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TITLE PAGE

Title

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). 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 summarized narratively.

Synthesis Of 1226 potentially relevant articles, 13 met the inclusion criteria and were included in the thematic synthesis. Multiple facilitators and barriers to enrollment 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 understanding of the barriers and facilitators to recruitment of South Asian participants to health research studies. Understanding of these approaches and implementation during the grant funding stages may reduce the risk of poor recruitment and representation of South Asians.

ARTICLE SUMMARY

Strengths and Limitations of this Study

- First scoping review to summarize 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 several countries and primarily in the clinical trial setting so generalizability to other contexts may be limited
- Small sample sizes and variable patient populations indicate that results may not be applicable to the broader South Asian population

INTRODUCTION

South Asians are the largest ethnic minority in Canada and the United Kingdom (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 (one quarter of the visible minority population, and 4.8% of the total population) and is projected to reach 3.2 to 4.1 million by 2031.[3] In the UK, South Asian ethnic groups, including people identifying as Pakistani and Indian, had some of the largest population increases over the 2001 to 2011 time period.[2]

South Asian populations face specific health challenges. Low socio-economic status,[4] racial and cultural discrimination,[5,6] geography,[7] language barriers,[8] and traditional hierarchies within families[9] have been reported to obstruct optimal health care of South Asians, and in particular South Asian women.[9] Frequently, South Asians maintain traditional religious, dietary, and healthcare practices, which may not align with conventional medicine and clinical research approaches.[10,11] Lack of support from families and communities in seeking healthcare and making healthcare decisions may discourage South Asians from engaging in risk-reducing health behaviors, including participation in research.[12] Lack of English language proficiency, unfamiliarity with local services, and lack of attention to cultural factors by health care providers may pose a particular challenge to healthcare service access for female South Asians.[13]

South Asians are more likely to report poor self-rated health than individuals of alternate ethnicity.[14] A higher proportion of South Asians suffer from health conditions including type 2 diabetes, cardiovascular disease, and asthma than people of European ethnicity,[15–19] and the rates of non-communicable disease are expected to rise.[20] It has been reported that South Asians develop non-communicable diseases at younger ages, despite fewer risk factors (e.g., at lower body mass index), than other ethnic

groups.[15,21,22] Mental health is also an emerging area of concern, particularly in immigrant women who have been demonstrated to have a higher risk of post-partum depression.[13,23]

Adequate ethnic minority representation in health research is important to support generalizability of research findings and to enable tailored health care for ethnic minorities.[24,25] However, South Asians are underrepresented in research, which drives healthcare practice.[26,27] In general, there is a lack of representative population health research comparing minority groups in Canada to European counterparts.[26] This under-representation also occurs in other countries; 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 6 multicenter randomized controlled trials.[2,28] Another review noted that trials assessing cardiovascular outcomes in type 2 diabetes patients had underrepresentation of South Asian populations compared to population proportions in the UK, but overrepresentation in the United States.[29] Even studies with sufficient numbers of South Asians may not be truly representative of the broad heterogeneous population.[30]

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.[31,32]. This methodology was justified given that there is limited knowledge on this topic, and there was 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 (TQ). A comprehensive search was conducted using PubMed and the Cochrane Library. 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 April 2016 (Table 1). Search terms are presented in Table 1.

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	

The full search strategy is available upon request from the authors. 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 included studies, searching 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. No restriction was made by publication type. Results from all searched were pooled and de-duplicated prior to screening.

Study Selection

All types of studies including primary randomized and non-randomized quantitative and qualitative studies, and systematic reviews were included. Commentaries and narrative reviews were excluded. We included studies involving South Asian individuals (e.g., Sri Lankan, Bangladeshi, Pakistani, Nepalese, Bhutanese, Maldivian, 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 determining, assessing the impact or effectiveness, or assessing the comparative impact or effectiveness of barriers, facilitators, and recruitment strategies. One reviewer (TQ) independently screened titles and abstracts against the pre-specified 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. Study authors were not contacted for further information.

