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Engagement Discussions with Black and Asian Communities to Understand Participation in Primary Care Research

October 2022

Commissioned by University of Nottingham



“We need to put our voice in the system, but they need to know us, our culture, our mentality and worth”



Comment from respondent





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Who are Healthwatch Nottingham & Nottinghamshire?

Healthwatch Nottingham & Nottinghamshire (HWNN) is the independent patient and public champion that holds health and social care services more accountable to their communities for the services they commission and provide.

We have 3 key roles:

Scrutiny of local health and care commissioners to ensure that they: listen to the public, provide excellent care, provide quality signposting and are totally transparent

Make a difference: We collect & provide insight from patients & communities, and use these to make recommendations to improve services for the public. We will then scrutinise how this insight helps to influence improvements.

To work in partnership across local, regional and national networks of Healthwatch and the CQC to ensure big issues/opportunities are acted upon & best practice is shared, whilst ensuring that our independence is maintained

Why is it important?


You are the expert on the services you use, so you know what is done well and what could be improved.

Your comments allow us to create an overall picture of the quality of local services. We then work with the people who design and deliver health and social care services to help improve them.

How do I get involved?

We want to hear your comments about services such as GPs, home care, hospitals, children and young people's services, pharmacies and care homes.

You can have your say by contacting us:

 0115 956 5313

 www.hwnn.co.uk

 @_HWNN

 [Facebook.com/HealthwatchNN](https://www.facebook.com/HealthwatchNN)

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Executive summary

Why was this project undertaken and who was it commissioned by?

The Nottingham University Division of Primary Care (UofN) identified that there is a shortfall in primary care research participation particularly among Black and Asian communities. Healthwatch Nottingham & Nottinghamshire (HWNN) received a grant from UofN to identify three or four representatives of ethnically diverse group to engage in primary care research activities.

The longer-term aim of UofN is to increase diversity within the contributor pool and to co-develop research to reflect the needs and views of the groups with whom they engage.

Who was spoken to?

HWNN had discussions with four community organisations. One was from the Black community and three were from the South-Asian community. All participants in the discussions were female.

What was good?

From discussions with representatives from the Black and Asian communities, HWNN were able to identify and understand the barriers they face when participating in primary care research and to propose recommendations.

HWNN identified three community representatives who were interested to participate in primary care research activities with the University of Nottingham and introduced them to the Primary Care Division (UofN). One individual represented the Black community, and two individuals represented the South-Asian community. This was achieved by HWNN through having trusted connections with grass roots organisations in Black and South-Asian communities.

What did HWNN conclude from the discussions with community representatives and the University of Nottingham Primary Care Division?

Ethnically diverse groups have barriers to participation in primary care research which has been acknowledged in the literature, by the communities themselves and by the University of Nottingham Primary Care Division (UofN). It is also acknowledged that much more work needs to be done to identify and address these barriers in advance and to factor them into the preliminary primary care research planning, design, budgeting, methodology, and timescales. Without the necessary procedures in place, researchers run the risk of not being able to recruit and retain the participants to whom the research directly relates. These barriers are highlighted in the findings of this report, with a number of recommendations included at the end of the report.

Why is this project important?

Underrepresentation from diverse communities in primary care research has been identified by the UofN primary research team. Increasing diverse participation would help to reduce health disparities, promote health equity and provide personalised, evidence-based medicine. Increasing diverse participation would also improve understanding of population differences in the efficacy of treatments and would assess how factors such as age, sex, race, and lifestyle impact their response to treatment. These outcomes are important for identifying and developing effective therapies and treatments for health conditions and, ultimately, for improving health for all.

UofN approached HWNN to initially identify representatives from Black and South Asian communities and introduce them to the primary care team. This is because UofN could not themselves engage effectively with these communities. When initial conversations between HWNN and community representatives proved unsuccessful, HWNN wanted to find out why they did not want to participate and to understand if these reasons contributed to underrepresentation of ethnically diverse populations in primary care research.

What does other literature and research say about this topic?

From basic literature research, the author of the report found that there is significant under-representation of patients from ethnically diverse populations participating in primary care research in major disease areas and a consistent lack of diversity across ethnicity in clinical trials.

¹This is despite being over-represented in the incidence of certain conditions such as type 2 diabetes. ²By not involving more patients from relevant ethnically diverse groups, industry restricts critical insights into diseases and into developing effective therapies for these. It also limits treatment and business potential. Inequalities and lack of diversity in primary care research and clinical trials are a threat to the industry's reputation and its ability to provide treatments for all. ³The latter comments were taken from a blog reference in June 2021 which may limit the liability of the evidence, but they do support similar evidence in other literature findings.

