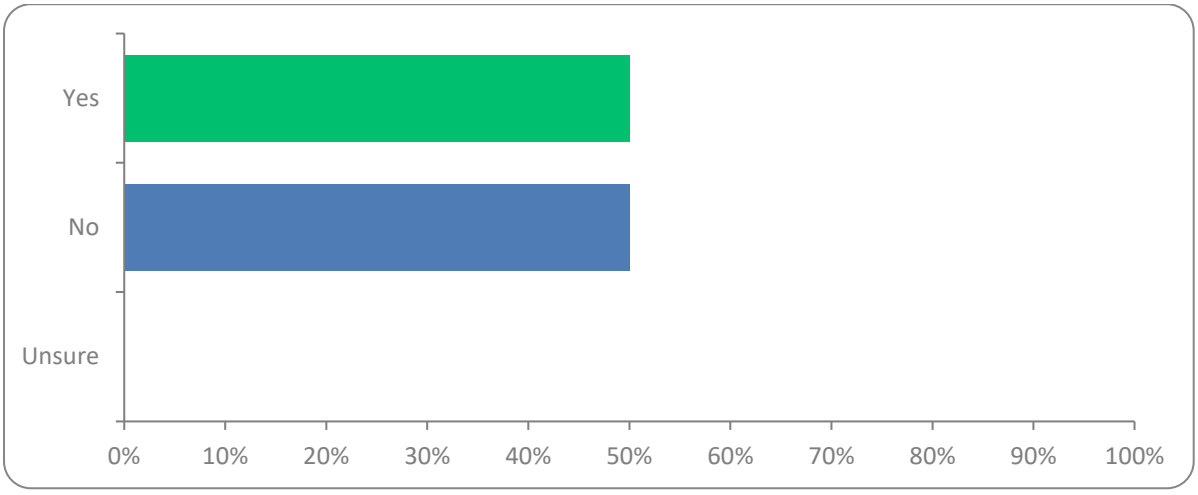
Filtered data set for Black African and Mixed White and Black African Ethnicities:



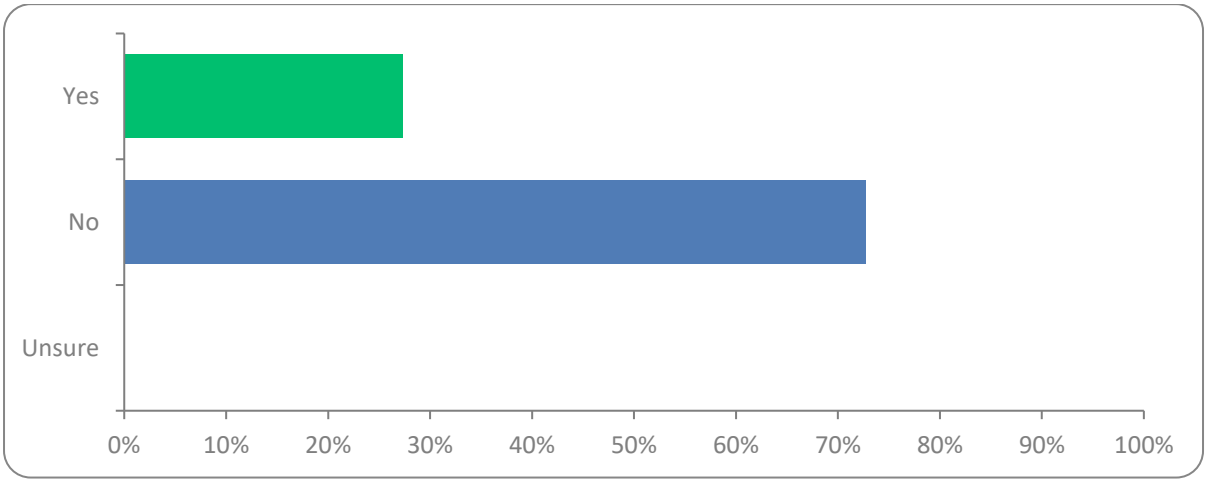
With both data sets, the majority of responses highlighted **"testing new medicines", "improving quality of care"** and **"improving quality of life"** as the main reasons for what people think is involved in research. **"Reducing how long you have to stay in hospital**" and **"looking at patient notes to see people have similar symptoms"** were less recognised by the African groups.

Question: Has anyone ever invited you to be part of a research study?

Full Data Set:



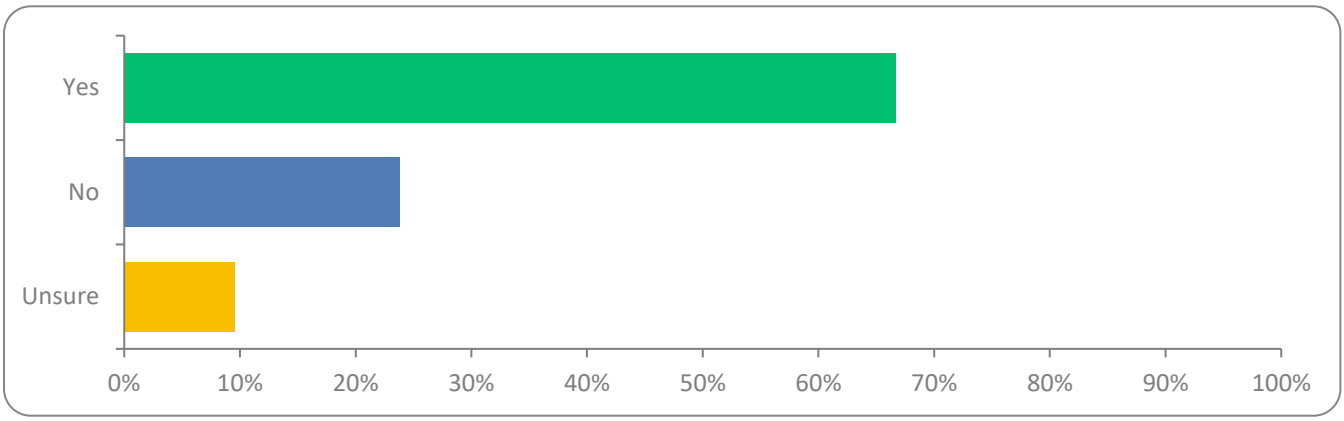
Filtered data set for Black African and Mixed White and Black African Ethnicities:



