Under-representation of minority ethnic groups in cardiovascular research: a semi-structured interview study

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Background. Minority ethnic groups are often excluded from research, and the reasons for this are complex.

Objective. This study aimed to explore why minority ethnic groups do not participate in research, and how their participation can be increased.

Methods. Ninety-one interviews were undertaken with people who either had (n = 48) or had not (n = 43) responded to the invitation to take part in a community heart failure screening study. These were split across four ethnic groups (African Caribbean, Bangladeshi, Indian and Pakistani) and between men and women. Participants were interviewed once, face-to-face, either in English or with an interpreter if they wished. Interview transcripts were analysed thematically.

Results. The main reason for participating in the screening study was for a health/heart check. Many participants either had not understood that it was research or had not known what this meant. Most people who did not participate had not remembered receiving the invitation or had been unavailable at the time. Few participants, including those who had and those who had not participated in the screening study, had any understanding of the objectives and nature of research. Once this had been briefly explained to them, many described altruistic reasons for why they would participate in research in the future.

Conclusions. We have shown that South Asians and Black African-Caribbean communities are willing to take part in research as long as they are approached directly and the reasons for the research and potential benefits are explained clearly to them.

Keywords. Ethnic, generalizability, recruitment, research, under-representation.

Introduction

Cardiovascular disease remains the leading cause of global morbidity and mortality.1 The burden of cardiovascular disease falls disproportionately on Black and Minority Ethnic groups (BMEGs) and those from lower socioeconomic groups at a younger age.2-8

The aim of health research is to determine the best strategies for preventing and treating disease and to inform health policy. To ensure health policies serve a diverse population, it is important that all ethnic groups participate in health research. This ensures the generalizability of research results.9-12 However, to date few UK studies feature BMEGs in research.13-16 This qualitative study explored why minority ethnic groups do not participate in cardiovascular research and how their participation can be increased.

Methods

Recruitment

Participants were recruited from our large community-based study (E-ECHOES: ethnic-echocardiographic heart of England screening study) of screening for heart failure in South Asians and Black African-Caribbean communities.17,18 For this we recruited 5406 participants for screening, and from the responders and non-responders who had given permission to be approached for further studies, potential participants for the current study were purposively selected to meet demographic criteria (ethnic group and sex) and to include those who had and had not taken part in the E-ECHOES study. Responders and non-responders who had given permission to be approached for further studies. To allow inclusion of the range of divergent views, a minimum of 80 participants were included, so that
there would be a minimum of 20 for each ethnic group (African Caribbean, Bangladeshi, Indian, Pakistani) and at least 10 men, 10 women, 10 responders and 10 non-responders within each ethnic group. This number is consistent with the numbers recommended to allow data saturation to be reached for this type of study.\textsuperscript{19}

Telephone calls were made in the appropriate languages (English, Bengali, Gujarati, Patwari, Punjabi and Urdu), explaining the study and inviting participation.

**Data collection**

Semi-structured, face-to-face interviews were conducted at either the participant’s health center or their home. The interview schedule was developed from existing literature on non-participation\textsuperscript{9,16} and refined throughout to incorporate emerging themes (see Appendix 1). Interviews lasted between 20 minutes and 1 hour. An interpreter was used when required, employing best practice.\textsuperscript{20–23} Three interpreters were used (two male, one female) to provide as much consistency as possible while providing linguistically competent speakers of each language. It was therefore not always possible to match participant and interpreter by gender/age. Interpreters had been briefed about the project aims and their role in the interviews. After each interview, the interpreter provided feedback, informing subsequent interviews. The interpreters took no role in transcription or any direct role in analysis.