Underrepresentation of ethnically diverse populations in primary care research has been attributed to several different factors. Examples include:

- Difficulties inherent in recruiting such groups for ⁴research.
- Lack of cultural competency training⁵ and of culturally appropriate educational materials for researchers on the importance of diversity in research and on effective strategies for recruiting and retaining minority populations.⁶
- Poor promotion and lack of knowledge about the ⁷research.
- Poor engagement with patients and communities (ibid)
- Language barriers making information unavailable in different languages as well as in plain English including avoiding terminology and jargon.(ibid)
- Distrust of researchers and clinicians stemming from racial discrimination, suspicion of the financial motives of the pharmaceutical industry, and/or disparities in the quality of care received. (ibid)
- Immigration status concerns (ibid)
- Time or travel commitments (ibid)

1 LAURA K. ROONEY, RAJ BHOPAL, LAILA HALANI, MARK L. LEVY, MARTYN R. PARTRIDGE, GOPAL NETUVELI, JOSIP CAR, CHRIS GRIFFITHS, JOHN ATKINSON, GRACE LINDSAY, AZIZ SHEIKH, PROMOTING RECRUITMENT OF MINORITY ETHNIC GROUPS INTO RESEARCH: QUALITATIVE STUDY EXPLORING THE VIEWS OF SOUTH ASIAN PEOPLE WITH ASTHMA, JOURNAL OF PUBLIC HEALTH, VOLUME 33, ISSUE 4, DECEMBER 2011, PAGES 604–615, [HTTPS://DOI.ORG/10.1093/PUBMED/FDQ100](https://doi.org/10.1093/pubmed/fdq100)

2 PRINJHA, S., MIAH, N., ALI, E. ET AL. INCLUDING 'SELDOM HEARD' VIEWS IN RESEARCH: OPPORTUNITIES, CHALLENGES AND RECOMMENDATIONS FROM FOCUS GROUPS WITH BRITISH SOUTH ASIAN PEOPLE WITH TYPE 2 DIABETES. BMC MED RES METHODOL 20, 157 (2020). [HTTPS://DOI.ORG/10.1186/S12874-020-01045-4](https://doi.org/10.1186/s12874-020-01045-4)

3 PATIENT DIVERSITY IN CLINICAL TRIALS NEEDS TO BE CENTRE STAGE. DANNY BUCKLAND 17TH JUNE 2021 [HTTP://WWW.PMLIVE.COM/PHARMA_INTELLIGENCE/PATIENT_DIVERSITY_IN_CLINICAL_TRIALS_NEEDS_TO_BE_CENTRE_STAGE_1371778](http://www.pmlive.com/pharma_intelligence/patient_diversity_in_clinical_trials_needs_to_be_centre_stage_1371778)

4 RENERT, H., RUSSELL-MAYHEW, S., & ARTHUR, N. (2013). RECRUITING ETHNICALLY DIVERSE PARTICIPANTS INTO QUALITATIVE HEALTH RESEARCH: LESSONS LEARNED. THE QUALITATIVE REPORT, 18(12), 1-13. [HTTPS://DOI.ORG/10.46743/2160-3715/2013.1542](https://doi.org/10.46743/2160-3715/2013.1542)

5 JUTLLA, K. AND RAGHAVAN, R. (2017) IMPROVING THE RECRUITMENT OF BLACK, ASIAN AND MINORITY ETHNIC (BAME) COMMUNITIES IN HEALTH AND SOCIAL CARE RESEARCH: A REVIEW OF LITERATURE. DE MONTFORD UNIVERSITY. LEICESTER. MARY SEACOLE RESEARCH CENTRE. SCHOOL OF NURSING AND MIDWIFERY [732] URI: [HTTP://HDL.HANDLE.NET/2086/13221](http://hdl.handle.net/2086/13221)

6 KUSNOOR, S.V., VILLALTA-GIL, V., MICHAELS, M. ET AL. DESIGN AND IMPLEMENTATION OF A MASSIVE OPEN ONLINE COURSE ON ENHANCING THE RECRUITMENT OF MINORITIES IN CLINICAL TRIALS – FASTER TOGETHER. BMC MED RES METHODOL 21, 44 (2021). [HTTPS://DOI.ORG/10.1186/S12874-021-01240-X](https://doi.org/10.1186/s12874-021-01240-x). [HTTPS://RDCU.BE/CKPQ5](https://rdcu.be/cKpQ5)

7 SHEBA GEORGE, PHD, NELIDA DURAN, RD, MS, AND KEITH NORRIS, MD. A SYSTEMATIC REVIEW OF BARRIERS AND FACILITATORS TO MINORITY RESEARCH PARTICIPATION AMONG AFRICAN AMERICANS, LATINOS, ASIAN AMERICANS, AND PACIFIC ISLANDERS. AM J PUBLIC HEALTH. 2014 FEBRUARY; 104(2): E16–E31.

