

BMJ Open Barriers and facilitators to recruitment of South Asians to health research: a scoping review

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ABSTRACT

Objectives People of South Asian ethnicity are under-represented in health research studies. The objectives of this scoping review were to examine the barriers and facilitators to recruitment of South Asians to health research studies and to describe strategies for improving recruitment.

Design Scoping review

Methods Using the Arksey and O'Malley framework for scoping reviews, we comprehensively searched electronic databases (MEDLINE via PubMed, Cochrane Library, CINAHL and PsycINFO). Studies that identified barriers and facilitators to recruitment, or recruitment strategies for South Asian populations were included. Recruitment barriers, facilitators and strategies were grouped thematically and summarised narratively.

Synthesis Of 1846 potentially relevant articles, 15 met the inclusion criteria and were included in the thematic synthesis. Multiple facilitators and barriers to enrolment of South Asians in health research studies were identified; these most commonly related to logistical challenges, language and cultural barriers, concerns about adverse consequences of participating and mistrust of research. Several actionable strategies were discussed, the most common being engagement of South Asian communities, demonstration of cultural competency, provision of incentives and benefits, language sensitivity through the use of translators and translated materials and the development of trust and personal relationships.

Conclusion There is a growing awareness of the barriers and facilitators to recruitment of South Asian participants to health research studies. Knowledge of effective recruitment strategies and implementation during the grant funding stages may reduce the risk of poor recruitment and representation of South Asians.

INTRODUCTION

South Asians are the largest ethnic minority in Canada and the UK.^{1,2} South Asian populations have demonstrated historical and projected growth in these regions. The total South Asian population in Canada is currently estimated at 1.6 million individuals; a quarter of the visible minority population (ie, 'persons who are non-Caucasian in race or non-white in colour and who do not report being Aboriginal')³ and 4.8% of the total Canadian population. It is projected to

Strengths and limitations of this study

- First scoping review to summarise evidence regarding factors that influence the involvement of South Asian participants in health research
- Comprehensive overview of the volume and characteristics of research published on this topic
- Actionable recruitment strategies and topics for further investigation clearly identified
- Published evidence only available from a few countries and primarily in the clinical trial setting with small sample sizes and variable patient populations, so transferability to other contexts may be limited.

reach 3.2–4.1 million individuals by 2031.⁴ Two-thirds of South Asians in Canada identify as East Indian with smaller proportions identifying as Pakistani, Sri Lankan and Punjabi.¹ In the UK, the South Asian ethnic group had some of the largest population increases over the 2001–2011 time period (ie, 0.4 million each in the Pakistani and Indian subgroups).²

South Asian populations face specific health challenges. An analysis of Canadian Community Health Survey data (2001–2013) concluded that South Asians are more likely to report poor self-rated health than Whites.⁵ A higher proportion of South Asians suffer from health conditions, including type 2 diabetes, cardiovascular disease and asthma than people of European ethnicity,^{6–10} and the rates of non-communicable disease are expected to rise.¹¹ South Asians are reported to develop non-communicable diseases at younger ages, despite fewer risk factors (eg, at lower body mass index), than other ethnic groups.^{6,12,13} Mental health is also an emerging area of concern, particularly in immigrant women, in whom a higher risk of postpartum depression has been reported.^{14,15}

In the context of healthcare access, low socioeconomic status,¹⁶ racial and cultural discrimination,^{17,18} geography (eg, distance from healthcare centre, lack of access to

transportation),¹⁹ language barriers²⁰ and traditional hierarchies within families²¹ have been reported to obstruct optimal healthcare of South Asians, and in particular South Asian women.²¹ Frequently, South Asians maintain traditional religious, dietary and healthcare practices, which may not align with modern Western or allopathic medicine²² and clinical research approaches.^{23 24} Lack of support from families and communities in seeking healthcare and making healthcare decisions may discourage South Asians from engaging in risk-reducing health behaviours, including participation in research.²⁵ Lack of English language proficiency, unfamiliarity with local services and lack of attention to cultural factors by healthcare providers may pose a particular challenge to healthcare service access for female South Asians.¹⁵

Adequate ethnic minority representation in health research is important to support generalisability of research findings and to enable tailored healthcare for ethnic minorities.^{26 27} However, South Asians are under-represented in research, resulting in healthcare practice based on research with limited external validity for the South Asian context.^{28 29} In general, there is a lack of representative population health research comparing minority groups in Canada with European counterparts.²⁸ This under-representation also occurs elsewhere; a UK-based analysis reported that while South Asians make up 4.5% of the total population, they represented on average only 0.6% of participants in six multicentre randomised controlled trials.^{2 30} Another review noted that trials assessing cardiovascular outcomes in patients with type 2 diabetes had under-representation of the South Asian population compared with the population proportion in the UK, but over-representation in the USA.³¹ Even studies with sufficient numbers of South Asians may not be truly representative of the heterogeneous subgroups that comprise the broader South Asian population. Diets, lifestyles and baseline health risk are noted to vary across South Asian subgroups based on differences in origin, culture and religion.³²

To better understand the current knowledge and perspectives on this topic, a scoping review of the evidence regarding barriers and facilitators to recruitment and strategies that have been employed or evaluated to improve representation of South Asians was undertaken. A preliminary search of the literature did not yield sufficient reports on the Canadian population, thus the review was expanded to include literature regarding South Asian populations residing in other countries.