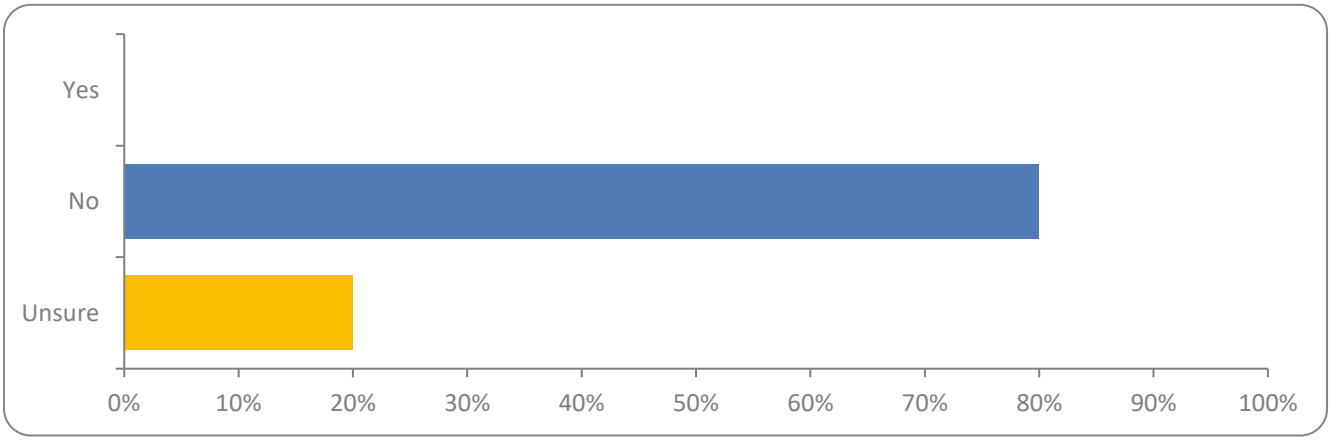
Surprisingly, over **50%** of respondents had never been invited to take part in a research study. This increased to **70%** when the data was filtered for the African ethnicities, further highlighting a concern around different ethnic groups being offered appropriate opportunities to get involved in research.

Question: If you answered yes, did you take part?

Full Data Set:



Filtered data set for Black African and Mixed White and Black African Ethnicities:

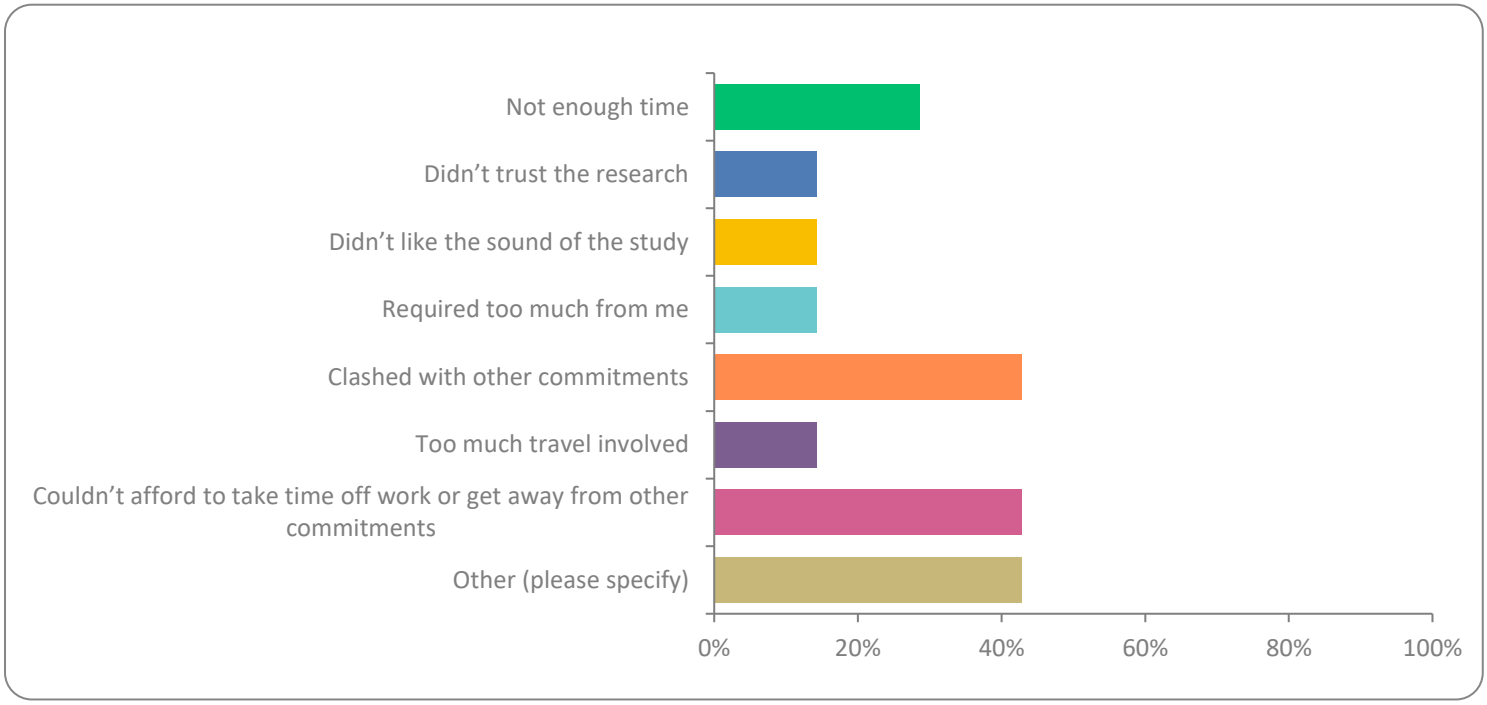


Over **67%** of the respondents chose to participate; however, when filtering the data, **80%** of the survey participants chose not to participate. No one from this group that responded chose to take part.