PUBLISHED ONLINE 2014 FEBRUARY. DOI: 10.2105/AJPH.2013.301706. [HTTPS://WWW.NCBI.NLM.NIH.GOV/PMC/ARTICLES/PMC3935672/](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3935672/)

- Failure to show respect by means of flexibility, in terms of timing, location and respecting/awareness of cultural and religious sensitivities regarding gender segregation.⁸
- Complexities arising where research is concerned with health issues that carry a stigma such as mental ill-health.⁹
- Willingness of communities to take part in research so long as there is direct contact and engagement and the reasons for the research and the potential benefits are explained clearly to them.¹⁰
- Providing incentives as key factors promoting participation.¹¹
- The importance of understanding people's motivations for taking part in research to improving the recruitment and retention of participants. These motivations include self-fulfilment (helping others, the overall gratification received from the opportunity, meaningful connections and a sense of purpose), improving healthcare, financial compensation, influencing change and having a perceptible impact on the health system, and learning new things.¹² Having a deeper knowledge of volunteer motivations creates meaningful engagement opportunities for patients, but also enables health organisations to gain from the experience of these individuals, thereby enhancing the quality and sustainability of patient engagement programmes in primary care research (ibid).
- Current research methods and designs not providing ethnically diverse groups the opportunity to participate (Hussain-Gambles et al 2004), meaning that they do not have fair access to research for almost the same reasons as their potential lack of fair access to services (e.g. due to language and cultural barriers).¹³

The initial conversations HWNN had with community representatives were met with resistance and it became clear that not many people understood what the term primary care research meant or what it involved and were hesitant to take part. HWNN wanted to compare the findings in the literature with what people were saying at a local level and to understand the reasons for underrepresentation of patients from ethnically diverse populations participating in primary care research.

The author has been unable to find a definition for Primary Care Research but for the purposes of this report, Primary care research will be defined as:

Primary Care is the first point of contact for healthcare and treatment such as the GP, pharmacist, dentist as opposed to secondary care which includes hospitals and emergency care.

8 STIRLAND, L., HALANI, L., RAJ, B. ET AL. RECRUITMENT OF SOUTH ASIANS INTO ASTHMA RESEARCH: QUALITATIVE STUDY OF UK AND US RESEARCHERS. PRIM CARE RESPIR J 20, 282–290 (2011). [HTTPS://DOI.ORG/10.4104/PCRJ.2011.00032](https://doi.org/10.4104/pcrj.2011.00032)

9 JUTLLA, K. AND RAGHAVAN, R. (2017) IMPROVING THE RECRUITMENT OF BLACK, ASIAN AND MINORITY ETHNIC (BAME) COMMUNITIES IN HEALTH AND SOCIAL CARE RESEARCH: A REVIEW OF LITERATURE. DE MONTFORD UNIVERSITY. LEICESTER. MARY SEACOLE RESEARCH CENTRE. SCHOOL OF NURSING AND MIDWIFERY [732] URI: [HTTP://HDL.HANDLE.NET/2086/13221](http://hdl.handle.net/2086/13221)

10 UNDER-REPRESENTATION OF MINORITY ETHNIC GROUPS IN CARDIOVASCULAR RESEARCH: A SEMI-STRUCTURED INTERVIEW STUDY. PARAMJIT S GILL, GILL PLUMRIDGE, KAMLESH KHUNTI, SHEILA GREENFIELD. OXFORD ACADEMIC. FAMILY PRACTICE, VOLUME 30, ISSUE 2, APRIL 2013, PAGES 233–241, [HTTPS://DOI.ORG/10.1093/FAMPRA/CMS054](https://doi.org/10.1093/famppra/cms054). PUBLISHED: 16 SEPTEMBER 2012