METHODS

A scoping review was undertaken according to the methods outlined by Arksey and O'Malley and Levac *et al.*^{33 34} The Arksey and O'Malley approach involves the identification of a research question; a search for relevant studies; selection of studies; charting the data; collating, summarising and reporting the results and an optional consultation with stakeholders to inform or validate the

findings.³³ We followed this approach with the exception of the consultation stage, due to limited resources, and employed several suggestions made by Levac *et al.*, including a focused research question, the conduct of thematic synthesis, duplicate study selection and standardised and duplicate extraction.³⁴ This methodology was justified given that there is limited knowledge on this topic, and the interest in assessing the depth and breadth of the evidence base. The aim was to identify barriers and facilitators to recruitment of South Asians to health research studies and associated strategies to improve participation. The following specific research questions were addressed:

1. What are the barriers and facilitators to recruitment of South Asian individuals to health research studies?
2. What are the evidence-based strategies for recruitment of South Asian individuals to health research studies?

DATA SOURCES AND SEARCH

The search strategy was developed and executed by one reviewer (TAWQ). A comprehensive search was conducted using PubMed, the Cochrane Library, CINAHL and PsycINFO. Medical subject headings and keywords including South Asian, minority groups, patient selection, recruitment, enrolment, recruitment strategies and specific South Asian ethnicities were searched from January 2004 through October 2014, and updated in April 2016 (table 1). Search terms are presented in table 1. The full search string is presented in online supplementary appendix 1.

The search dates were restricted in the interest of identifying the most up-to-date evidence on the topic. The search was supplemented by scanning reference lists of

Table 1 Scoping review search terms

| A. Ethnicity-related search terms | B. Strategy-related search terms |
|-----------------------------------|----------------------------------|
| South Asian or South Asia | Patient selection ([MeSH term]) |
| Minority groups ([MeSH term]) | Recruitment |
| Minority health ([MeSH term]) | Enrolment |
| Sri Lankan or Sri Lanka | Recruitment strategies |
| Bangladeshi or Bangladesh | OR any of the above |
| Pakistani or Pakistan | |
| Nepalese or Nepal | |
| Bhutanese or Bhutan | |
| Maldivian or Maldives | |
| Indian or India | |
| OR any of the above | |
| A and B | |

MeSH, medical subject heading.

included studies, searching <https://clinicaltrials.gov/> and PROSPERO for ongoing work and by a focused internet search. Study selection was limited to English language articles or articles that could be translated using Google Translate. Due to the noted limitations of this approach,³⁵ translations were to be verified by research staff familiar with the language of publication if possible. Study staff were proficient in German, French, Spanish, Mandarin, Cantonese and several South Asian languages. No restriction was made by publication type. The results from all searches were pooled and deduplicated prior to screening.

Study selection

All types of studies including primary randomised and non-randomised quantitative studies, qualitative studies, and systematic reviews were included. Commentaries and narrative reviews were excluded to avoid identifying themes from single or few perspectives. We included studies involving South Asian individuals (eg, Sri Lankan, Bangladeshi, Pakistani, Nepalese, Bhutanese, Maldivian and Indian) in any setting or studies involving multiple ethnic groups where South Asians were a specified subgroup or comprised the majority of participants. Studies assessing or reporting on barriers and facilitators to recruitment and recruitment strategies were included. This includes studies assessing the impact or effectiveness, or assessing the comparative impact or effectiveness of barriers, facilitators and recruitment strategies.

One reviewer (TAWQ) independently screened titles and abstracts against the prespecified eligibility criteria. A second reviewer (LF) then screened selected abstracts. Full-text articles were obtained and reviewed by both authors for studies that appeared to meet the eligibility criteria or where eligibility could not be adequately judged. Disagreement was resolved by discussion among the two reviewers with a third reviewer consulted if deemed necessary. Study authors were not contacted for further information.

Data abstraction

Data abstraction was conducted in duplicate by two authors (TAWQ and LF) using a structured extraction form piloted on two studies. Disagreement was resolved via discussion. Data including (a) study classifiers (lead author, publication year, country), (b) study characteristics (sample size, study design, subject characteristics) and (c) recruitment barriers, facilitators for participation and recruitment strategy data were extracted. Specific descriptions of recruitment barriers, facilitators and strategies were recorded.

Barriers and facilitators, and recruitment strategies were grouped thematically into key topics that emerged on review of the literature. Once established, these themes were presented and discussed narratively. No formal data synthesis or assessment of intervention effectiveness was undertaken. Quality appraisal of selected studies was not conducted as this is not typical of scoping reviews,³³ but

general limitations are discussed. In addition, no formal consultation exercise with stakeholders was conducted.

RESULTS

Literature search

The original search on PubMed and Cochrane (2004–October 2014) identified 1027 potentially relevant publications. A further 10 studies were identified from grey literature sources. The original search was updated in April 2016 and 199 more potentially relevant articles were identified. Also, the databases CINAHL and PsycINFO were added and these searches (2004–April 2016) identified 645 more potentially relevant articles. After removal of duplicates, a total of 1846 records were screened. All of the publications were available in English, so no translation was required. Based on title and abstract, 1648 records were excluded and 198 full-texts were screened (figure 1). Of the 198 studies included for full-text review, 183 were excluded for various reasons (ie, irrelevant outcomes, study of alternate ethnic groups, review or commentary) and 15 articles met the inclusion criteria and were included in this report (n=9 from original PubMed search; n=4 from PubMed search update; n=2 from CINAHL and PsycINFO).

