TRIAL FORGE

STRIDE
SupporTing Recruitment & retention
Improvements for Diverse Ethnicities

Design considerations for including diverse ethnic groups in cancer 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

PROSPER (breast cancer)	
Trial registration document	
INCLUDE Framework	
Challenges	
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ProtecT (prostate cancer)	
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Challenges	
Reported across several ethnic backgrounds	• 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. • Men from ethnic minority backgrounds often do not feel comfortable speaking with healthcare providers from different racial or ethnic groups (Blocker et al., 2006; Bustillo et al., 2015). • Getting to hospital can be an issue for a variety of reasons including – poor transport links, the timing and length of research visits, financial reasons. Many of these factors disproportionately impact people from poor socioeconomic backgrounds. People from ethnic minority groups are at higher risk of experiencing socioeconomic disadvantage. • Lack of translation or interpretation may limit participation of people that don't speak or read English well. • Ethnic minority populations are known to be at higher risk of socioeconomic disadvantage, so the trial team should think about contributions to WiFi or mobile data costs.

SCOT (colorectal cancer)	
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• Individuals from a Black, Asian and Minority Ethnic background have higher stigma scores (on the Cancer Stigma Scale) than those from a White background (Vrinten et al., 2019).
• There are a number of themes in relation to to interactions with healthcare services (discrimination, lack of autonomy, language barrier, embarrassment, preference or/use of “traditional medicine”), emotional reactions to cancer (fatalism, God’s will, punishment from god, superstition, cancer is deadly, fear delaying help seeking, fear motivating help seeking, secrecy, avoidance, stigma, taboo) and knowledge and beliefs (low health literacy abut cancer, causes of cancer, cancer treatment and prognosis, and cancer signs and symptoms) in minority ethnic groups (Licqurish et al., 2016).
• Many minority ethnic languages do not have a word for cancer (White, 1997).
• Ethnic minority patients face inequalities such as feeling like they were being forced into a treatment decision and a dismissive attitude towards incorporating alternative forms of medicine as part of their treatment (NHS England, 2021b).
• Getting to hospital can be an issue for a variety of reasons including – poor transport links, the timing and length of research visits, financial reasons. Many of these factors disproportionately impact people from poor socioeconomic backgrounds, which often includes ethnic minority groups.
• Ethnic minority patients report lower satisfaction and less positive experiences of care overall.
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Asian/Asian British

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Only reported in Asian/Asian British participants	• In the South Asian community, there's evidence of stigma associated with a cancer diagnosis, linked to cultural values of 'shyness,' 'modesty,' and 'embarrassment,' which may also impact screening attendance (Anderson de Cuevas, et al., 2018). • South Asians are frequently excluded from research due to perceived cultural and communication challenges (Khunti, Kumar, & Brodie, 2009). • Many South Asians decline participation due to viewing their illness as a divine punishment or fearing the nature of research (Choudhury, et al., Intervention, recruitment and evaluation challenges in the Bangladeshi community: Experience from a peer lead educational course, 2008). • Cultural norms significantly shape health-seeking behaviours. For South Asian groups, where community holds greater importance, health promotion strategies may need to reconsider assumptions of individualism and self-investment (Lucas, Murray, & Kinra, 2013). • Cultural barriers for South Asians, especially among older generations, include a preference for traditional remedies and linguistic issues (Goff, 2019).

ProtecT (prostate cancer)	
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Only reported in Asian/Asian British participants	• Uptake of bowel screening (FOB) is lower among Indian, Pakistani, Bangladeshi and other South Asian men and women (Campbell et al., 2020).

STAR-TREC (rectal cancer)
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Challenges	
Reported across several ethnic backgrounds	• Bowel cancer incidence rates are lower in the Asian and Black ethnic groups and in people of mixed or multiple ethnicity compared to the White ethnic group (Cancer Research UK, 2015). • Symptom awareness for bowel cancer is significantly lower among all non-white ethnic groups (Kerrison et al., 2021). • Individuals from a Black, Asian and Minority Ethnic background have higher stigma scores (on the Cancer Stigma Scale) than those from a White background (Vrinten et al., 2019). • There are a number of themes in relation to to interactions with healthcare services (discrimination, lack of autonomy, language barrier, embarrassment, preference or/use of “traditional medicine”), emotional reactions to cancer (fatalism, God’s will, punishment from god, superstition, cancer is deadly, fear delaying help seeking, fear motivating help seeking, secrecy, avoidance, stigma, taboo) and knowledge and beliefs (low health literacy abut cancer, causes of cancer, cancer treatment and prognosis, and cancer signs and symptoms) in minority ethnic groups (Licqurish et al., 2016). • Many minority ethnic languages do not have a word for cancer (White, 1997). • Ethnic minority patients face inequalities such as feeling like they were being forced into a treatment decision and a dismissive attitude towards incorporating alternative forms of medicine as part of their treatment (NHS England, 2021b). • Getting to hospital can be an issue for a variety of reasons including – poor transport links, the timing and length of research visits, financial reasons. Many of these factors disproportionately impact people from poor socioeconomic backgrounds, which often includes ethnic minority groups. • Ethnic minority patients report lower satisfaction and less positive experiences of care overall. • If written material is a key part of the information provision for the trial this is likely to limit participation of individuals from any ethnic group with low literacy levels. Even with translation, older people from some ethnic groups do not read the language they speak.
Only reported in Asian/Asian British participants	• Uptake of bowel screening (FOB) is lower among Indian, Pakistani, Bangladeshi and other South Asian men and women (Campbell et al., 2020).

