TRIAL FORGE

STRIDE

SupporTing Recruitment & retention Improvements for Diverse Ethnicities

Design considerations for including diverse ethnic groups in cardiovascular disease trials

This document summarises findings from the INCLUDE Ethnicity Frameworks completed for the STRIDE project. The identified challenges have been organised into the five main Office for National Statistics ethnicity categories: White, Mixed/Multiple ethnic groups, Asian/Asian British, Black/African/Caribbean/Black British, and Other ethnic groups. The intention is to support trial teams working in cancer, cardiovascular diseases, diabetes, maternal and infant health, mental health, smoking cessation, COVID, surgery, and dental health. By consulting these summaries, teams can quickly see the key challenges they may need to consider when designing inclusive trials and enabling participation from people across diverse ethnic backgrounds. Where a challenge is relevant to more than one ethnic group, it appears under each applicable heading. The challenges span factors such as cultural beliefs, practical concerns, and aspects of trial design.

Mixed/Multiple ethnic groups

REACH-HF (cardiovascular; cardiac rehab)	
Trial registration document	
INCLUDE Framework	
Challenges	
Reported across several ethnic backgrounds	• CVD risk scores used in the UK do not work well for ethnic minority individuals. QRISK2 under-predicted risk in South Asian and European men and women, while Framingham under-predicted risk in South Asian women and over-predicted in African Caribbeans (Tillin et al., 2013). • Generally, trials are known to lack diversity – much of this may be down to lack of trust in the medical and research systems due to historical abuse and exploitation of Black and minority ethnic populations. • Language and cultural differences are barriers that impact all minority groups – with people from non-White-European populations seeking healthcare at later stages of their disease than their White counterparts. • Language and literacy factors are also known factors that impact on overall health literacy. Study participants have reported that both the spoken and written health information provided were sometimes meaningless, even when translated into their own language (Claydon et al., 2023). • Black and ethnic minority populations are known to distrust the medical and research systems due to historical abuse and exploitation and may remain unconvinced that research participation is something for them. • In general, those tasked with screening and recruitment will need cultural competence training to ensure that people from ethnic groups different to their own are approached, and that both recruiter and potential recruit feel comfortable about the discussion. Depending on the language requirements of target ethnic groups, this may require interpretation and/or translation. • It is plausible that people from different ethnic groups may have different perspectives on health professionals coming to their homes to deliver care, and whether this is an acceptable form of health care (Abdu et al., 2015). • Getting to the hospital might be an issue for people from poor socioeconomic background (e.g., poor transport links, timing, length, financial reasons) which often includes ethnic minority groups. • Community radio can be a useful tool for some ethnic groups (e.g. Sikhs), as can social media.

Asian/Asian British

REACH-HF (cardiovascular; cardiac rehab)	
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Challenges	
Reported across several ethnic backgrounds	• CVD risk scores used in the UK do not work well for ethnic minority individuals. QRISK2 under-predicted risk in South Asian and European men and women, while Framingham under-predicted risk in South Asian women and over-predicted in African Caribbeans (Tillin et al., 2013). • Generally, trials are known to lack diversity – much of this may be down to lack of trust in the medical and research systems due to historical abuse and exploitation of Black and minority ethnic populations. • Language and cultural differences are barriers that impact all minority groups – with people from non-White-European populations seeking healthcare at later stages of their disease than their White counterparts. • Language and literacy factors are also known factors that impact on overall health literacy. Study participants have reported that both the spoken and written health information provided were sometimes meaningless, even when translated into their own language (Claydon et al., 2023). • Black and ethnic minority populations are known to distrust the medical and research systems due to historical abuse and exploitation and may remain unconvinced that research participation is something for them. • In general, those tasked with screening and recruitment will need cultural competence training to ensure that people from ethnic groups different to their own are approached, and that both recruiter and potential recruit feel comfortable about the discussion. Depending on the language requirements of target ethnic groups, this may require interpretation and/or translation. • It is plausible that people from different ethnic groups may have different perspectives on health professionals coming to their homes to deliver care, and whether this is an acceptable form of health care (Abdu et al., 2015). • Getting to the hospital might be an issue for people from poor socioeconomic background (e.g., poor transport links, timing, length, financial reasons) which often includes ethnic minority groups. • Community radio can be a useful tool for some ethnic groups (e.g. Sikhs), as can social media.
Only reported in Asian/Asian British participants	• South Asians living in the UK have a high rate of CVD compared to the majority population. Women of South Asian origin do not seem as protected from CVD as women in the general population. Young men of South Asian origin experience a high relative risk, at a younger age (British Heart Foundation, 2021). • Mortality from CHD is significantly worse for South Asians than White individuals (Commission on Race and Ethnic Disparities, 2021). • South Asians may think heart attacks and heart disease cannot be prevented. Fatalism has been mentioned as a commonly held belief among South Asians (Kandula et al., 2017; Lord et al., 2013). • South Asians are often excluded from research due to perceived cultural and communication difficulties (Khunti et al., 2009). • Many South Asian people are unwilling to participate because they accept their illness as an unalterable punishment from God or have a fear of what research entails (Choudhury et al., 2008). • Health promotion activities tend to be based on assumptions of individualism and self-investment, which may need to be re-thought for South Asian groups in particular where community is often more important.