**Data analysis**

Interviews were transcribed verbatim and analysed thematically.\textsuperscript{24} Data from the first eight interviews (four with responders and four with non-responders) were classified and organised into main themes and sub-themes by three authors of differing disciplines (GP, a research fellow with a social sciences background; SG, a medical sociologist and PG, an academic family physician). These were then incorporated into a hierarchical framework.\textsuperscript{25} The framework was subsequently modified to incorporate new emerging concepts and previously analysed interviews were revisited to ascertain whether similar concepts had been overlooked. Data were then coded using the software package NVIVO-8, providing a structure for reporting of findings. Particular attention was paid to comparing the findings of responders and non-responders and between the four groups. Preliminary findings informed subsequent interviews to allow validation of emerging themes.\textsuperscript{26}

**Results**

Ninety-one people were interviewed (Table 1), 48 who had taken part in the E-ECHOES study (the responders) and 41 who had declined (the non-responders).

There were no discernable differences in the two groups’ responses in terms of basic understanding of or attitude towards research. Table 2 shows the five main themes and subcategories that emerged from the analysis. There were no differences in themes emerging between the four ethnic groups.

These themes discussed below are using direct quotes that reflect the subcategories occurring within each theme. We have used these quotes not only to illustrate the emerging themes but also to provide a voice for participants to speak for themselves. Further, this provides higher impact and demonstrates the value of what they said—sometimes reflecting their own opinion and at other times the collective opinion.\textsuperscript{27}

**Main barriers to participation**

*Understanding of research.* The main barrier was a lack of understanding of the nature and purpose of research. Most people who had participated in the screening study\textsuperscript{18} had seen this as a health check. Many said they had been told it was research but had not understood what this meant.

Ascertaining what participants understood was further complicated by difficulties in translation. Interpreters felt there was not a suitable translation for the word ‘research’ and when discussing understanding and experience, they used the English word. When participants had little or no understanding, a basic explanation of research and its purpose was given. Some participants then said they were familiar with the concept but had not known that this was called research, but most said the idea was new to them.

I’m not understanding what research is...

Bangladeshi female (75–84), non-responder

If I don’t understand what the thing is I would not take part in it, that’s for certain.

African Caribbean male (45–54), responder
Participants who did have some understanding of research were often still unsure about what participation might involve and who might benefit; participants themselves or society more generally. Very few knew how research informs health care. Additionally most participants demonstrated a lack of confidence about any knowledge they did have. Where participants had a limited understanding of research this could lead to misperceptions that acted as barriers to participation. Some thought, for example, that all research was laboratory based, involved testing new drugs, harmed, or treated participants as guinea pigs or that the main beneficiaries were pharmaceutical companies. Such perceptions were often linked to media stories.

Well research I think, if they bring new drugs out they want to try it out, they want to take a guinea pig.

**African Caribbean male (65–74), non-responder**

When asked what the public in general would think about research, participants felt that the public in general would not know about research or understand its importance. There would be no motivation to take part in something they did not fully understand and, in particular, they would not understand how their participation could benefit others.

**Negative previous experiences.** Some participants had experiences of research more generally, such as market research or local authority evaluations, where they had seen no resultant changes and felt their participation had been tokenistic. Some non-responders described negative experiences within the health care system, which deterred them from anything to do with doctors or health services.

Before the election they did some research about the bins, what do you need to be happening in your street and you tell them you don’t need plastic bags you need the proper bins because of the mice and the cats, they don’t take any notice, they just still have the plastic bags out there! and sometimes you think oh why did I bother.

**African Caribbean female (65–74), responder**

**Language barrier.** In addition to the practical barrier, many felt that those speaking little or no English might feel uncomfortable or intimidated, even with an interpreter present, and so be less willing to participate.

... they [potential participants from BMEGs] are interested but most of these people can’t speak English. I know you’ve got an interpreter but some people might come up and turn up with the interpreter there. But some people will say what am I going to say? I can’t speak and won’t participate.

**Pakistani male (55–64), non-responder**

**Lack of confidence.** Participants said they and others may feel uncomfortable if they do not have anything worth saying. This was related particularly to non-working women or older people who had never been to school and sometimes to language barriers/literacy.

... because of your background people can feel intimidated or not quite willing to come forward to do it...especially people who don’t speak English properly and as I said people who can’t read properly, they’re probably a little bit more intimidated.