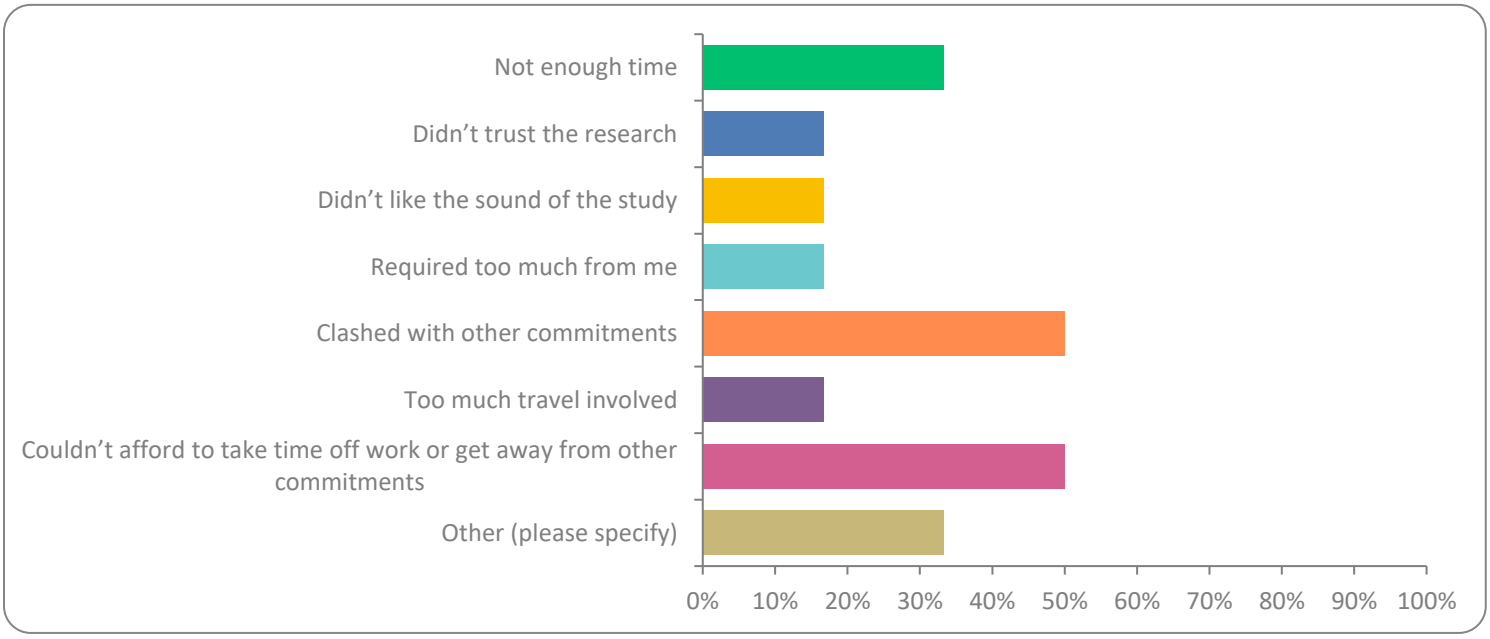
This again raised questions as to the reasons why people of African ethnicity did not participate.

Question: If you answered no, why did you not take part?

Full Data Set:



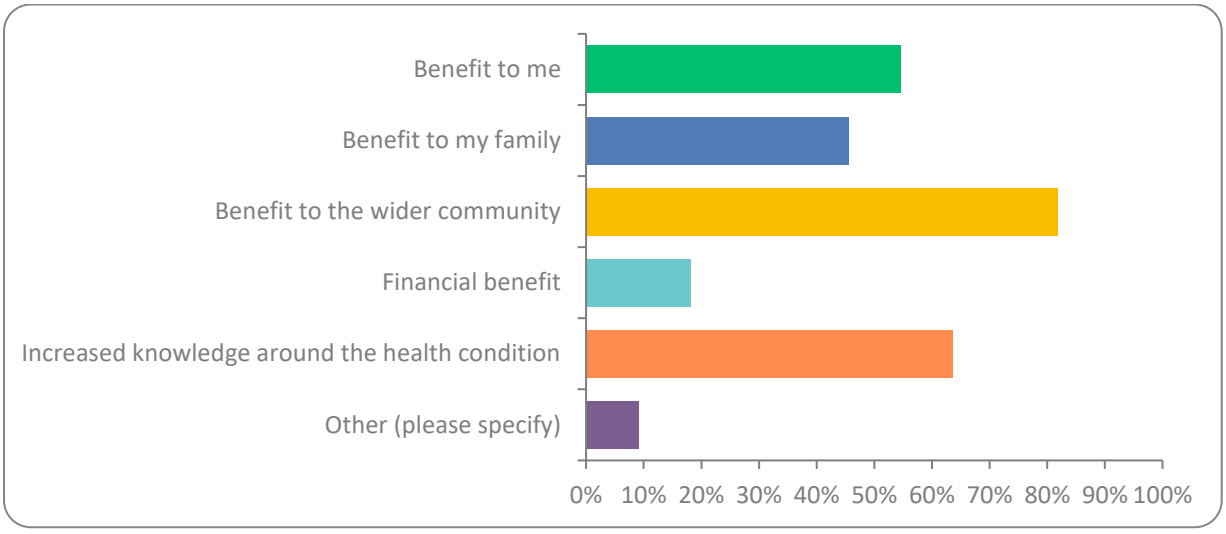
Filtered data set for Black African and Mixed White and Black African Ethnicities:



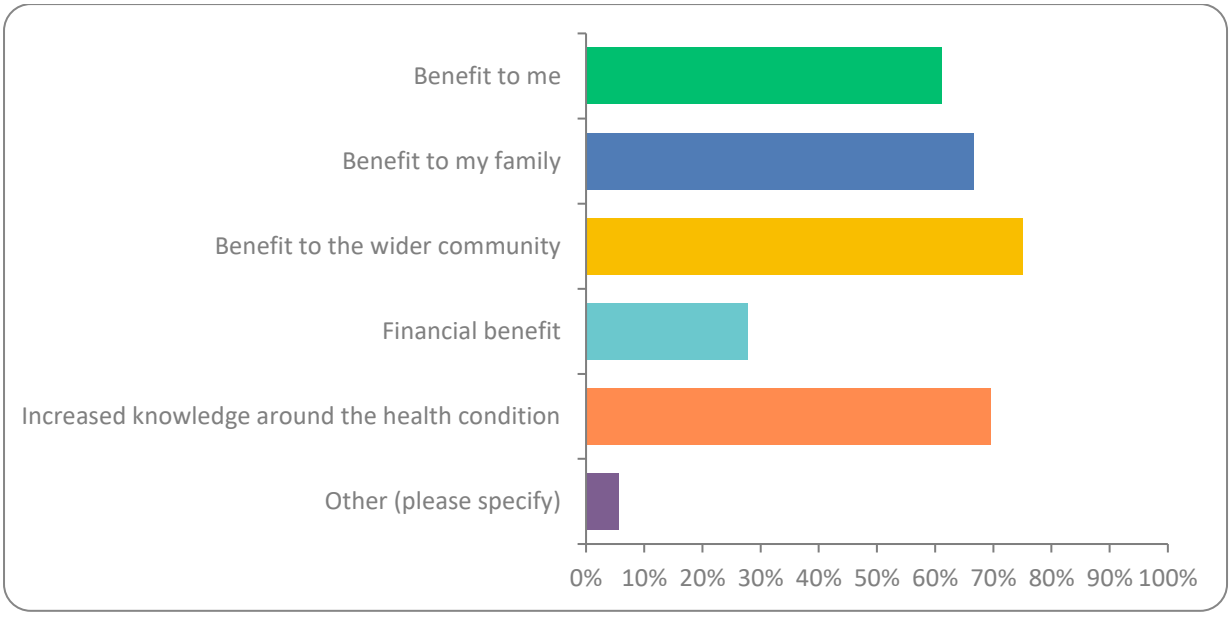
The responses that had the highest response rate were all associated with a perception of time. This included a feeling of not enough time, or that it clashed with other commitments, or that people could not take time from work to participate.

Question: What would make you more likely to take part in research?

Full Data Set:



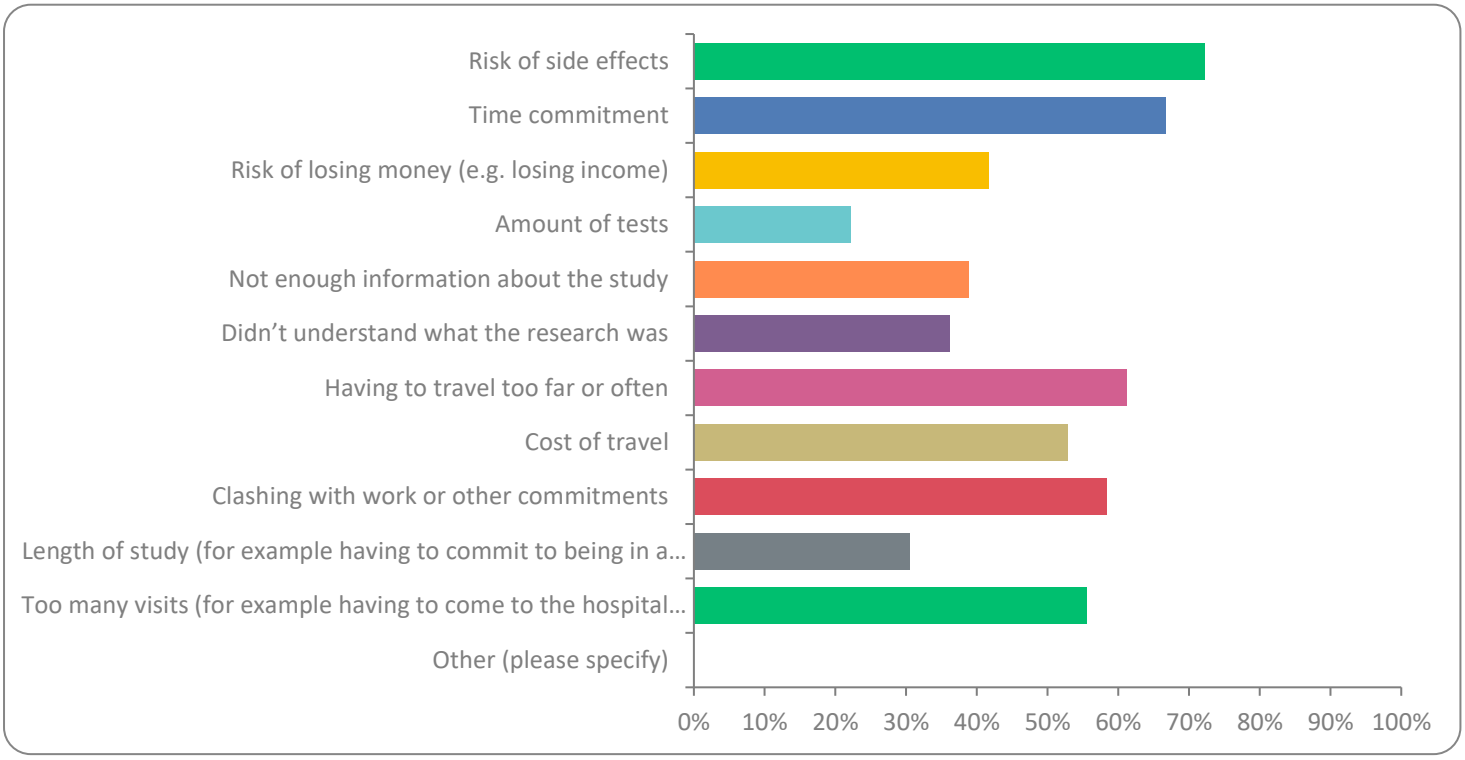
Filtered data set for Black African and Mixed White and Black African Ethnicities:



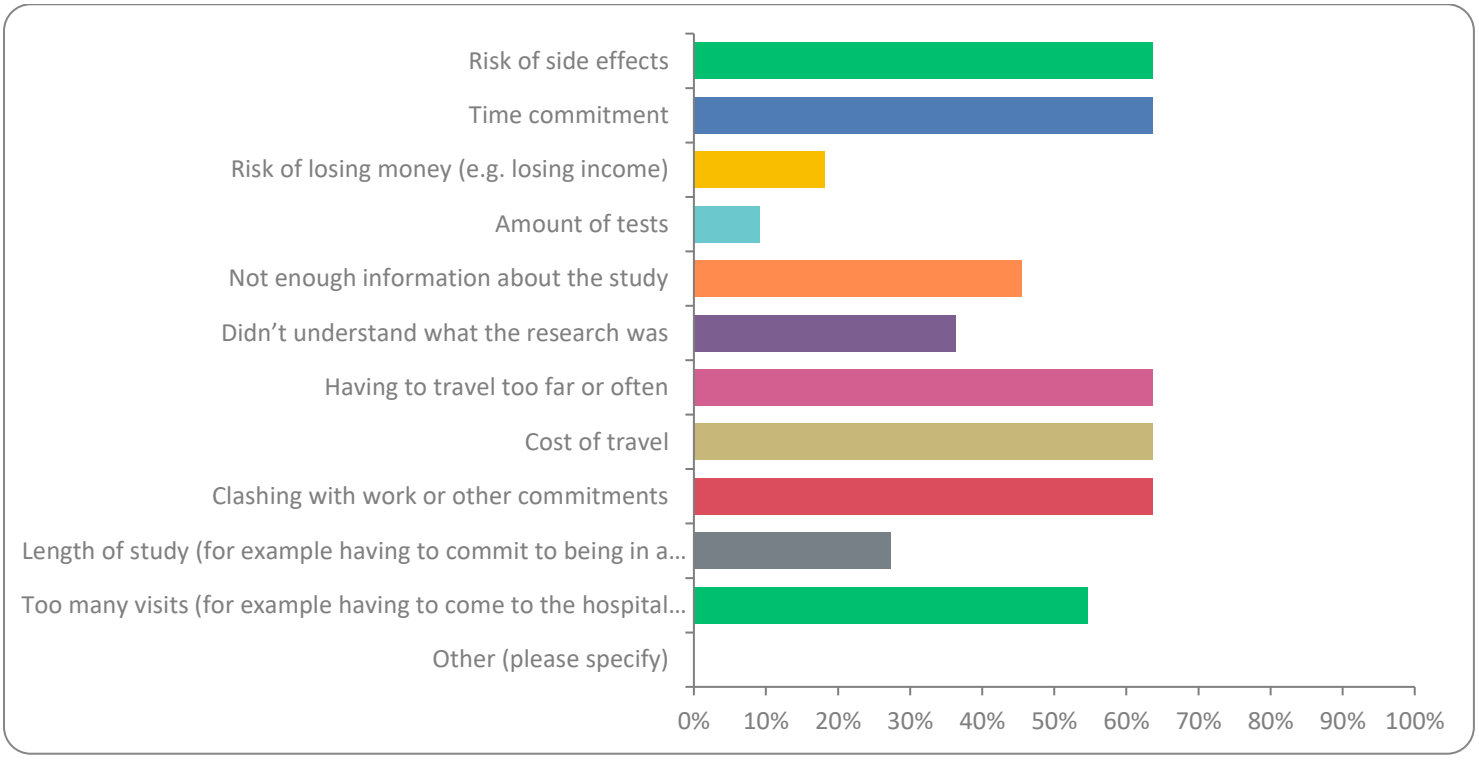
As anticipated, the main reasons that people get involved in research are for altruistic reasons, of it benefiting other people, whether that be their families or the wider community. Research for financial benefit was selected, however low percentages compared to the other reasons.

Question: What would discourage you from taking part in research?

Full Data Set:



Filtered data set for Black African and Mixed White and Black African Ethnicities:



Both data sets highlighted a range of reasons that would discourage people from taking part, including concerns about risks of side effects and factors associated with time being the highest reason.

Survey Summary

The purpose of the survey was to give some current perspectives on research amongst some of the local Medway population. Whilst the number of returns was limited to 40, it did give some good insights and correlated well with some of the previous national surveys undertaken in this area.

Our local survey highlighted some key elements that people of African ethnicity do not appear to be offered the same opportunities to get involved in research, and those who do have limitations in engaging due to time factors.

Despite people saying that they would be more likely to get involved if the research benefited their families or community, there were concerns raised about the risk of side effects or the time and cost commitment to getting involved.

This information was extremely useful as it then formed the basis of the focus groups, where we then wanted to “check in” with our communities to see if this information resonated and was a true perception of research.

Focus Groups- November 2023 -March 2024

Whilst the survey continued to run, a plan was made to host some focus groups in January/February 2024. The focus groups aimed to take the information obtained from the surveys and sense check this with some of the identified communities to see if it was representative, but also, more importantly, gain a wider, greater understanding of their perspectives regarding engagement in research.

Through our links established earlier with Healthwatch Medway, Medway Diversity Forum, Medway African Caribbean Association, the Nigerian Association and the latter emergence of the Community Research Engagement network, 3 focus groups were set up.

A social media campaign was again launched, advertising the desire to have a focus group as highlighted below, and one of the contacts we had from an Afro-Caribbean community created his own poster to share in his community:

Focus Group Challenges

Due to feedback obtained throughout the engagements, we were keen to reach out to newer groups as there was a lot of reported frustration around "***survey fatigue***" and that ***"the NHS"*** had ***"already spoken to us about this"*** (quote from a community leader about engagement in research). We didn't want to duplicate previous work.

We therefore approached several smaller local sports teams across Gillingham and Chatham, as well as speaking to leaders from some local running groups.

A fourth focus group was being scheduled with a local football club that had several players from a South American background. We had planned to hold the focus group at their ground after an evening training session. However, this was unable to be facilitated due to conflicting schedules and logistical challenges with getting the players to the venue earlier than usual.

Three focus groups were held. They took longer than planned to organise due to our lack of understanding that the contacts were doing the work in their own time. Finding a mutually acceptable venue, time and making catering arrangements also added to the timeline. This was reflective of the previously gained intelligence from the surveys that time commitments were a potential barrier.

We worked with the contacts from the Afro-Caribbean, African and Nigerian Communities to agree on a venue. 2 were hosted in the evening at Ourzone (formerly Balfour Centre) in Rochester. Food was provided, and the groups were held after normal "working hours"- this came as a suggestion from the group leaders. 1 group was hosted at De Honorables restaurant, which was well known to the Nigerian Community.