Study characteristics

The final 15 articles included in this review focused on South Asian populations and discussed barriers and facilitators for participation in research and potential strategies for recruitment. Primary study characteristics including research area, study populations, sample size and study design are noted in table 2.

Study populations ranged in size from n=2 to n=1319. The majority of studies were conducted in specific clinical populations. This included patients with mental health issues,^{36 37} nutritional concerns,³⁸ asthma,^{9 29 39 40} diabetes,^{41–43} obesity,⁴² in hospital (ie, tertiary care),⁴⁴ with reproductive health concerns,⁴⁵ who were being recruited for clinical trials^{27 32} and for a study on spousal abuse.⁴⁶ Study designs included prospective cohort studies,⁴⁵ thematic analysis,³⁷ qualitative surveys, interviews and focus groups,^{9 27 29 32 39 40 43 46} literature reviews,^{32 38} quantitative surveys,^{38 42} retrospective descriptive accounts of recruitment experiences,⁴¹ hermeneutic studies⁴⁴ and mixed-methods syntheses.³⁶

Most of the studies employed qualitative or survey-based techniques. As such, most outcome data are sourced from direct interview statements and personal experience. Limited empirical evidence on the effectiveness of the various recruitment strategies discussed was available.^{36 38 42 45} Most of the included studies were conducted in the UK^{9 27 29 32 36–43} and dealt with recruitment of clinical populations to clinical trials.^{9 27 29 32 36 39–43}

Facilitators

Three studies conducted in the UK^{27 29 42} reported on facilitators of participation in research. Subjects perceived participation in research to be a possible route

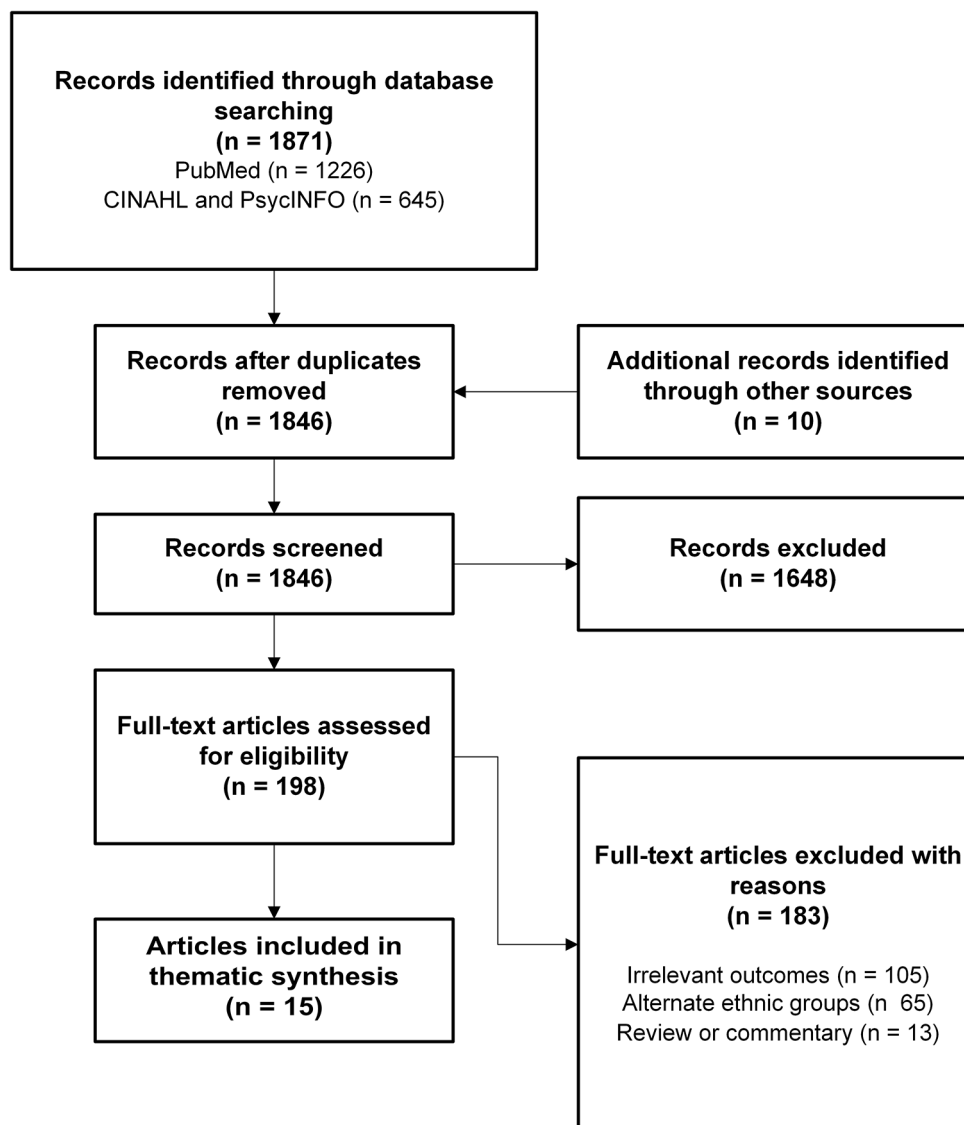


Figure 1 Flow chart of included and excluded studies.

to improved treatment and health.^{27 29} Participants also reported being motivated by the importance of disease prevention and potential to contribute to scientific knowledge,^{27 42} by the potential to help society through participation²⁷ and by a sense of obligation to healthcare providers.²⁷ It was reported that higher social class and education, and younger age influence the level of awareness of clinical trials in South Asians.²⁷

Barriers

Potential barriers to recruitment of South Asians are outlined in table 3. Participant-related factors followed themes of disinterest or lacking a feeling of belonging, conflicts, education or training-related deficits, logistical issues or opportunity cost, and factors related to fear or inhibition. Factors attributed to the researcher or research process followed themes of culture or language-related issues, logistical issues, issues related to study design and lack of awareness.

