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WHAT IS RESEARCH? VIEWS OF MINORITY GROUPS

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Background and Objectives Black and minority ethnic groups are often excluded from research, and the reasons for this are complex. E-ECHOES (Ethnic-echocardiographic heart of England screening) was a large community based heart failure study among South Asian and Black African and Black Caribbean communities. The research study reported here followed on from E-ECHOES, and aimed to explore why minority ethnic groups are under-represented in cardiovascular research, and how their participation can be increased.

Methodology and Participants Ninety-one semi-structured interviews were undertaken with people who either had (n=48) or had not (n=43) responded to the invitation to take part in the E-ECHOES study. These were split across four ethnic groups (African Caribbean, Bangladeshi, Indian and Pakistani) and between men and women. Participants were recruited from the original E-ECHOES study lists. They were interviewed once, face-to-face, either in English, or with an interpreter if they wished. Interview transcripts were analysed using constant comparative analysis.

Findings By far the main reason for participating in the E-ECHOES study was for a health or heart check. Many participants had either not understood that it was research, or said they did not really know what this meant. Most people who did not participate did not remember receiving the invitation or said they had been unavailable at the time. Almost all of this group expressed a willingness to participate in a similar project if given the chance. Few participants, including those who had and those who had not participated in E-ECHOES, 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. They suggested that the main reason other people did not take part in research was because they did not understand it, but also felt they could be lazy or selfish or simply too busy.

Conclusion Findings suggest that if people in the groups included in the study understand more about research, most wish to participate for a number of reasons, including helping to advance knowledge and helping other people. However a lack of understanding of what research is presents a major barrier to initial participation. Thus to encourage people in black and minority

ethnic groups to participate in research it is necessary to increase awareness of research and its purposes more generally.