Data Abstraction

Data abstraction was conducted by two authors (TQ and LF) using a structured and piloted extraction form. 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 was extracted by a single reviewer. Specific descriptions of recruitment barriers, facilitators, and strategies were recorded. Barriers and facilitators, and recruitment strategies were grouped thematically into key topics. 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 is outside the scope of this review, but general limitations are discussed. In addition, no formal consultation exercise with stakeholders was conducted.

RESULTS

Literature Search

The original search identified 1027 potentially relevant publications. After exclusion of 846 publications based on title and abstract, 181 full-texts were screened and 20 articles selected for duplicate assessment (Figure 1). An updated search (to April 2016) identified a further 199 potentially relevant articles, from which 3 studies were selected for full-text review. Of the 23 studies included for full-text review, 13 articles met the inclusion criteria and were included in this report.

Study Characteristics

The final thirteen articles included in this review focused on South Asian populations and discussed barriers and motivations for participation in research, and potential strategies for recruitment (Table 2).

Table 2. Study Characteristics.

First Author, Year	Country	Research Area	Ethnic Populations	Sample Size	Study Design
Waheed, 2016[33]	UK	Mental Health (Depression)	South Asians	5 studies (n = 292)	Mixed-methods study
Garduno-Diaz, 2014 [34]	UK	Diet and Nutrition	South Asians	n = 300 adults, n = 100 children	Literature review and dietary survey
Mac Neill, 2013 [27]	UK	Asthma, Clinical Trials	Multiple ethnic groups (primarily Bangladeshi)	n = 42 parents (n = 20 Bangladeshi, n = 22 other)	Qualitative Interviews
Douglas, 2011 [35]	UK	Diabetes	South Asians	n = 1319 potential recruits	Descriptive review of recruitment experiences
Rooney, 2011 [36]	UK	Asthma	South Asians	n = 58 people with asthma	Qualitative focus groups
Samsudeen, 2011 [37]	UK	Diabetes - Obesity	South Asians	n = 22 health professionals, n = 27 community workers	Quantitative survey
Stirland, 2011 [38]	US/UK	Asthma	South Asians	n = 36 researchers	Qualitative interviews
Sheikh, 2009 [18]	UK/UK	Asthma	South Asians	n = 36 researchers (19 UK, 17 US), n = 10 community members)	Qualitative interviews
Lloyd, 2008 [39]	UK	Diabetes	South Asians (Sylheti and Mipuri peoples from Bangladesh)	n = 31 participants	Qualitative interviews
Mohammadi, 2008 [40]	Australia	Hospitalized Patients	Islamic South Asians	n = 13 participants enrolled	Interpretive hermeneutic study
Krupp, 2007 [41]	India	Reproductive Health Research	South Asian women	n = 918 enrolled participants	Prospective cohort study
Hussain-Gambles, 2006 [30]	UK	Clinical Trials	South Asian health professional and lay persons	25 health professionals, n = 60 lay persons	Qualitative interviews
Hussain-Gambles*, 2004* [25]	UK	Clinical Trials	South Asians	n = 25 health professionals, n = 60 lay persons, n = 15 trial participants	Literature review and qualitative interviews

*Some common data between publications
UK = United Kingdom, US = United States

Study populations ranged in size from n=13 to n=1319. The majority of studies were conducted in specific clinical populations. This included patients with depression,[33] nutritional concerns,[34] asthma,[18,27,36,38] diabetes,[35,37,39] obesity,[37] in hospital,[40] with reproductive health concerns,[41] and who were being recruited for clinical trials.[25,30] Study designs included prospective cohort studies,[41] qualitative interviews and focus groups,[18,25,27,30,36,38,39] literature reviews,[30,34] quantitative surveys,[34,37] retrospective descriptive accounts of recruitment experiences,[35] hermeneutic studies,[40] and mixed-methods syntheses.[33]

Most of the studies employed qualitative or survey-based techniques. As such, most outcome data is sourced from direct interview statements and personal experience. Limited empirical evidence on the effectiveness of the various recruitment strategies discussed was available. Most of the included studies were conducted in the UK and dealt with recruitment of clinical populations to clinical trials.