**African Caribbean female (65–74), responder**

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**Table 2: Main themes emerging from both responders and non-responders**

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Fear or worry. For some, fear of doctors or hospitals generally could act as a barrier to participation. Others expressed fear of the unknown or about not knowing what procedures (e.g. a scan) would actually involve. In the case of the E-ECHOES study participants were afraid that a serious illness may be found.

I think the perception of people getting scared is that someone’s going to put something in your body, drugs or something that’s why people get scared of coming.

Indian Male (65–74), responder

Main facilitators and motivations for participation
Availability of appropriate language. Availability of the appropriate language was seen as the most important facilitator to participation, both for recruitment and during the research. Having someone who spoke the participant’s first language present during the research also gave participants confidence; however, most people were not concerned whether this was the researcher or an interpreter.

...you’re speaking to me in my own language so I have a little bit of confidence...you’re speaking to me in my own language so I trust you.

Pakistani female (65–74), responder

Research taking place in a health center. Participants expressed confidence in something that was linked to the doctor and felt that the researcher must be trustworthy for the doctors to have allowed them to be at the practice.

I’ll come because you’re working with the doctor. That’s the main reason of me coming. If you were to do it apart from the doctor, I wouldn’t come. Because you are with the doctor so I believe it may be of benefit for me or future for others.

Indian female (65–74), responder

Seeing self as different in some way. A common perception was that people in general were not likely to participate in research and those who did were different in some way. This could be related to their experiences and knowledge (e.g. their job, position in the community or church) but more often related to their attitudes. Participants saw themselves as less selfish and less anxious and more interested in health and in finding out about new things in general.

Cause I understand research... if I said to my dad she’s a researcher, my dad understands research as a laboratory sort of thing.

Indian male (45–54), non responder

Attitude towards the National Health Service. Many participants were very positive about the National Health Service. They felt because it is a free service people should support it in any way they can and saw taking part in this research project as doing that.

I’m happy with the service, with the GPs...so if there’s anything like this that we feel can help we will always be prepared to help.

Indian male (85+), responder

Factors that could act as barriers or facilitators to participation
Age. When asked about age, participants felt that older people were often considered less likely to participate due to not understanding about research and feeling it is a greater imposition on their personal lives. Some linked this to immigration patterns suggesting being born outside the UK was more of a factor than age. Conversely some people said they had participated because they had reached an age when health care becomes more relevant.

...older people tend not to come into research than younger people... they’re scared because they’re going to take the blood and what are they going to do with my blood.

Pakistani female (45–54), non-responder

Younger people will probably say they haven’t got the time... older people I think, for them, they may see the benefits of it...

Indian female (45–54), non-responder

Reward. There was a mixed response to the idea of participants being offered a financial reward (such as a shopping voucher) for participation. However, while there was little suggestion that a lack of incentive would stop people participating some participants were upset at the idea that people could be ‘paid’ for such things. Most participants saw health checks as more beneficial than financial reward, and several suggested that lifestyle advice would also be an incentive to participate in research.

...it must not be a bribe because it’s not acceptable within the faith.

Pakistani female (55–64), responder

If people are getting an incentive out of it, oh yeah, they’ll come along whether they answer the questions yes or no they’ll show up!

African Caribbean female (65–74), responder
Willingness to participate
Most participants initially said that they had chosen to participate in this study, and where appropriate in the E-ECHOES study, for personal benefit or interest. Such benefits included receiving a health check and increasing their own understanding of health-related issues or heart disease. Some related this to their own health problems and others to a general curiosity. Few had altruistic motivations; when they did, these were sometimes related to helping or representing their specific ethnic group.

Once participants had some understanding of research, almost all were happy to participate even when there were no tangible benefits for them. The most common reason given was primarily to help others and to increase knowledge for the future, even when there were no tangible benefits for them. Many, however, felt that there were benefits for themselves in taking part in the interview, as this was a new experience where they were both learning and having a chance to share their opinions. Once participants gained a better understanding of research, there was a strong view that people ‘should’ participate and some offered to encourage friends and family to participate.

I’m happy about coming down because I’ve had a chance to talk and I’ve learnt some things, and then also what you’re doing, is basically beneficial for everybody else, so it’s a good thing.