Sadly, with the first group, only 2 people turned up, and one had to leave due to an emergency, so the group was cancelled. However, conversations were followed up with the participants at a later date.

Due to the above challenges, the focus groups happened in March 2024.

Focus Group Format

The focus groups followed the format of an informal presentation highlighting the aims of the project and also sharing the initial results of the surveys. Participants in the group were then asked 3 key questions in an open conversation format.

The questions were as follows:

1. **In what ways have you used healthcare services?**
2. **If there were a research study in your healthcare area, what would encourage you to take part?**
3. **If there were a research study in your healthcare area, why might you be less keen to take part?**

Focus group presentation:

Focus Group Presentation.pptx

Focus group themes:

The focus groups with the African and Nigerian communities were well attended and fun to facilitate. At least 2 members of the project team were in attendance, and this was required to help facilitate the conversations and keep the participants focused, as at times, conversations went off topic. However, this was useful, as it not only enabled the facilitators to build rapport with the groups, but also to gain a wider understanding of their experiences of healthcare and research.

Focus group write-up:

Focus Group Write Up.docx

The information obtained from the focus groups was collated, and feedback was themed into 4 main areas:

- Knowledge (both communities and ours)
- Safety
- Trust
- Inclusivity

Knowledge insights…

Feedback highlighted that the participants were keen to engage with research as a means to improve their understanding of their conditions, but that the information needs to be presented in a way that is understandable, with no jargon and gives the “full picture” of what is involved and includes the risks.

One group discussed that there was a real lack of understanding about what research actually is and recommended that more work be done with communities to build this knowledge. They also suggested developing a greater understanding of the communities themselves and what topics are important to them.

Recommended actions/learnings:

- Develop a rapport first with communities by spending time with them with no research agenda.
- Build knowledge of research through offering training and "drip feeding" of information to the communities.
- Develop an understanding of what health issues impact specific communities and recognise that they have differing healthcare needs- they would then be more likely to get involved in specific studies.
- Provide appropriate jargon-free information about research studies to communities and be transparent about what is involved, including side effects and any risks or safety concerns.

Safety Insights…

Safety in research was a strong theme that came through in the groups. Participants talked about a perception of being seen as "guinea pigs for science" and that they would be "tested on". There was also a mention of an associated fear of hospitals and that hospitals were for "sick people". They also talked about not wanting to go to hospitals in case they brought something back to their communities. There were still some concerns as a result of the COVID-19 pandemic. Other concerns were raised around the stigmatisation of certain disease groups, and not getting involved in research for that reason.

Recommended actions/learnings:

- Where possible, try to arrange for research studies to happen more locally in the community settings rather than the acute hospital setting.
- Ensure that particular attention is paid to talking about the risks and benefits of being involved in a study, even if there are minimal/low risks, i.e. with a survey study and any possible side effects.

Trust Insights…

Trust was identified as a huge priority by all of the participants. Trust in the authenticity of the research, but more so in the person talking to them about the research. Some previous bad experiences of the participants with GPs and local health services, as well as the experience of research conducted in Africa with poor outcomes has led to a negative view about getting involved in research.

Participants stated that people did not need to "look like them" (participant words) or be from the same culture to talk to them about being involved in research, as long as they came across as genuine and had an interest or concern for their community.

Recommended actions/learnings:

- Researchers to take time to get to know communities and their needs and perspectives, being honest and respectful of their cultures.
- Researchers do not just expect to come to an event/forum/meeting and expect people to sign up for a study.
- Researchers to consider working with trusted gatekeepers within the different communities and discuss how best to support and encourage research participation within that particular community.

Inclusivity Insights…

Participants had a range of views on the inclusivity of research and made some good recommendations on how to work more effectively with their communities. Some participants felt that in the past they had been pushed aside and that there was some dismissal of their culture and experience.

Recommended actions/learnings:

- Ask the communities what is important to them- they don't want generic services, and research should follow this too.
- Involve communities more in the development of research questions or ideas so it is relevant and addresses their needs.
- Consider the impact of time involvement in research- try to minimise the time commitment needed, and the flexibility with timing of clinics or visits around working hours.
- Offer alternative locations to participate in research, including at local community venues, i.e. churches or community halls.
- Offer incentives for people participating in research, including consideration of travel and parking arrangements.

Community Research Engagement Network- February 2024 onwards

During the lifetime of the project, a new networking opportunity presented itself in the form of the Community Research Engagement Network (CREN).

NHS England and the Department of Health and Social Care developed a £7.2 million-funded programme with the aim of supporting Integrated Care Systems (ICS) to increase diversity in research participation. Some of the aims of the various cohorts were as follows:

- Growth of local research engagement networks with under-served communities
- Embed consideration of diversity in research within ICS operations/governance structures
- The development of transferable recommendations to address specific, systemically embedded inclusion barriers to taking part in research and an understanding of how this can be applied locally.

Locally, within Kent and Medway, funding was awarded to an organisation called Social Enterprise Kent, as part of the Kent and Medway Voluntary, Community and Social Enterprises (VSCE) Health Alliance to help develop a more local CREN. This was locally known as “Community Voices in Research: Kent and Medway.” This was an opportunity to engage with local community organisations, voluntary sector partners, as well as Health and social care organisations and academia.

Their aims were:

- Gain trust and build relationships with underrepresented communities in matters of research through local events and tailored training.
- Support and fund co-ordination of the VCSE, local communities and researchers.
- Formalise community engagement by acting on what communities are telling us matters to them.
- Be transparent- sharing insights from research back with local communities.
- Be effective and build sustainability for the continued growth CREN.

Whilst this presented as an opportunity for further engagement, it also presented as a risk to the project by being another body that was going out into the community, engaging with under-served communities.

Two engagement events were facilitated by the CREN in Ashford in February 2024 and Medway in March 2024; the project team attended both events.

The project team were able to share information about their own organisations and also details of the project itself. The second engagement session actually allowed Julie Webster to follow up with a contact made at a Medway Diversity Forum event with a leader from a Ghanaian community, which then led to one of the focus groups being facilitated, as mentioned previously.