11 STIRLAND, L., HALANI, L., RAJ, B. ET AL. RECRUITMENT OF SOUTH ASIANS INTO ASTHMA RESEARCH: QUALITATIVE STUDY OF UK AND US RESEARCHERS. PRIM CARE RESPIR J 20, 282–290 (2011). [HTTPS://DOI.ORG/10.4104/PCRJ.2011.00032](https://doi.org/10.4104/pcrj.2011.00032)

12 MCCARRON TL, NOSEWORTHY T, MOFFAT K, ET AL. UNDERSTANDING THE MOTIVATIONS OF PATIENTS: A CO- DESIGNED PROJECT TO UNDERSTAND THE FACTORS BEHIND PATIENT ENGAGEMENT. HEALTH EXPECT. 2019; 22:709–720. [HTTPS://DOI.ORG/10.1111/HEX.12942](https://doi.org/10.1111/hex.12942)

13 JUTLLA, K. AND RAGHAVAN, R. (2017) IMPROVING THE RECRUITMENT OF BLACK, ASIAN AND MINORITY ETHNIC (BAME) COMMUNITIES IN HEALTH AND SOCIAL CARE RESEARCH: A REVIEW OF LITERATURE. DE MONTFORD UNIVERSITY. LEICESTER. MARY SEACOLE RESEARCH CENTRE. SCHOOL OF NURSING AND MIDWIFERY [732] URI: [HTTP://HDL.HANDLE.NET/2086/13221](http://hdl.handle.net/2086/13221)

Research is the process of enquiry or study into a particular concern or problem through collection and analysis of data, documentation and information using a variety of scientific methods.

To understand the reasons for underrepresentation of people from ethnic minority populations in Nottingham in primary care research, HWNN held semi-structured discussions with four representatives from Black and South Asian communities. The discussions were not recorded or transcribed but, instead, the data in this report is based upon the author's field notes and observations. Each community representative was asked the following four questions:

- What does primary care research mean to you?
- Would people in your community take part in primary care research?
- What do you think are the barriers for Black and South Asian communities taking part in primary care research?
- What would encourage more people in your community to take part in shaping primary care research?

HWNN wanted to know what difference participation would make, the level of engagement UofN had already undertaken with Black and South Asian communities, and the challenges UofN encountered. This was carried out by emailing the following three questions to the Division of Primary Care team:

1. What difference will it make if people from Black and South Asian communities take part in primary care research at Nottingham University?
2. What involvement has there already been in primary care research at Nottingham University from people from Black and South Asian communities?
3. What were the challenges you faced?

How did HWNN identify people to engage with?

HWNN has links and existing relationships with several Black and South Asian community organisations in Nottingham. After they were all contacted, one representative from the Black community and three representatives from the South Asian community agreed to take part in the discussion with HWNN. This engagement report therefore, represents the views of a total of four community organisation representatives.

No men took part in these discussions which may have limited the findings. However, Black and South Asian women are some of the most difficult groups to engage with and their voices often excluded from research into health care because of their gender, race and ethnicity and in some cases religion. So the inclusion of their views in the present report reflects their seldom heard experience, helping to understand their unique experiences of marginalisation and exclusion. These are significant findings if participation in primary care research activities are to be truly inclusive.

The four questions to the community representatives (See in 'Our Approach,' above) were posed by the author of the report. Their responses are taken from the author's field notes and observation data. Quotes from representatives are highlighted blue.

The three questions posed to UofN Primary Care Division (also see 'Our Approach' were emailed to the Primary Care Division. The responses are highlighted in blue.

Questions posed to Community Representatives

1. What does primary care research mean to you?

Most of the representatives who were asked this question did not understand what the term 'primary care research' mean, nor how to define it. This is because it is academic language and they are not familiar with this terminology. One community representative knew that primary care research involved care from the NHS at primary, clinical level, while two representatives thought that it involved drug trials.

The term 'primary care research' may not be clear to the average person. Primary care research is also a very broad definition so people would need to know exactly what it is and what it would involve.

2. Would people in your community take part in designing primary care research?

Two representatives we spoke to said people from the Black and South Asian communities in Nottingham would participate in primary care research given certain conditions. Two representatives said they did not think they would participate because of specific certain barriers. These conditions and barriers are explained in the findings below.

3. What do you think are the barriers for Black and Asian communities taking part in designing primary care research?

People may not know about or hear about opportunities to participate.

'You cannot sit behind a desk and then say, 'We couldn't get the community to participate'

Barriers to participation are due not providing enough clear information for participants to enable them to understand what the research is about, its purpose and intended outcomes and how their voice will make a difference.