African Caribbean male (45–54), non-responder

Increasing participation
Recruitment process: Overall there was a preference for recruitment by letter rather than telephone but nearly as many people said either was acceptable. Some participants suggested that talking face-to-face with potential participants was ideal so they would know exactly who they were dealing with. Participants suggested that the best recruitment strategy was to go to religious and community organisations and talk directly to people about the research. Some suggested that involving religious and community leaders in research recruitment would enable reaching many people easily and increase the likelihood of participation because people place importance in what religious leaders say. Several participants said that now that they had experienced the study themselves they could invite family or friends to participate or speak positively of the experience if anyone they knew independently said that they had been invited to take part.

Participants felt that recruitment should be undertaken using simple language and that the benefits to the participant and wider society should be made clear, particularly ‘how’ the research will benefit others and how important it is. Potential participants should also be given more detail of what will actually happen, how long it would take and whether they are being asked to attend only once or whether this will lead to further requests.

I think the best thing to do is to approach these organisations, there are a lot of Asian organisations who may be able to help, they can hold a session, like on the Eid we usually have a get together so that’s a good opportunity, cause there’s a lot

Indian male (45–54), non-responder

Experience of poor health. People who had experienced serious ill health themselves or in their family were seen as more likely to participate, often because they would have a greater understanding of the need for health research. However, those currently receiving a lot of medical attention felt that they did not want to be further involved with anything medical.

I don’t know if I would really, I have to go on dialysis three times week you know and they take tests like what I just showed you, every month... and the doctor come once a month as well at the clinic, do the checking up, so I think that’s enough anyway.

African Caribbean male (75–84), non-responder

People might benefit directly from me... I’m not interested in me, I’m interested with a whole lot of people, benefiting from this project.

Bangladeshi male (45–54), non-responder

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of people there… you don’t need to make it too long otherwise it becomes boring, just a short, 10 minutes.

Pakistani male (55–64), responder

... you’re looking at ethnic minorities... first port of call would be the central point the point where a lot of people would go to, so take for example mosques, churches community centres, interacting with people who have an active role within the community because they can influence it and they can bring things up, in areas you couldn’t.

African Caribbean male (45–54), non-responder

Basically the thing is, yes I would like to have a scan in the surgery, but could you explain the procedures to me?

Bangladeshi female (65–74), non-responder

Collecting data in different ways. Many female participants, especially of Pakistani and Bangladeshi origin, said they had no formal education, had never worked and lived a very home-based life. Some of them articulated a lack of confidence in being able to give the value of their opinions and they may not have been used to doing so. Interviews are likely to be very difficult for such people and thus are not the most useful way of obtaining information.

I stay at home; I don’t go out, what would I know about research?

Pakistani female (55–64), responder

This was substantiated by interpreters who felt we would have got more information from a focus group and a more informal arrangement, with food and drinks available.

Some people were not happy to commit themselves in advance to an appointment time and indeed participants often came very early or very late. An open surgery-type arrangement may work better, although this would clearly introduce other practical issues.

Discussion

We have shown in this novel study that South Asian and Black African-Caribbean people were willing to participate in research. They wanted to know more about research, what it entails and how they and others would benefit from their participation. The major barrier for them was not understanding research and what they were being asked to do and why. There is no reason to assume that this would be related to these ethnic groups or cardiovascular disease only, as there is confusion among the general population about what research entails. Some aspects however may be related to specific ethnic groups for example because they are more isolated by language from any basic information about research such as television news reports about major research discoveries. Participants suggested issues with regard to confidence for lack of participation, and fear or worry about participating may also be exacerbated by language barriers. There are also differences between the study population and those who have grown up in the UK, as within the age group included (45–82 years), the latter are likely to have been educated until at least 14 or 16 years of age. This may impact on their lives and abilities in many ways and may for example make them feel more confident about participating in research.

In terms of motivation to participate Shah et al. found that Indian participants were reassured by research connected to authority, particularly government. Similarly we found South Asian groups were reassured by links to doctors. A positive attitude towards the National Health Service may also be more likely in groups that have not always lived in the UK, who have something to compare with it.