Julie Webster (Research AHP) and Sandra Mononga (Research Nurse) attending 1st CREN at Ashford International Hotel (February 2024) and Chris Gedge attending 2nd CREN at Chatham Dockyard (March 2024).

The team have continued to work with CREN partners as well as the NIHR PPIE lead to ensure a coordinated approach to engagement across Kent and Medway, as well as looking at developing Research Ambassador/Champion roles across different voluntary sector organisations and identified communities. The CREN is now being utilised as a platform for further community engagement, which wasn’t planned for at the beginning of the project.

Part 3

Our learning and recommendations

A reporting requirement for the project was to submit an impact template, which can be found here, with an additional impact template that was requested in March 2024:

Submitted Under-served impact

Additional Impact Questions.docx

COM-B Methodology and analysis:

To enable the development of a structured approach for our next steps and to understand the rationale behind what we were going to do next, and why, we analysed the recommended actions/learning from our engagement work using the COM-B methodology.

Description of the COM-B methodology

The COM-B methodology is the first step in the process of the Behaviour Change Wheel, a framework used to design behaviour change interventions. It identifies and maps the element for the intervention to target, and from this can be used to identify the intervention functions needed to bring the desired change about. It is applicable for use with individuals, groups and at a population level.

In the case of this project, the behaviour we were seeking to influence is an increase in the number of people from under-served communities signing up to take part in research.

COM-B stands for Capability, Opportunity and Motivation. The B is for Behaviour you are seeking to modify.

Below is a set of statements that can be used to identify which element the intervention seeks to increase. For the behaviour to be modified, it is recognised that a mix of the three elements is desirable, however, it is possible to modify a behaviour with an increase in only one element, e.g. if motivation is very high and the person wants to make the change and feel it is the right thing to do, they will be motivated to make that change. However, the behaviour change has a higher chance of success if, for example, the capability is increased, they know more about why it is important, and the opportunity is increased, making it more easily accessible.

Capability:	
Know more about why it is important	Have more mental strength
Know more about how to do it	Overcome physical limitations
Have better physical skills.	Overcome mental obstacles
Have better mental skills.	Have more physical stamina.
Have more physical strength.	Have more mental stamina.

Opportunity :	
Have more time to do it.	Have more triggers to prompt them.
Have more money	Have more support from others.
Have the necessary materials.	
Make it more easily accessible.	
Have more people around them doing it	

Motivation:	
Feel that they want to do it enough	Develop better plans for doing it
Feel that they need to do it enough	Develop a habit of doing it
Believe that it would be a good thing to do	

Intervention Function:	
Education	Enablement
Persuasion	Modelling
Incentivisation	Environmental restructuring
Coercion	Restrictions
Training	

More information on the COM-B method can be found at:
02.09.19_COM-B_and_changing_behaviour_.pdf

Focus Group Recommended Actions/Learnings:

Due to the extensive volume of recommendations made from the focus groups and engagement activities, the following table is the COM-B analysis representing the collated recommendations for all researchers or organisations looking to support community engagement or research activity with under-served communities.

Focus Group Recommended Actions/Learning	Capability	Opportunity	Motivation
1.Researchers to develop a rapport first with communities by spending time with them with no research agenda and not just expect people to come to an event/forum/meeting and sign up for a study			X
2. Researchers to develop an understanding of what health issues impact specific communities & recognise that they all have differing health needs	X		X
3. Researchers should ask the communities what health issues are important to them.	X		X
4. Researchers to be respectful of different communities' cultures.		X	
5. Researchers to involve communities more in the development of research questions or ideas so it is relevant to everyone	X		X
6. Researchers to involve communities more in the development of research questions or ideas so it is relevant and addresses their health needs.	X		X
7. Researchers to provide appropriate jargon free information about research studies to communities (what is the health literacy of our communities?)	X		
8. Researchers to be honest and transparent about the risks and any possible side effects; as well as the benefits, of being part of a study even if the risks are low or minimal i.e. with a survey study.	X		
9. Researchers to consider working with trusted gatekeepers within the different communities and discuss how best to support and encourage research participation within that community.		X	
10. Researchers to support communities to build their knowledge of health and research through offering training and "drip feeding" of information. Not expect people to absorb everything in one go.	X		
11. Where possible and appropriate for the study, Researchers to arrange for research studies to happen more locally within the community e.g. churches or community halls, rather than acute hospital setting.		X	
12. Researchers to consider the impact of time involvement in research- try and minimise how much time commitment is needed and the flexibility with timing of clinics or visits around working hours.		X	
13. Researchers to offer incentives for people participating in research including consideration of travel and parking arrangements.		X	

Additional Funding, opportunities and activities:

Due to some project start delays and the time taken to meaningfully engage with the communities, additional funding was sought to continue the project and see it through to its conclusion.

An award was made by the CRN for the completion of the focus groups that had been agreed with other groups that responded. It also allowed time to fully write up the findings and plan next steps. This included going back to the groups who attended the focus groups to provide feedback on the outcomes and the actions we will be taking.

It also allowed time to continue to build on the established relationships. This included working with other system partners, including the CREN and the CRN PPIE regional forum.

"Space To Lead"- Patient and Public Involvement and Engagement Forum March 2025

As part of sharing the learning from the project, the team presented the project and the results to a Kent, Surrey and Sussex-wide CRN forum in March 2025.

There was a fantastic opportunity to share the journey and life of the project, as well as key lessons learned. The team facilitated an active learning session for other teams to consider how they may apply some of the learning into their own organisations, and in particular, thinking about the COM-B methodology.

Copy of the presentation used and breakout session write-up:

Space to Lead in PPIE Presentation(2).pptx

Breakout Session Write up.docx

Part 4

The Final Conclusions and Next Steps

As a project team, we would firstly like to say a huge thank you to all contributors to this project, as without their support, we would not have been able to deliver what has been written about in this extensive report.

This includes funders and colleagues from the CRN, MFT and MCH staff; colleagues within the various engagement networks and the voluntary sector, and contributors to our survey.

We would particularly like to thank the members of the Nigerian and Ghanaian Communities who warmly welcomed us into their communities and kindly gave up their time to engage with us. Their knowledge and insights have played a key role in improving our understanding of their perspectives and in shaping our approach to engagement and how we can support people to have opportunities to engage in meaningful research and therefore not be seen as "under-served."