'Need a guarantee that they will put forward our suggestions and make an impact'

Impact:

People need to understand how relevant the research is, what it means to them and what the benefits are. This information would provide incentives for people to participate in primary care research.

'We don't see any benefits. Where are the changes...need proof it actually changes anything or makes a difference to our community.'

and

'If the research doesn't go anywhere, it's a waste of time and energy (to participate)'

Language and literacy:

People are less likely to participate if the information contains academic language, medical jargon and too much unnecessary detail. It needs to be clear and concise.

Time constraints:

People are very busy and have little or no time to take part.

'The researcher needs to take on most of the unnecessary paperwork and make it [the participation process] as easy as possible.'

Mistrust

The representatives we spoke to said people from Black and South Asian communities do not trust institutions or professionals because they have been consulted too often for years and see few, if any changes or results. They also cited inequalities, stereotyping and lack of transparency as playing a role. One representative stated that there is a negative history for Black and South Asian people. Mistrust arises from how the communities have been treated in the past and present, for example with racism and discrimination; from having been harmed in US drug research¹⁴; from concerns over confidentiality and in sharing personal details; and from misinformation and lack of information¹⁵.

'Consultation is just a tick box exercise to show they spoke to us so they can get funding for their research by having a certain percentage of minority people involved'

and

'They (researchers) will listen but then they will always do what they think is right'

and

'What's the point in wasting our time? We haven't seen any results or improvements...'

and

'NHS is linked to immigration control'

Lack of confidence:

Some people lack confidence in engaging with institutions such as universities.

'University is a strange environment; people aren't confident especially if they don't speak the language.'

¹⁴ [HTTPS://WWW.CDC.GOV/TUSKEGEE/TIMELINE.HTM](https://www.cdc.gov/tuskegee/timeline.htm)

¹⁵ RENERT, H., RUSSELL-MAYHEW, S., & ARTHUR, N. (2013). RECRUITING ETHNICALLY DIVERSE PARTICIPANTS INTO QUALITATIVE HEALTH RESEARCH: LESSONS LEARNED. THE QUALITATIVE REPORT, 18(12), 1-13. [HTTPS://DOI.ORG/10.46743/2160-3715/2013.1542](https://doi.org/10.46743/2160-3715/2013.1542)

No financial incentive

Most of the community representatives said that participants should be paid for their time and knowledge. By giving their unpaid time, many people do not feel they have any power in making decisions or influencing change. Universities need to invest a certain amount of time and money when hearing the voices of the community, and ensure they factor financial incentives into their research budgets and planning. If participants are not paid for lost earnings, the community do not believe that their views and opinions are given value or worth.

'Time is money... we could be working, fund raising for our charity, or being with our families.'

and

'They (researchers) have the funding so they can afford to pay participants'

and

'We need to put our voice in the system, but they need to know us, our culture, our mentality and worth.'

and

'Gone are the days when they come to us for free and don't even bother to tell us the result.'

Additional support

The representatives we spoke to also said that people would require additional support needs to participate in primary care research. These include:

Digital access

Some people have no or limited phone credit or data, poor access to digital technology resources or poor I.T. skills.

Segregated meetings for men and women

If meetings are gender specific people will feel more comfortable and willing to discuss personal medical issues openly and freely.

'Offer gender segregated meetings so people feel comfortable to participate.'

Practicalities

Some people do not have transport, parking may be an issue for people who drive, parking fees; childcare issues; support for health conditions or disability needs e.g. easy read literature.

4. What would encourage more people in your community to take part in designing primary care research?

The author's field notes and observation data revealed the following suggested recommendations by community representatives for researchers:

Effective communication and information sharing

- Set up expectations from the start. Explain what research is, what is required of participants, how long the research participation process will take and the stages, so that they can decide whether to commit to it.
- Explain the impact of participation for the individual and for the community as a whole.
- Use plain English without jargon or academic language.
- Use simple methods of sharing information such as videos or leaflets with bullet points.
- Explain how confidentiality is safeguarded. Who decides the outcome? Where do the results go? Allay any concerns about these.
- Reduce paperwork and remove elements that create unnecessary time and work so that participation is easier; for example, simple administration forms, easy to read information and not too much of it.
- Maintain regular communication with participants through feedback and updates before, during and after the research.
- Be honest and transparent about the change or difference the research will make and has made, and feedback the outcomes to participants once the research has been completed.