	• Material targeting the individual is a strategy that works from a White ethnic group perspective but may be less effective in South Asians (who tend to have more of a sense of community, so appeals to community may be useful). • Cultural barriers for South Asians, especially among older generations, include a preference for traditional remedies and linguistic issues (Goff, 2019). • South Asian women, particularly older women make decisions about their healthcare in consultation with members of their community and family. Involvement of family members in the consent process should therefore be considered, including for other genders (Grewal et al., 2005).

Black/African/Caribbean/Black British

REACH-HF (cardiovascular; cardiac rehab)	
Trial registration document	
INCLUDE Framework	
Challenges	
Reported across several ethnic backgrounds	• CVD risk scores used in the UK do not work well for ethnic minority individuals. QRISK2 under-predicted risk in South Asian and European men and women, while Framingham under-predicted risk in South Asian women and over-predicted in African Caribbeans (Tillin et al., 2013). • Generally, trials are known to lack diversity – much of this may be down to lack of trust in the medical and research systems due to historical abuse and exploitation of Black and minority ethnic populations. • Language and cultural differences are barriers that impact all minority groups – with people from non-White-European populations seeking healthcare at later stages of their disease than their White counterparts. • Language and literacy factors are also known factors that impact on overall health literacy. Study participants have reported that both the spoken and written health information provided were sometimes meaningless, even when translated into their own language (Claydon et al., 2023). • Black and ethnic minority populations are known to distrust the medical and research systems due to historical abuse and exploitation and may remain unconvinced that research participation is something for them. • In general, those tasked with screening and recruitment will need cultural competence training to ensure that people from ethnic groups different to their own are approached, and that both recruiter and potential recruit feel comfortable about the discussion. Depending on the language requirements of target ethnic groups, this may require interpretation and/or translation. • It is plausible that people from different ethnic groups may have different perspectives on health professionals coming to their homes to deliver care, and whether this is an acceptable form of health care (Abdu et al., 2015). • Getting to the hospital might be an issue for people from poor socioeconomic background (e.g., poor transport links, timing, length, financial reasons) which often includes ethnic minority groups. • Community radio can be a useful tool for some ethnic groups (e.g. Sikhs), as can social media.
Only reported in Black/ African/ Caribbean/ Black British participants	• Black groups in the UK have a significantly lower risk of heart disease compared to the majority of the population, despite having a high prevalence of hypertension and diabetes. Lower cholesterol levels may protect them against heart disease (Raleigh & Holmes, 2021). • Black groups have lower than expected rates of access to and use of cardiovascular care (Raleigh & Holmes, 2021). • Material targeting the individual is a strategy that works from a White ethnic group perspective but may be less effective Black individuals, where appeals to family may be more useful.

Other ethnic groups

REACH-HF (cardiovascular; cardiac rehab)	
Trial registration document	
INCLUDE Framework	
Challenges	
Reported across several ethnic backgrounds	• CVD risk scores used in the UK do not work well for ethnic minority individuals. QRISK2 under-predicted risk in South Asian and European men and women, while Framingham under-predicted risk in South Asian women and over-predicted in African Caribbeans (Tillin et al., 2013). • Generally, trials are known to lack diversity – much of this may be down to lack of trust in the medical and research systems due to historical abuse and exploitation of Black and minority ethnic populations. • Language and cultural differences are barriers that impact all minority groups – with people from non-White-European populations seeking healthcare at later stages of their disease than their White counterparts. • Language and literacy factors are also known factors that impact on overall health literacy. Study participants have reported that both the spoken and written health information provided were sometimes meaningless, even when translated into their own language (Claydon et al., 2023). • Black and ethnic minority populations are known to distrust the medical and research systems due to historical abuse and exploitation and may remain unconvinced that research participation is something for them. • In general, those tasked with screening and recruitment will need cultural competence training to ensure that people from ethnic groups different to their own are approached, and that both recruiter and potential recruit feel comfortable about the discussion. Depending on the language requirements of target ethnic groups, this may require interpretation and/or translation. • It is plausible that people from different ethnic groups may have different perspectives on health professionals coming to their homes to deliver care, and whether this is an acceptable form of health care (Abdu et al., 2015). • Getting to the hospital might be an issue for people from poor socioeconomic background (e.g., poor transport links, timing, length, financial reasons) which often includes ethnic minority groups. • Community radio can be a useful tool for some ethnic groups (e.g. Sikhs), as can social media.

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