Black/African/Caribbean/Black British

PROSPER (breast cancer)	
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Reported across several ethnic backgrounds	• Cultural barriers cause delayed healthcare access for non-white populations, while language and literacy issues impact overall health literacy (Claydon, Campbell-Richards, & Hill, 2013). • Training in cultural competence is essential for those involved in screening and recruitment to ensure comfortable and inclusive discussions with individuals from diverse ethnic backgrounds. • Accessibility challenges to hospitals, such as inadequate transport, inconvenient research visit timing, and financial constraints, particularly affect individuals from low socioeconomic backgrounds, often including ethnic minority groups. • BMI threshold do vary by ethnic groups (South Asians certainly) and the BMI cut-off of 30 may be inappropriate for some ethnic groups. • Translation of trial materials into languages other than English is crucial, especially for ethnic groups, including those for whom English is not their first language.
Only reported in Black/ African/ Caribbean/ Black British participants	• Factors contributing to breast cancer disparities between Black and white women include lower awareness, stigma, fear, time constraints, fear of treatment, mistrust of healthcare professionals, financial burden, and service inaccessibility (Jones C. E., et al., 2014). • Generational differences exist, with second-generation Black women sharing attitudes toward breast cancer more closely with white women than first-generation Black African and Caribbean women (Jones C. E., et al., 2015). • Historical abuse and exploitation have led to distrust among Black and ethnic minority populations towards medical and research systems, making them sceptical about participating in research.

ProtecT (prostate cancer)	
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Reported across several ethnic backgrounds	• 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. • Men from ethnic minority backgrounds often do not feel comfortable speaking with healthcare providers from different racial or ethnic groups (Blocker et al., 2006; Bustillo et al., 2015). • Getting to hospital can be an issue for a variety of reasons including – poor transport links, the timing and length of research visits, financial reasons. Many of these factors disproportionately impact people from poor socioeconomic backgrounds. People from ethnic minority groups are at higher risk of experiencing socioeconomic disadvantage. • Lack of translation or interpretation may limit participation of people that don't speak or read English well. • Ethnic minority populations are known to be at higher risk of socioeconomic disadvantage, so the trial team should think about contributions to WiFi or mobile data costs. • There is significant social stigma around prostate cancer, particularly in men self-identifying as Black and Latino. Dominant themes around prostate cancer diagnosis include the stigma surrounding the condition and the perceived role of an 'unhealthy lifestyle' and certain sexual behaviours as risk factors for prostate cancer development (Vapiwala et al., 2021).
Only reported in Black/ African/ Caribbean/ Black British participants	• Black men are predisposed to prostate cancer due to several genetic mutations, and environmental factors such as diet and socioeconomic disadvantage are also thought to be contribute too (Kheirandish & Chinegwundoh, 2011). • Black men may not participate in prostate cancer studies due to mistrust of researchers, lack of understanding of the research process and mechanisms of prostate cancer and a reliance on herbal medicine. • Black men enrolled in trials presented with more aggressive disease features, but had better treatment and disease-specific outcomes with radiotherapy-based therapy compared with white men. If Black men are aware of this research, they may be less likely to engage with the trial due to wanting to receive radiotherapy, in this case randomisation and risk of being allocated to either active monitoring or surgery is the problem (Ma et al., 2021). • The exclusion criteria of major cardiovascular or respiratory comorbidities have the potential to inadvertently exclude Black men disproportionately due to them having a higher risk of high blood pressure (British Heart Foundation, 2016). • It is not clear how the exclusion criteria, 'an estimated life expectancy of <10 years' will be measured or arrived at, and criteria like this that may be subjective do run the risk of unconscious bias creeping in that may exclude people from ethnic minority backgrounds, particularly with anti-Blackness coming into play. • There is a secrecy around family death due to prostate cancer due to a cultural reticence to discuss medical problems with the family in the Black/African-American culture, particularly if it was a 'personal, sexual type situation' as prostate cancer is perceived (Vapiwala et al., 2021).

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Only reported in Black/ African/ Caribbean/ Black British participants	• Black Afro-Caribbean background individuals were diagnosed at a younger age and were more likely to present with Stage IV tumours (Askari et al., 2017).

STAR-TREC (rectal cancer)	
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Reported across several ethnic backgrounds	• Bowel cancer incidence rates are lower in the Asian and Black ethnic groups and in people of mixed or multiple ethnicity compared to the White ethnic group (Cancer Research UK, 2015). • Symptom awareness for bowel cancer is significantly lower among all non-white ethnic groups (Kerrison et al., 2021). • Individuals from a Black, Asian and Minority Ethnic background have higher stigma scores (on the Cancer Stigma Scale) than those from a White background (Vrinten et al., 2019). • There are a number of themes in relation to to interactions with healthcare services (discrimination, lack of autonomy, language barrier, embarrassment, preference or/use of “traditional medicine”), emotional reactions to cancer (fatalism, God’s will, punishment from god, superstition, cancer is deadly, fear delaying help seeking, fear motivating help seeking, secrecy, avoidance, stigma, taboo) and knowledge and beliefs (low health literacy abut cancer, causes of cancer, cancer treatment and prognosis, and cancer signs and symptoms) in minority ethnic groups (Licqurish et al., 2016). • Many minority ethnic languages do not have a word for cancer (White, 1997). • Ethnic minority patients face inequalities such as feeling like they were being forced into a treatment decision and a dismissive attitude towards incorporating alternative forms of medicine as part of their treatment (NHS England, 2021b). • Getting to hospital can be an issue for a variety of reasons including – poor transport links, the timing and length of research visits, financial reasons. Many of these factors disproportionately impact people from poor socioeconomic backgrounds, which often includes ethnic minority groups. • Ethnic minority patients report lower satisfaction and less positive experiences of care overall. • If written material is a key part of the information provision for the trial this is likely to limit participation of individuals from any ethnic group with low literacy levels. Even with translation, older people from some ethnic groups do not read the language they speak.
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Other ethnic groups

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