Facilitators

Three studies conducted in the UK [25,27,37] reported on facilitators of participation in research. Subjects perceived participation in research to be a possible route to improved treatment and health [25,27]. Participants also reported being motivated by the importance of disease prevention and potential to contribute to scientific knowledge [25,37], by the potential to help society through participation [25], and by a sense of obligation to healthcare providers [25]. It was reported that higher social class and education, and younger age influence the level of awareness of clinical trials in South Asians.

Barriers

Potential barriers to recruitment of South Asians are outlined in Table 3.

Table 3. Barriers to Recruitment of South Asian Populations

	First Author, Year of Publication								
Recruitment Barrier	Waheed, 2016 [33]	Mac Neill, 2013 [27]	Douglas, 2011 [35]	Rooney, 2011 [36]	Samsudeen, 2011 [37]	Sheikh, 2009 [18]	Lloyd, 2008 [39]	Hussain-Gambles, 2004[25]	Hussain-Gambles, 2006[30]
Participant-related									
Concerns about adverse effects*		X		X	X			X	
Time spent away from work, travel time, family and other commitments	X		X	X	X	X		X	X
Potential costs associated with participating	X		X						
Stigma of being labeled with a health condition	X			X					
Prior treatment for disease (trial participation perceived as unnecessary)	X				X				
Utilization of disease-specific services (e.g., mental health services)	X								
Lack of interest, misgivings about scientific importance					X	X			
Fear of finding out health status					X				
Mistrust of research	X				X			X	
Poor understanding of research intentions among community or religious leaders						X			
Previous poor experiences participating in research								X	
Immigrant perceptions of not belonging to society meant to benefit from research								X	X
Religious or cultural conflicts	X								X
Lack of being approached								X	
Decisional hierarchies and gender	X							X	
Fear of being reported to immigration	X								
Substance abuse or mental health issues	X								
Logistical issues related to transportation or location	X								
Lack of understanding about consent process	X								
Researcher or research-related									
Stereotypes about difficulties of engaging with South Asian populations	X								X
Researchers attitudes (e.g. antipathy)	X					X			

Narrow entry criteria			X		
Limited time to recruit	X		X		
Language (lack of study materials and communication in South Asian languages) or cultural issues (e.g., lack of respect for gender segregation, religious practices)	X	X		X	X
Costs associated with elevated recruitment requirements	X			X	
Lack of appropriate assessment tools	X				
Underrepresentation of ethnic population at recruitment sites	X				

*Related to interventions in clinical trials

Treatment or participation related factors included perception of risk of adverse effects, fear of finding out health status or experiencing the stigma of being labeled with a health condition, previous poor experiences, mistrust of research, inability to participate due to substance abuse or mental health issues, and fear of being reported to immigration. Logistical concerns focused on cost of participating, time away from work, family and other commitments, transportation and location, underrepresentation of South Asians at recruitment sites, and lack of access to disease-specific services. Language- or culture-specific barriers included religious or cultural conflicts, decisional hierarchies within families, lack of understanding about the consent process, researcher stereotypes about difficulties engaging with the South Asian population, inability to provide staff with language and cultural competency training, inability to translate study materials, and traditional gender roles. Some barriers related to general disinterest or lack of awareness, including lack of interest due to previous treatment and the perception that participation would not confer any further benefit, misgivings about the scientific importance of the work, poor understanding of research intentions, perception of not belonging to the society standing to benefit from research, simply not being approached to participate, and researcher antipathy towards achieving proper representation of South Asians. Finally, some study-specific issues included a lack of appropriate assessment tools (e.g., translated or adapted tools) for South Asian populations, as well as narrow entry criteria.