Sheikh et al. found that researchers saw many challenges in recruiting BMEGs and several researchers saw this as a ‘major hassle’. Others however thought that logistical barriers were not insurmountable and that BMEGs do participate if appropriately approached. It is also important to increase awareness of the research project within the community generally as well as the target population.

Hussain-Gambles et al. investigated reasons for non-participation in clinical trials among South Asians only, including motivation and deterrents. Professional views included lack of time, resources and inadequate support. Similarly, Sheikh highlighted a number of strategies in recruiting minority groups to research but they focussed on researchers’ and community leaders’ views only. We have actively sought views of participants and non-participants to a large community-based study.

It has also been suggested that racial/ethnic minority groups, at least in the USA, are as willing as non-minority individuals to participate in health research but that they are underrepresented among the invited participants.

Strengths and limitations

A key strength of this study is that it obtained views of responders and non-responders from one large heart failure community screening study. As far as we are aware this has not been reported before. Further,
previous studies have focussed on one particular ethnic group, whereas we included two of the largest UK minority ethnic groups. We also undertook individual face-to-face interviews while others have utilised focus groups with patients or lay people or have interviewed researchers only. Using direct quotes, views articulated sometimes from people’s own perspective and other times from a collective perspective, has enriched the depth of understanding of why individuals and groups participate in research.

Seen as a strength and as a limitation is the use of interpreters as they increased our understanding of participants’ role in research. However, the three interpreters were language- and not sex-concordant with the participants. Furthermore having several interpreters can result in slightly different interpretations that could influence both data dependability and credibility.

Conclusion

In conclusion, South Asian and Black African-Caribbean minority groups are willing to participate in health research if appropriately approached with a clear explanation of what this entails and if asked by researchers and clinicians.

Further, there is a need for legislation such as in the US National Institutes of Health Revitalization Act of 1993, which would promote representation of ethnic minority groups. In addition funders and ethics committees should encourage researchers to address this issue.

Acknowledgements

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Declaration

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Ethical approval: Birmingham East North & Solihull Research Ethics Committee (10/H1206/8). All participants gave informed consent.

Conflict of interest: none.

References


Appendix 1: Topics covered in semi-structured interviews

Knowledge/beliefs about cardiovascular disease

What types of heart problems can people have
Are some people more likely to have problems than others
What is responsible for keeping peoples hearts healthy/making them unhealthy
Where does this information come from
How can we keep our hearts healthy and try to prevent disease
Do you get information about healthy lifestyle, preventing illness. Where? what? What do you think of it?

Research

What is research
What is it for
Who does it
What might it involve for the people taking part
Who might benefit from it and how
What is good/bad about it
Any experience of research
What research is most important (e.g. finding cures, particular illness etc)
Why might someone/you choose to take part or not to take part

E-echoes

Reasons for taking part/ not taking part in e-echoes
Own decision or made with others—who?
Quick decision or think about for a while
Would it have been different if it had been about something else (different illness or not health)

Any worries about taking part
How did they feel afterwards about taking part
What were the benefits for them personally and also what are the benefits for wider society

This research

Impact of invitation to take part—e.g. between agreeing and attending did they think or worry about it or talk to family/friends about it
Discuss these in relation to any other research they have taken part in

Participation in research

Aspects of research they would be happy/ unhappy to take part in (e.g. interviews/questionnaires/ health checks, being examined, having blood taken, having to undress, blood pressure, ECG, echocardiogram)
Views regarding particular people who may be more or less likely to take part
Any reasons why their particular ethnic/gender/ age group may choose to take part or not to take part

What would make you/people more likely to take part?

Qualities of researcher (personal and job related)
Place (GP, hospital, own home)
Time (how long it takes, when, time of day)
Advance information—the way we ask, who asks
What should information include
Should personal benefits/incentives be offered
Would health benefits to self influence decision
Ideas they might have—if organizing some research like the E-ECHOES study, which they felt to be important for people to take part in—about how they might present it to people in their community
For non-responders do they feel any differently about research after this interview