Effective community engagement

- Engage in person with the community to build mutual trust and respect.
- Identify places and approach potential participants in advance before the research is undertaken e.g. health clinics, self-help groups, community venues or places of worship, existing community group meetings.
- Liaise with community leaders/Imams/Black and Asian doctors or medics the community trust to promote the research and encourage participation.
- Demonstrate genuine commitment to change; listen without making false promises; show understanding, and feedback change to the community once the research has been completed. Also show that you respect the need for, value of and the impact of improving primary healthcare and service delivery for Black and South Asian communities.

Provide incentives

Financial and non-financial) for participants' time, expertise by experience and knowledge, and meet their specific needs so that this does not hinder participation.

- Payment should be given to people who are participating in research to show that their input has value and worth.
- Financial incentives should be provided on condition that they participate in all stages of the research process. This will encourage commitment and prevent drop-out.
- Reimburse out-of-pocket expenses for example travel, parking fees, childcare, IT (phone credit, internet data) or by offering free crèche facilities
- Provide additional support for example IT, transport or use a venue that is familiar, safe, and easy to access for in-person meetings such as local community centre, a mosque, or existing community group meetings.
- Offer gender segregated meetings. People will feel more comfortable about participating and discussing personal medical matters openly and freely if meetings are segregated. This is particularly relevant to Muslims from Black, Asian, Arab and other communities.

Questions posed to the UofN Division of Primary Care Division

The email responses to the three questions posed to the UofN Division of Primary Care Division are as follows:

1. What difference will it make if people from Black and Asian communities take part in designing primary care research at Nottingham University?

Most research that decides how to manage health is based upon white middle class cohorts that are not representative of the population. It is important that primary care research also represents ethnically diverse populations so that culturally sensitive management is developed and implemented.

2. What involvement has there already been in primary care research at UofN from people from Black and South Asian communities?

UofN identified a deficit in primary care research participation from ethnically diverse communities, specifically from Black and South Asian communities. More patient participant involvement is required and to involve them throughout the journey rather than merely being a tick box exercise.

3. What were the challenges you faced?

When we involved people from the south Asian community to use pedometers, it was a challenge to train people how to use them. The issue was the research team hadn't planned and set up procedures properly and needed to include this training earlier in the research.

Participation in women's familial breast cancer research is a stigma in some communities. It's important to find out before the research commences what the barriers are and how to overcome them.

It has been a challenge to identify children from ethnically diverse communities to participate in research to understand familial family history of blood cholesterol to improve services that treat and manage heart disease.

This report highlights significant barriers that exist systemically and institutionally for people from Black and South Asian communities that hinder participation in primary care research activities. Comparing the literature and the voice of the community with the understanding of the UofN research team, it is clear that gaps exist between what the team perceives as limitations and what the barriers are in reality. An active and sustained engagement with the community is necessary to build trust, not just approaching the community when they are needed and expecting them to participate. The University of Nottingham primary care research team acknowledge that they are not fully aware of all the reasons for lack of participation and agree that so much more needs to be done. They also acknowledge that certain barriers are realised far too late and should be identified and planned for in the research proposal before the actual research is undertaken. This is crucial if they want to demonstrate a genuine commitment to inclusivity in the research participation process. Research teams would benefit from diversity training and from having networks in the community to identify the barriers in advance and factor them into the preliminary planning, research design, budget, methodology, and timescales.

Barriers to participation in primary care research focus mainly on the research team's engagement, communication, and information sharing processes, all of which fail to address the specific needs and concerns of communities. The term 'primary care research' is not a familiar term to most people, highlighting the need to define 'primary care research' clearly using plain English, and avoiding medical jargon and professional terminology. In order to invest their time and energy in research activities, potential participants also need to know what the research is about, how long it will take and what it will involve. This is standard research ethical protocol, and should always be followed regardless of participant. UofN should already adhere to this. Nevertheless, it should be explained clearly and concisely with minimal paperwork and tailored specifically to the participants from diverse communities whilst also addressing their barriers to participation.

The issue of mistrust must not be undermined or dismissed as it is one of the largest barriers to research participation and has arisen due to historical and structural racism, discrimination, stereotyping, and lack of transparency. Building trust in communities takes time and is a worthwhile investment not only for research participant recruitment but, more importantly, for retention. Providing financial incentives will attract participants demonstrating that their voice and opinion have value and worth, as opposed to ethnically diverse groups being consulted with as a tick box exercise in order to secure research funding. Proper financial remuneration should be considered when the time spent participating is time taken away from earning a living in the case of significant swathes of the population who are not middle class with the privilege of spare time.