This project has been a journey, and as a Project team feel that it needs to continue, and will continue. Some key next steps we intend to take:

- Continue to meaningfully engage with our newly established Communities and maintain those relationships.
- Share our learning from the project with other system-wide partners and stakeholders
- Support the development of region-wide forums, i.e. CREN, enabling as many people as possible to hear about research and how they may get involved.
- Utilise the learning from our project with any engagement activities we do, both from a research perspective and also wider organisation community engagements
- Explore any funding opportunities that may arise for any bespoke Community engagement activities.

Personal Reflections:

As a project team, please find some of our personal reflections about the project and engagement with the local communities:

Julie Webster's Reflections:

"Joint short-term project funded by the NIHR with MFT (Laura Adams) and MCH (Chris Gedge and me) to explore why under-served communities are not coming forward to be part of research. It is hoped that through engagement, we will discover the reason why this is the case and Then, using the COM-B methodology, be able to suggest ways in which this behaviour could be modified. Ultimately, with a view to increasing the number of people from under-served communities who take part in research.

However, that is a long-term outcome that may not be seen during the life of this project. My main role within the project was to reach out and establish links with our target population, with pre-existing contacts and develop new ones. Organise and facilitate focus groups, contribute to report writing and identify resources/publications that enhance our understanding of this subject.

The project is significant because if it is successful, it will increase our understanding of the barriers to taking part in research and suggest ways to overcome these, build strong relationships, and hopefully trust, between our organisations and the local target communities, and a more diverse group of people will take part in research. We would then have more assurance that the research results represent the whole population. It is giving communities a voice. It is also significant because if handled badly, e.g. not following through on a promise or raising unrealistic expectations, it has the potential to damage relationships and trust in our organisations with the communities.

The project is significant for me personally as I have recently changed roles, and this has allowed me to explore this topic in depth and to hear first-hand the communities' views and thoughts. It is significant to me as I want to support people to be heard and allow them to be part of the solution. I have also been able to increase my experience in facilitating focus groups.

My initial thoughts about the project were that my aspect of the work would be easy to achieve in a short time frame. Even though I have previous experience of engaging with people and knew it to be difficult, I hadn't fully anticipated that we were working on a different timeline than the communities. Our project may be time-limited and an end date rushing towards us, but the communities have no end date. Their lives will still go on the day, week, month and year after our project finishes. Also, people have busy lives. I had also not fully anticipated the lack of trust that the communities had in the NHS and authority as a whole, and the scepticism that this time would be any different. I had also not fully understood the fatigue felt by people who had been asked similar questions, and nothing changes or the level of duplication around the work we were doing with similar projects in the area.

To try to ensure that I delivered on my aspect of the project, I built on existing relationships and developed new ones via other existing contacts. I used my communication and engagement skills to their full extent and ensured there was flexibility with meeting days and times offered to the communities outside of working hours to increase their ease of attendance. Venues used were in the community with access to parking. People were also given recognition for their contributions to the project. Despite all of this, some of the initial conversations with potential communities/groups to engage with did not come to fruition, and time was spent on these that the project timeline could ill afford. Even with the communities that did fully engage with the project, getting dates set took longer than anticipated.

With hindsight, a more realistic timeline would have included additional time at the beginning of this part of the process.

My thoughts and feelings about this work have changed over the course of the project. I have an increased awareness of how important this work is, and as my understanding of increasing uptake in research generally, and more specifically from under-served communities, has increased it has increased, so has this aspect of this work within our research teams, and within my role.

Continuing this work in some form or another would hopefully continue to build relationships with the communities we have already worked with and hopefully some more communities in the future. It would also allow me to use my engagement skills and get job satisfaction from helping to give people a voice.

However, the extent of that work needs to be realistic, and expectations need to be realistic to avoid breaking promises and damaging relationships and trust.
If engagement work were to continue, these are the areas of knowledge and skills that I have identified that I need to be developed further.
-Diseases/health conditions specific to the target population.
-Cultural aspects specific to the target population. E.g. handshakes, hugs, eye contact, diet.
-Deeper understanding of psychology and behaviour change.
-Understanding of the wider picture of research engagement being undertaken locally and in the region."

Laura Adams reflection:

What have I learnt from this project?

"Engagement is hard. Years of poor engagement, poor research processes, and poor communication have built huge barriers between healthcare and research and the Black community. I had learned about errors in research in the past from our Good Clinical Practice training, but didn't consider how this could still impact people today. In my head, we had learned lessons and practices had changed, so there shouldn't be a reason to distrust research. This was very naïve and ignorant. I hadn't considered before that approaching people as a white person would be a potential issue, as I was always friendly and knew I was going to be honest. The project has highlighted to me that consideration needs to be taken by people, whether it be being a healthcare professional with the knowledge of research or ethnicity, and adapting interactions to ensure trust is not assumed. The project also highlighted the lack of knowledge around research and how national work needs to be done to improve this."

Chris Gedge's reflection:

"Meaningful Community engagement is hard! The length of the project has highlighted the sheer amount of time and dedication it takes to firstly identify the right people to talk to, but secondly, how best to go about doing so- there's no real blueprint!.

So much learning has been taken from the project, and in particular, when you do manage to talk to people, to really take the time to get to know them first and what it is that is important to them.

Relationships take time to build, and you need to be authentic in your approach and really get to understand what people's personal challenges are- this isn't just about research, it's about wider health and socio-economic factors too.

Also, you can't expect to be able to go into a community, ask them some questions and go away again! You need to keep maintaining these relationships and supporting them with their needs and wishes.

Being a Stroke Specialist Physiotherapist by profession, I was very honoured to be asked to attend a Community meeting to talk about Stroke Prevention and my colleague Julie, being a Diabetes Dietitian asked to attend a similar event about Diabetes. This wasn't really in scope for the project, but we felt important to support as it was identified as a specific need for these communities- this is what true community engagement and serving the needs of these people is all about!"

(all photos shared with permission)

Thank you to all the staff in both organisations and the volunteers from our local communities for supporting this project.

Thank you for reading, and please do not hesitate to contact us:

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Thank you for reading.

NHS
Medway
NHS Foundation Trust

MCH
medway community healthcare