Treatment or participation-related factors included perception of risk of adverse effects (eg, treatment-related side effects),^{27 29 39 42} fear of finding out health status⁴² or experiencing the stigma of being labelled with a health condition,^{36 39} previous poor experiences,²⁷ mistrust of research,^{27 36 42} inability to participate due to substance abuse or mental health issues³⁶ and fear of being reported to immigration.³⁶ Logistical concerns focused on cost of participating,^{36 41} time away from work, family and other commitments,^{9 27 32 36 37 39 41 42} transportation and location,³⁶ under-representation of South Asians at recruitment sites³⁶ and lack of access to disease-specific services.³⁶ Language-specific or culture-specific barriers included religious or cultural conflicts,^{32 36 37} decisional hierarchies within families,^{27 36 37} lack of understanding about the consent process,³⁶ researcher stereotypes about difficulties engaging with the South Asian population,³⁶ inability to provide staff with language and cultural competency training, inability to translate study

Table 2 Study characteristics.

| First author, year | Country | Research area | Ethnic populations | Sample size | Study design |
|--------------------------------------|-----------|------------------------------|---|--|---|
| Waheed, 2016 ³⁶ | UK | Mental Health (Depression) | South Asians | Five studies (n=292) | Mixed-methods study |
| Brown, 2014 ³⁷ | UK | Mental Health | South Asians | n=10 study participants; n=9 non-participants; n=5 researchers | Qualitative (thematic analysis of research diaries) |
| Garduno-Diaz, 2014 ³⁸ | UK | Diet and Nutrition | South Asians | n=300 adults, n=100 children | Literature review and dietary survey |
| Mac Neill, 2013 ²⁹ | UK | Asthma, Clinical Trials | Multiple ethnic groups (primarily Bangladeshi) | n=42 parents (n=20 Bangladeshi, n=22 other) | Qualitative interviews |
| Douglas, 2011 ⁴¹ | UK | Diabetes | South Asians | n=1319 potential recruits | Descriptive review of recruitment experiences |
| Rooney, 2011 ³⁹ | UK | Asthma | South Asians | n=58 people with asthma | Qualitative focus groups |
| Samsudeen, 2011 ⁴² | UK | Diabetes–Obesity | South Asians | n=22 health professionals, n=27 community workers | Quantitative survey |
| Stirland, 2011 ⁴⁰ | USA/UK | Asthma | South Asians | n=36 researchers | Qualitative interviews |
| Sheikh, 2009 ⁹ | USA/UK | Asthma | South Asians | n=36 researchers (19 UK, 17 USA), n=10 community members | Qualitative interviews |
| Lloyd, 2008 ⁴³ | UK | Diabetes | South Asians (Sylheti and Mirpuri people from Bangladesh) | n=31 participants | Qualitative interviews |
| Mohammadi, 2008 ⁴⁴ | Australia | Hospitalised Patients | Islamic South Asians | n=13 participants enrolled | Interpretive hermeneutic study |
| Krupp, 2007 ⁴⁵ | India | Reproductive Health Research | South Asian women | n=918 enrolled participants | Prospective cohort study |
| Hussain-Gambles, 2006 ³² | UK | Clinical Trials | South Asian health professional and lay persons | n=25 health professionals, n=60 lay persons | Qualitative interviews |
| Hussain-Gambles*, 2004 ²⁷ | UK | Clinical Trials | South Asians | n=25 health professionals, n=60 lay persons, n=15 trial participants | Literature review and qualitative interviews |
| Shelton, 2004 ⁴⁶ | USA | Spousal Abuse | South Asian women (Bangladeshi) | n=2 researchers; number of participants NR | Qualitative survey |

*Some common data between publications. NR, not reported.

materials^{9 32 36 37 39} and traditional gender roles.^{36 37} Some barriers related to general disinterest or lack of awareness,^{9 37 42} including lack of interest due to previous treatment and the perception that participation would not confer any further benefit,^{36 42} misgivings about the scientific importance of the work,^{9 37 42} poor understanding of research intentions,⁹ perception of not belonging to the society standing to benefit from research,^{27 32} simply not being approached to participate²⁷ and researcher apathy towards achieving proper representation of South Asians.^{9 36} Finally, some study-specific issues included a lack of appropriate assessment tools (eg, translated or adapted tools) for South Asian populations,^{36 37} as well as narrow entry criteria (eg, restrictions on age and waist circumference).⁴²

Recruitment strategies

Themes that emerged for recruitment strategies included language and culture-driven methods, communication and engagement strategies, logistical changes and accommodations, policy and study design measures, and compensation and incentives. The most commonly reported strategy was involvement of the South Asian community through mobilisation of key community figures or community partnerships.^{9 27 36 38 41 42 45} The second most commonly reported strategies were incentives and reciprocal benefits^{9 36–40 46} and demonstrated respect and knowledge of South Asian culture, traditions and ethics.^{36–40 44 46} Multiple studies also mentioned the development of trust and personal relationships,^{36 37 39 40 42 46} the use of visual aids and reduced