Providing non-financial incentives and additional support such as digital access and specific culturally sensitive needs would also enhance participation. These would include, for instance, training participants in how to use equipment, showing awareness of and overcoming any cultural sensitivities relating to the nature of the research such as breast cancer or mental health, and providing segregated meetings on the basis of gender so that participants feel more comfortable about discussing personal medical matters.

Equality, diversity, and inclusion should be at the forefront of research.

Inequalities in the health service are widely known. Understanding the barriers as well as recommendations for improving the participation of Black and South Asian communities in primary care research is also becoming more widely understood. Diversity training may be a solution for educating research teams in strategies for successful recruitment and retention of participants in primary care research (see Appendix 1). Sharing best practice, resources, and knowledge among key research organisations who have Public Involvement Leads may also help to increase the participation, engagement and involvement of ethnically diverse communities in health and social care research (See Appendix 2).

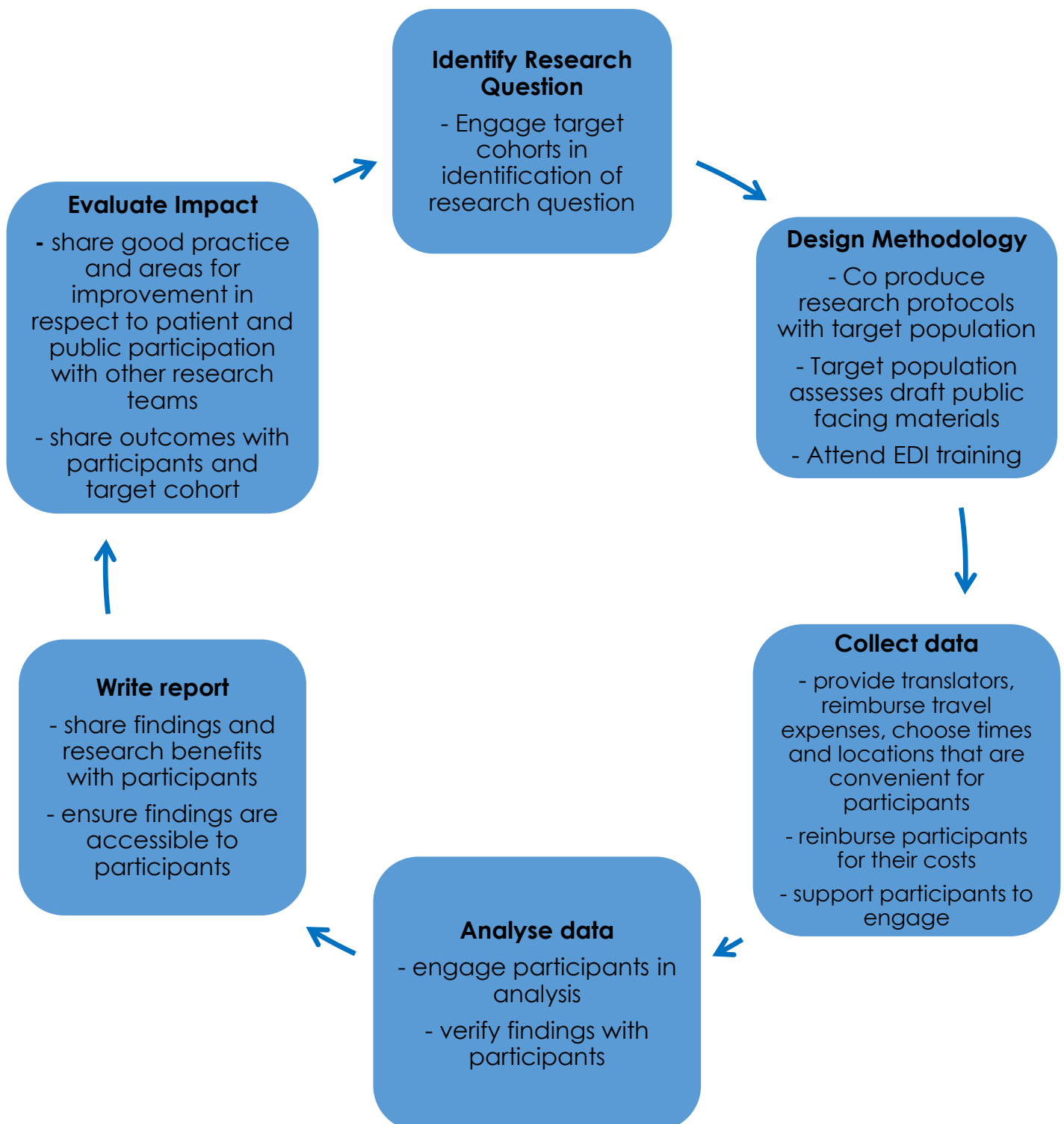
From the literature review it seems that there is still a need to test different recruitment strategies for communities and evaluate their effectiveness. More research is also needed on effective strategies for promoting inclusion in clinical trials and research and to develop culturally appropriate research methods, materials and data collection instruments.