Recruitment Strategies

The most commonly reported strategy was involvement of the South Asian community through mobilization of key community figures or community partnerships.[18,25,33–35,37,41] The second most commonly reported strategies were incentives and reciprocal benefits,[18,33,34,36,38] and demonstrated respect and knowledge of South

Asian culture, traditions, and ethics.[33,34,36,38,40] Multiple studies also mentioned the development of trust and personal relationships,[33,36–38] the use of visual aids and reduced reliance on verbal exchange,[27,34,39] providing language support and translated materials,[33,34,37,38] personal versus written contact,[36,37,39] training for staff in cultural competency,[18,25,33] conducting recruitment at places with high concentrations of South Asian attendance or residence,[25,33,34] and improving flexibility of appointment scheduling, location, childcare and transportation.[33,36,38] Several additional strategies for recruiting South Asian populations reported by two or fewer studies, as well as those previously discussed as outlined in Table 4.

Table 4. Recruitment Strategies for South Asian Populations

Recruitment Strategy	First Author, Year											
	Waheed, 2016[33]	Garduno-Diaz, 2014 [34]	Mac Neill, 2013 [27]	Douglas, 2011 [35]	Rooney, 2011 [36]	Samsudeen, 2011 [37]	Stirland, 2011 [38]	Sheikh, 2009 [18]	Lloyd, 2008 [39]	Mohammadi, 2008 [40]	Hussain-Gambles, 2004 [25]	Krupp, 2007 [41]
Involvement of community members, sustainable community partnerships	X	X		X		X		X			X	X
Involving family members in recruitment process	X											
Translated informed consent and option for verbal consent	X											
Incentives (financial or otherwise), reciprocal benefits	X	X			X		X	X				
Demonstrated respect and knowledge of culture and traditions, ethics, training of staff in cultural awareness	X	X			X		X			X		
Development of trust and personal relationships	X				X	X	X					
Visual aids and reduced reliance on verbal exchange		X	X						X			
Language knowledge or translators; employing staff with language and cultural similarities to participants; translated materials and interpreters	X	X				X	X					
Personalized versus written contact					X	X			X			
Employment of multiple strategies										X	X	
Support structure for education and training of staff in minority specific issues	X							X			X	
Constant communication and follow up, effective dissemination		X					X					
Snowball sampling		X								X		
Recruitment at places of worship and community centers, health practices with high percentage of minorities, ethnically dense areas, through ethnic specific modes of communication	X	X									X	
Flexibility (location, timing of appointments, childcare, transportation)	X				X		X					

Demonstration of religious and cultural knowledge and sensitivity	X								
Culture specific research tools	X	X							
Face-to-face conduct of data collection			X						
Direct physician recruitment, interaction with senior investigators	X			X					
Funding to support logistic considerations related to involvement of South Asians in research	X					X			
Government supported mandates to include South Asians in research							X		
Focus groups to identify recruitment barriers									X
Widening eligibility criteria									X
Offering of educational opportunities to attract South Asian health professionals									X
Engagement of South Asian media	X								
Employing patients and public or seeking input into study design and conduct	X								
Academic-community partnerships	X								
Providing counseling or education on participants clinical condition	X								
Assurance of confidentiality	X								
Catering to gender-specific needs	X								
Provision of culturally appropriate incentives and hospitality	X								
Produce validated translated or culture-specific assessment tools	X								

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 summarized in this review identified multiple strategies to improve the success of recruitment strategies among South Asian populations. This information may help researchers to develop evidence-based strategies to improve representation of this minority 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 health care providers. Interest in health and research may vary according to social class and education. As a result, strategies that aim to capitalize on altruism and awareness may systematically exclude South Asians of lower socioeconomic status. 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. 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.[42] Recruitment involving senior physicians or researchers through partnerships between hospitals and academic centers is preferred to recruitment by individuals with perceived lesser hierarchical status by South Asians living in the UK [43]. 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.