Table 3 Barriers to recruitment of South Asian populations

First author, year of publication

| Recruitment barrier | Waheed, 2016 ³⁶ | Brown, 2014 ³⁷ | Macneill, 2013 ³⁸ | Douglas, 2011 ⁴¹ | Rooney, 2011 ³⁸ | Samsudeen, 2011 ⁴² | Sheikh, 2009 ⁹ | Lloyd, 2008 ⁴³ | Hussain-Gambles, 2004 ²⁷ | Shelton, 2004 ⁴⁰ | Hussain-Gambles, 2006 ⁴² |
|--|----------------------------|---------------------------|------------------------------|-----------------------------|----------------------------|-------------------------------|---------------------------|---------------------------|-------------------------------------|-----------------------------|-------------------------------------|
| PARTICIPANT RELATED | | | | | | | | | | | |
| Disinterest or lack of feeling of belonging | | | | | | | | | | | |
| Immigrant perceptions of not belonging ³⁷ to society meant to benefit from research | | | | | | | | X | X | | X |
| Lack of interest, misgivings about scientific importance or benefit | X | | | | | X | X | | | | |
| Prior treatment for disease (trial participation perceived as unnecessary) | X | | | | | X | | | | | |
| Utilisation of disease-specific services (eg, mental health services) | X | | | | | | | | | | |
| Conflicts | | | | | | | | | | | |
| Decisional hierarchies and gender | X | | X | | | | | | X | | |
| Substance abuse or mental health issues | X | | | | | | | | | | |
| Religious or cultural conflicts | X | | X | | | | | | | | X |
| Education or training related | | | | | | | | | | | |
| Poor understanding of research intentions among community or religious leaders | | | | | | | X | | | | |
| Lack of understanding about consent process | X | | | | | | | | | | |
| Logistics or opportunity costs | | | | | | | | | | | |
| Potential costs associated with participating | X | | | X | | | | | | | |
| Time spent away from work, travel time, family and other commitments | X | X | | X | X | X | X | | X | | X |
| Logistical issues related to transportation or location | X | | | | | | | | | | |
| Lack of being approached | | | | | | | | | X | | |
| Fear or inhibitions | | | | | | | | | | | |
| Fear of being reported to immigration | X | | | | | | | | | | |
| Stigma of being labelled with a health condition | X | | | X | | | | | | | |
| Concerns about adverse effects (i.e., related to interventions in clinical trials) | | | X | | X | X | X | | X | | |
| Fear of finding out health status | | | | | | X | | | | | |
| Mistrust of research | X | | | | | X | | | | | X |

Continued

Table 3 Continued

| | First author, year of publication | | | | | | | | | | |
|--|-----------------------------------|---------------------------|------------------------------|-----------------------------|----------------------------|-------------------------------|---------------------------|---------------------------|-------------------------------------|-----------------------------|-------------------------------------|
| Recruitment barrier | Waheed, 2016 ³⁶ | Brown, 2014 ³⁷ | Macneill, 2013 ³⁹ | Douglas, 2011 ⁴¹ | Rooney, 2011 ³⁹ | Samsudeen, 2011 ³² | Sheikh, 2009 ⁹ | Lloyd, 2008 ⁴³ | Hussain-Gambles, 2004 ²⁷ | Shelton, 2004 ⁴⁶ | Hussain-Gambles, 2006 ³² |
| Previous poor experiences participating in research | | | | | | | | X | | | |
| RESEARCHER OR RESEARCH RELATED | | | | | | | | | | | |
| Culture or language related | | | | | | | | | | | |
| Language (lack of study materials and communication in South Asian languages) or cultural issues (eg, lack of respect for gender segregation, religious practices) | X | X | | | X | | X | | | | X |
| Logistics | | | | | | | | | | | |
| Under-representation of ethnic population at recruitment sites | | | | | | | | | | | |
| Costs associated with elevated recruitment requirements | | | | | | X | | | | | |
| Limited time to recruit or requirement for repeated recruitment efforts | X | X | | | | | | | | | |
| Need for care coordinator to be present | | | | | | | | X | | | |
| Study design | | | | | | | | | | | |
| Lack of appropriate (ie, South Asian specific or validated) assessment tools | X | | | | | | | | | | |
| Narrow entry criteria | | | | | | X | | | | | |
| Awareness | | | | | | | | | | | |
| Stereotypes about difficulties of engaging with South Asian populations | | | | | | | | | | | X |
| Researchers' attitudes (eg, apathy) | | | | | | | X | | | | |

reliance on verbal exchange,^{29 38 43} providing language support and translated materials,^{36 38 40 42} personal versus written contact,^{39 42 43} training for staff in cultural competency,^{9 27 36} conducting recruitment at places with high concentrations of South Asian attendance or residence^{27 36 38} and improving flexibility of appointment scheduling, location, childcare and transportation.^{36 39 40} Several additional strategies for recruiting South Asian populations reported by two or fewer studies, as well as those previously discussed are outlined in [table 4](#).

DISCUSSION

To our knowledge, this is the first summary of evidence regarding factors that influence the participation of South Asians in health research studies. The studies summarised in this review identified multiple strategies to improve the success of recruitment efforts among South Asian populations. This information may help researchers to develop evidence-based strategies to improve representation of this minority group in health research.