Applying the knowledge and the recommendations will demonstrate a genuine commitment to equitable health care and service delivery for everyone.

HWNN recommends that researchers:

- Build and maintain long term relationships with the communities they would like to engage with – this could be done by a third party
- Co-produce research protocols (including barriers to engagement) with target cohorts of the sample population
- Attend Equality Diversity and Inclusion (EDI) training and make themselves aware of the resources available to support researchers in order to understand how EDI affects the research process
- Empower individuals and communities to participate by meeting their specific needs for example providing translators, reimbursing travel expenses, choosing times and locations that are convenient for participants
- Provide feedback during certain stages of the research process to include verification of findings, and to share the research findings and research benefits with participants and target audience (communities) once the research is completed. This will encourage greater participation through co production.
- Ensure that:
 - All patient and public- facing material is assessed by a lay patient group representative of the community before starting. This information should include a readily intelligible brief of the project, to be given to participants, explaining why the project is being carried out, what it hopes to find out, and why, and how the findings will be useful.
 - In order to enable fully informed consent, information is presented in a form that avoids academic or professional jargon and does not use acronyms.
 - Sufficient time is provided for potential participants to ask questions before research begins so that they can consider whether to take part and know who to ask for more information.
 - A friendly invitation to take part in the project is provided, explaining why the prospective participants have been selected to take part, emphasising the value of their participation, while making it clear that accepting the invitation is optional. The invitation will include a clear account of what participation will involve, in sufficient detail to allow participants to understand what they will be asked to do, how long it will take, and where it will take place. This will include information about how participants will be recompensed for their time, expenses, or inconvenience.
- Participants' expenses are reimbursed in line with NIHR/research funder policy.
- Individual and community empowerment will be facilitated by the research team.
- Participants are offered support with any aspects of the research design (e.g. using technology) that might otherwise create barriers to their full participation.
- On completion of the project, good practice in patient and public participation is shared with the Primary Care Team at Nottingham University.
- Participants are offered an opportunity to be debriefed on their experience of taking part, to enable the Primary Care team to learn lessons for improving the design of future research.

Recommendations within the Project Cycle



Appendix 1:

Few institutions provide training to educate research teams in minority recruitment strategies for increasing diversity among clinical trial participants. To address this need, Faster Together has created an open online course. The goal of the course is to help individuals involved in the clinical research enterprise (including investigators, recruiters, and clinical research coordinators), gain the knowledge and skills needed to successfully recruit and retain ethnically diverse participants in clinical trials.

Preliminary evidence indicates that the course increased knowledge of how to recruit minorities into clinical trials and effected changes in recruitment practices.

To find out more - <https://rdcu.be/ckPq5>

Appendix 2:

Sharing best practise, resources and knowledge from among key local research organisations who have Public Involvement Leads will help to increase participation, engagement and involvement of ethnically diverse populations in health and social care research.

- NIHR Applied Research Collaboration (ARC) East Midlands <https://arc-em.nihr.ac.uk/>
ARC host the Centre for Ethnic Health <https://arc-em.nihr.ac.uk/about/centre-ethnic-health-research>
- NIHR Clinical Research Network East Midlands <https://local.nihr.ac.uk/lcn/east-midlands/>
- NIHR Research Design Services East Midlands <https://www.rds-eastmidlands.nihr.ac.uk/>
These support research staff at the very early stage of design such as how to involve the public as co-applicants
- East Midlands Sharebank <https://arc-em.nihr.ac.uk/about/public-involvement/sharebank> This provides training to staff on how to involve the public in research
- Nottingham University Primary Care Unit <https://www.nottingham.ac.uk/Medicine/about/PrimaryCare/index.aspx> with a link to the NIHR School for Primary Care Research <https://www.spcr.nihr.ac.uk/> which include a report on Diversifying Patient & Public Involvement – showcase of SPCR funded projects <https://www.spcr.nihr.ac.uk/news/blog/diversifying-patient-public-involvement-showcase-of-spcr-funded-projects?ref=image>



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