Factors that facilitated South Asian participation in research included wanting to improve one's health and engage in disease prevention, to contribute to scientific knowledge and greater societal advances and a sense of obligation to healthcare providers. Interest in health and research may vary according to social class and education.²⁷ Strategies that aim to capitalise on altruism and awareness^{27 32} may systematically exclude individuals of lower socioeconomic status, resulting in recruitment bias, if there is a lack of perceived benefit to self. Benefits to self, including financial incentives, were factors associated with motivation to participate in research in Chinese patients in rural areas of lower socioeconomic status.⁴⁷ Strategies such as using assessment tools with less emphasis on literacy, reducing participation costs and inconvenience and snowball sampling within broad South Asian communities could potentially mitigate this to some extent.⁴⁸ Obligation to healthcare providers may be more common in South Asians than other ethnic groups. A literature review on South Asian perspectives on clinical and research ethics reported that medical paternalism persists in South Asian society.⁴⁹ Recruitment involving senior physicians or researchers through partnerships between hospitals and academic centres is preferred to recruitment by individuals with perceived lesser hierarchical status by South Asians living in the UK.⁵⁰ While this dynamic may be beneficial for increasing numbers where physician recruitment is feasible, potential abuse of this power dynamic may be detrimental. It may be necessary to have systems in place to limit exploitation of this relationship in the interest of reducing selection and performance bias. For instance, junior research staff could be involved in participant engagement until the stage that it is necessary for physicians to participate in the research process. Alternative methods of improving recruitment may be required where physician involvement is either not necessary or inappropriate.

Many of the barriers to participation in research relate to cultural insensitivity, lack of awareness of research or lack of efforts by the researchers to make contact, and tangible issues like time and cost of participating ([table 3](#)). Language was also a frequently cited issue. Language compatibility is reported to be of great importance to South Asian patients.⁵¹ Jolly *et al*²⁰ observed a significantly higher proportion of South Asian individuals being excluded from participation in research due to language barriers compared with 'White Europeans' or those of 'Other' ethnicities. The use of multilingual research assistants, or principal investigators from the same ethnic background, or with language and cultural competency training is proposed as a possible strategy to overcome language barriers. This approach may also allow for larger recruitment pools if these staff are part of or able to access networks within the South Asian community.⁵² The effectiveness of this strategy was demonstrated in the successful recruitment and long-term retention of pregnant South Asian women for a study involving sample collection from mothers and their babies in the UK.⁵³ The retention of study participants is another noted challenge for the South Asian population,^{27 42} not addressed by this scoping review.

Other common barriers are related to negative perceptions of researchers towards South Asian participants and vice versa. Various stereotypes held by health professionals conducting research on South Asian populations were highlighted as recruitment deterrents.^{9 32 36} Specific examples include perceptions or generalisations that South Asians are not punctual, that they have language limitations and that certain subpopulations (eg, seniors) would not have an interest in participating.^{9 32} In addition, perceived issues with gender hierarchies (eg, inability of women to make independent decisions),^{27 36 37} the misconception that South Asians are less motivated about disease prevention^{24 54} and the association of English speaking with intelligence and potentially greater trial compatibility have been noted.³² On the other hand, South Asians reported that mistrust, mistreatment and disrespectful behaviour, sub-par care for non-English speakers and previous poor experiences participating in research would deter willingness to participate.³² Cross-cultural education of individuals working in research to dispel incorrect racial and cultural stereotypes, as well as education of South Asian communities to dispel some misconceptions about health research should be encouraged.⁵⁵

From a logistical perspective, studies focused on South Asians may require upfront budgeting for enhanced recruitment strategies to address the unique barriers discussed. In particular, funds for multiple research sites, transportation of patients, incentives and childcare may need to be accounted for at the grant funding stages. Support for minority recruitment may be better in the USA where the National Institutes of Health Revitalization Act of 1993 promotes opportunities for women and minorities to participate in health research.^{56 57} There is mandated support for gender representation, but not

Table 4 Recruitment strategies for South Asian populations

| Recruitment strategy | First author, year | | | | | | | | | | | | | |
|---|----------------------------|---------------------------|----------------------------------|------------------------------|-----------------------------|----------------------------|-------------------------------|------------------------------|---------------------------|---------------------------|-------------------------------|-------------------------------------|-----------------------------|---------------------------|
| | Waheed, 2016 ³⁶ | Brown, 2014 ³⁷ | Garduno-Diaz, 2014 ³⁸ | Macneill, 2013 ³⁹ | Douglas, 2011 ⁴¹ | Rooney, 2011 ³⁹ | Samsudeen, 2011 ⁴² | Stirland, 2011 ⁴⁰ | Sheikh, 2009 ⁹ | Lloyd, 2008 ⁴³ | Mohammadi, 2008 ⁴⁴ | Hussain-Gambles, 2004 ²⁷ | Shelton, 2004 ⁴⁶ | Krupp, 2007 ⁴⁵ |
| Language or culture driven | | | | | | | | | | | | | | |
| Translated informed consent and option for verbal consent | X | X | | | | | | | | | | | | |
| Demonstrated respect and knowledge of culture and traditions, ethics, training of staff in cultural awareness | X | X | X | | | X | X | X | | X | | | X | |
| Language knowledge or translators; employing staff with language and cultural similarities to participants; translated materials and interpreters | X | X | X | | | X | X | X | | | | | X | |
| Support structure for education and training of staff in minority-specific issues | X | | | | | | | | X | | | X | | |
| Culture-specific research tools | X | | | | | | | | | | | | | |
| Demonstration of religious and cultural knowledge and sensitivity | X | X | | | | | | | | | | | | |
| Produce validated translated or culture-specific assessment tools | X | | | | | | | | | | | | | |
| Provision of culturally appropriate incentives and hospitality | X | | | | | | | | | | | | | |
| Communication and engagement | | | | | | | | | | | | | | |
| Involvement of community members, sustainable community partnerships | X | | X | | X | X | X | X | X | | | X | | X |
| Involving family members in recruitment process | X | | | | | | | | | | | | X | |
| Development of trust and personal relationships | X | X | | | | X | X | X | | | | X | X | |
| Constant communication and follow-up, effective dissemination | | | X | | | | | | | | | | X | |

Continued

Table 4 Continued

| | First author, year | | | | | | | | | | | | | |
|---|----------------------------|---------------------------|----------------------------------|------------------------------|-----------------------------|----------------------------|-------------------------------|------------------------------|---------------------------|---------------------------|-------------------------------|-------------------------------------|-----------------------------|---------------------------|
| | Waheed, 2016 ³⁶ | Brown, 2014 ³⁷ | Garduno-Diaz, 2014 ³⁸ | Macneill, 2013 ²⁹ | Douglas, 2011 ⁴¹ | Rooney, 2011 ³⁹ | Samsudeen, 2011 ⁴² | Stirland, 2011 ⁴⁰ | Sheikh, 2009 ⁹ | Lloyd, 2008 ⁴³ | Mohammadi, 2008 ⁴⁴ | Hussain-Gambles, 2004 ²⁷ | Shelton, 2004 ⁴⁶ | Krupp, 2007 ⁴⁵ |
| Recruitment strategy | | | | | | | | | | | | | | |
| Recruitment at places of worship and community centres, health practices with high percentage of minorities, ethnically dense areas, through ethnic-specific modes of communication | X | | X | | | | | | | | | X | X | |
| Direct physician recruitment, interaction with senior investigators | X | X | | | X | | | | | | | | | |
| Engagement of South Asian media | X | | | | | | | | | | | | | |
| Employing patients and public or seeking input into study design and conduct | X | | | | | | | | | | | | | |
| Academic-community partnerships | X | | | | | | | | | | | | | |
| Engagement with study participants post-study completion | | | | | | | | | | | | | X | |
| Logistics and accommodations | | | | | | | | | | | | | | |
| Allowing sufficient time to review study materials and information during recruitment | | | | | | | | | | | | | | X |
| Personalised versus written contact | | | | | | X | X | | | X | | | | |
| Flexibility (location, timing of appointments, childcare, transportation) | X | | | | | X | | X | | | | | | |
| Funding to support logistic considerations related to involvement of South Asians in research | X | X | | | | | | X | | | | | | |
| Face-to-face conduct of data collection | | | | | | | | | | | | X | | |
| Catering to gender-specific needs | X | | | | | | | | | | | | | |
| Focus groups to identify recruitment barriers | | | | | | | | | | | | | X | |
| Visual aids and reduced reliance on verbal exchange | | | X | X | | | | | | X | | | | |

Continued

Table 4 Continued

| | First author, year | | | | | | | | | | | | | |
|---|----------------------------|---------------------------|----------------------------------|------------------------------|-----------------------------|----------------------------|-------------------------------|------------------------------|---------------------------|---------------------------|-------------------------------|-------------------------------------|-----------------------------|---------------------------|
| | Waheed, 2016 ³⁶ | Brown, 2014 ³⁷ | Garduno-Diaz, 2014 ³⁸ | Macneill, 2013 ²⁹ | Douglas, 2011 ⁴¹ | Rooney, 2011 ³⁹ | Samsudeen, 2011 ⁴² | Stirland, 2011 ⁴⁰ | Sheikh, 2009 ⁹ | Lloyd, 2008 ⁴³ | Mohammadi, 2008 ⁴⁴ | Hussain-Gambles, 2004 ²⁷ | Shelton, 2004 ⁴⁶ | Krupp, 2007 ⁴⁵ |
| Recruitment strategy | | | | | | | | | | | | | | |
| Policy and study design | | | | | | | | | | | | | | |
| Assurance of confidentiality | X | | | | | | | | | | | | | |
| Widening eligibility criteria | | | | | | | | | X | | | | | |
| Government supported mandates to include South Asians in research | | | | | | | | X | | | | | | |
| Snowball sampling | | | X | | | | | | | | X | | | |
| Employment of multiple strategies | | | | | | | | | | X | | | | |
| Compensation and incentives | | | | | | | | | | | | | | |
| Incentives (financial or otherwise), reciprocal benefits | X | X | X | | | X | | X | X | | | | X | |
| Offering of educational opportunities to attract South Asian health professionals | | | | | | | | | | | | X | | |
| Providing counselling or education on clinical condition of participants | | | | | | | | | | | | | | X |

for minority representation in Canada.⁵⁸ In the UK and other European countries, the Research Governance Framework encourages researchers to consider factors including race during research conduct when relevant, but it is not enforced.^{59 60} Government or institutional regulations promoting minority representation may encourage researchers to confront various barriers, despite the challenges involved.

There were similarities and differences in the findings of this scoping review in contrast to what is reported for other ethnic groups. Congruent with our findings, a systematic review of recruitment barriers and facilitators in African Americans, Latinos, Asian Americans and Pacific Islanders in the USA reported that issues of mistrust, competing demands, unintended outcomes (eg, adverse effects of intervention, lack of access to healthcare should injury or disease arise), lack of access to research information, stigma, health insurance coverage and jeopardising legal status in the USA were barriers to participation in research.²⁶ Facilitators included cultural congruence, benefits to participation, altruism, convenience of participation and low risks associated with participation. They also found that there were issues specific to ethnic groups. For instance, the legacy of the Tuskegee Syphilis Study—an investigation noted for unethical abuse against African Americans—may discourage African Americans from participating in research, and Asian Americans often required the endorsement from family members. Another systematic review⁶¹ that assessed barriers and facilitators in indigenous populations in several countries, including the USA, Canada, Australia and New Zealand, reported that relationships and partnership, indigenous staff, indigenous knowledge models, targeted recruitment and adaptation of study material were associated with improved recruitment. Conversely, factors such as distrust of research attributable to the participants, study-centric issues such as trial design (no phone, travel costs) and lack of incorporation of indigenous knowledge systems dissuaded individuals from participating. While some barriers such as logistical issues may be common to multiple ethnic groups, the strategies to address cultural factors may differ depending on ethnicity. This highlights the importance of establishing targeted recruitment strategies that are not only specific to an individual ethnic group, but also consider heterogeneity between ethnic subgroups. This is pertinent to South Asians who as a group are multicultural, multilingual and multiethnic.⁶²

A strength of this review is that a range of perspectives and ideas regarding recruitment of South Asians have been summarised and grouped thematically. Accordingly, this review represents a comprehensive in-depth overview of this subject area and provides a good estimate of the volume and characteristics of the published literature. Further, this review highlights areas for future investigation such as evaluation of the effectiveness of the proposed recruitment strategies in settings with large South Asian populations. There were several limitations to this review and the individual studies that were included. Published

evidence was only available from the UK, the USA, India and Australia; therefore, transferability to the Canadian context may be limited. Also, the variable patient populations and sample sizes suggest that results may not be generalisable to all South Asian populations. In addition, there was a relative paucity of evidence regarding recruitment strategies for South Asians in these studies, and the majority of the evidence is in the context of clinical trials. The usefulness of the proposed recruitment strategies outside of the clinical trial setting is unknown. The applicability of the strategies presented may vary, as some proposed solutions are relatively straightforward, while others are more complex and difficult to apply. As discussed by Waheed *et al*,³⁶ changing recruitment venues may be easy, but provision of appropriate incentives and catering to specific health and cultural beliefs may be more difficult to execute. The primary types of studies that have been used to investigate potential recruitment strategies in South Asian populations include focus groups and interviews. These studies provide valuable insight into participant and researcher perspectives, but do not directly address the quantitative impact of barriers or facilitators or effectiveness of recruitment strategies. Where empirical data exist, it is often limited to descriptive rates of recruitment and retention based on the results of quantitative surveys or prospective cohort studies. Documentation of barriers to recruitment in future studies including South Asian participants via qualitative interviews during the recruitment process would help to address this gap. As well, assessment tools, such as the Barriers to Research Participation Questionnaire, may assist in determining hurdles to research participation in specific populations in a structured manner.⁶³ Since this was a scoping review aimed at mapping the current literature on this topic, we did not complete a quality assessment of the data. The search date restrictions that were imposed may have excluded studies with valuable historical perspectives. However, we believe this review captures a relevant snapshot of the most up-to-date research on this topic.

The evidence reviewed suggests that recruitment methods aimed at engaging with the target population may have a positive impact. One such intervention that was not discussed explicitly by the included studies is community-based participatory research. This research method aims to increase the mutual value of the research initiative for the researchers and the community.⁶⁴ This approach employs strategies such as involving trusted community members as study staff, which may effectively mitigate ethical and cultural challenges in research.⁶⁵ This approach may have the potential to mobilise individuals to take ownership of their health and encourage education and participation within their communities and to ensure appropriate dissemination of findings.^{66 67} One study in South Asian women concluded that participatory action research provided a platform for the participants to 'create and share knowledge'.⁶⁶ The overall paucity of evidence, particularly in the Canadian context, suggests

that work is still needed to determine context-specific barriers and facilitators to recruitment and associated strategies to increase the participation of South Asians in health research. A mixed-methods synthesis from the Canadian perspective linking experiences of individuals and groups to the evidence on effectiveness of recruitment strategies may shed some light on potential approaches researchers could employ in future studies. Given the lack of empirical data, proposed recruitment strategies should be quantitatively evaluated, ideally using prospective experimental methods, to determine their relative effectiveness and value. Further, adequate representation of South Asians in research also relies heavily on the retention of participants, which has been reported to be variable in South Asians.^{68 69} The identification and investigation of retention strategies that ensure the successful recruitment is not undone should be of highest priority.

CONCLUSIONS

Better representation of South Asians in health research may promote development of tailored treatment and increased awareness and ownership of health. This would support the ultimate goals of improving the health of the South Asian population, reducing healthcare spending and addressing health inequity. The information presented in this review can be used to assist researchers when preparing to conduct research and may help to inform a more in-depth analysis of this issue from a Canadian perspective. Consideration of these issues during the grant writing and protocol stages of research may decrease the risk of encountering recruitment problems at latter stages.

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