Many of the barriers to participation in research relate to cultural insensitivity, lack of awareness of research or contact by researchers, and tangible issues like time and cost of participating. Language was also a frequently cited issue. Language compatibility has been reported to be of great importance to South Asian patients.[44] Jolly *et al*. [8] observed a significantly higher proportion of South Asian individuals being excluded from participation in research due to language barriers compared to '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 has been 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.[45] The effectiveness of this strategy has been demonstrated in the successful recruitment and long-term retention of pregnant South Asian women for a study involving sample collection from the mother and baby in the UK.[46]

Other common barriers related to negative and discordant perceptions between researchers and South Asian participants. Various stereotypes held by health professionals conducting research on South Asian populations were highlighted as recruitment deterrents. Specific examples include perceptions that South Asians are not punctual, that they will have language limitations, generalizations that certain subpopulations (e.g., seniors) would not have an interest in participating, perceived issues with gender hierarchies (e.g., inability of women to make independent decisions), the misconception that South Asians are not interested in disease prevention, and the association of English speaking with intelligence and potentially greater trial

compatibility. On the other hand, South Asians reported that mistrust, mistreatment and disrespectful behavior, sub-par care for non-English speakers, and previous poor experiences participating in research would deter willingness to participate.[30] 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.[47]

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 US where the National Institutes of Health Revitalization Act of 1993 promotes opportunities for women and minorities to participate in health research.[48,49] There is mandated support for gender representation, but not for minority representation in Canada.[50] Government or institutional regulations promoting minority representation may encourage researchers to confront various barriers, despite the challenges involved.

There were some similarities and differences in the findings of this scoping review compared to what has been 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 US reported that issues of mistrust, competing demands, unintended outcomes, lack of access to research information, stigma, health insurance coverage, and jeopardizing legal status in the US were barriers to participation in research.[24] 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, African Americans were disturbed by the legacy of the Tuskegee syphilis study, and Asian Americans often required the endorsement from family members. Another systematic review[51] that assessed barriers and facilitators in indigenous populations in several countries including the US, 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, whereas 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 specific not only to an individual ethnic group, but also that address heterogeneity within an ethnic group.

A strength of this review is that a range of perspectives and ideas regarding recruitment of South Asians have been summarized 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 the Canadian setting. There were several limitations to this review and the individual studies included. Published evidence was only available from the UK, the US, India and Australia; therefore, generalizability to the Canadian context may be limited. Also, the variable patient populations and sample sizes suggest that results may not be generalizable 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.,[33] 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 exists, 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 [52]. 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. Also, we did not search databases of qualitative research, which may have resulted in oversight of relevant evidence. We attempted to overcome this to some extent with the grey literature search strategies. 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, which employs strategies such as involving trusted community members as study staff, which has been shown to be effective at mitigating ethical and cultural challenges in research [53]. This approach may have the potential to mobilize individuals to take ownership of their health and encourage education and participation within their communities, and to ensure appropriate dissemination of findings [54,55]. The 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 to determine the relative effectiveness and value.

Conclusions

Better representation of South Asians in health research may promote development of tailored treatment, increased awareness and ownership of health, and support the ultimate goals of improving the health of the South Asian population and reducing healthcare spending. 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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COMPETING INTERESTS

We have read and understood BMJ policy on declaration of interests and declare the following interests: TQ is an employee of the Canadian Agency for Drugs and Technologies in Health.

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AUTHOR CONTRIBUTIONS

TQ, PJ, and YL were all involved in the conception of the review. TQ wrote the review protocol and TQ and LF were involved in conduct of the review. TQ wrote the initial draft. LF, PJ, and YL were involved in reviewing the manuscript and in critical revision of the manuscript. All authors read and approved the final manuscript.

DATA SHARING STATEMENT

A copy of the unpublished study protocol is available upon request from the corresponding author.

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FIGURE LEGENDS

Figure 1: Flowchart of Included and Excluded Studies

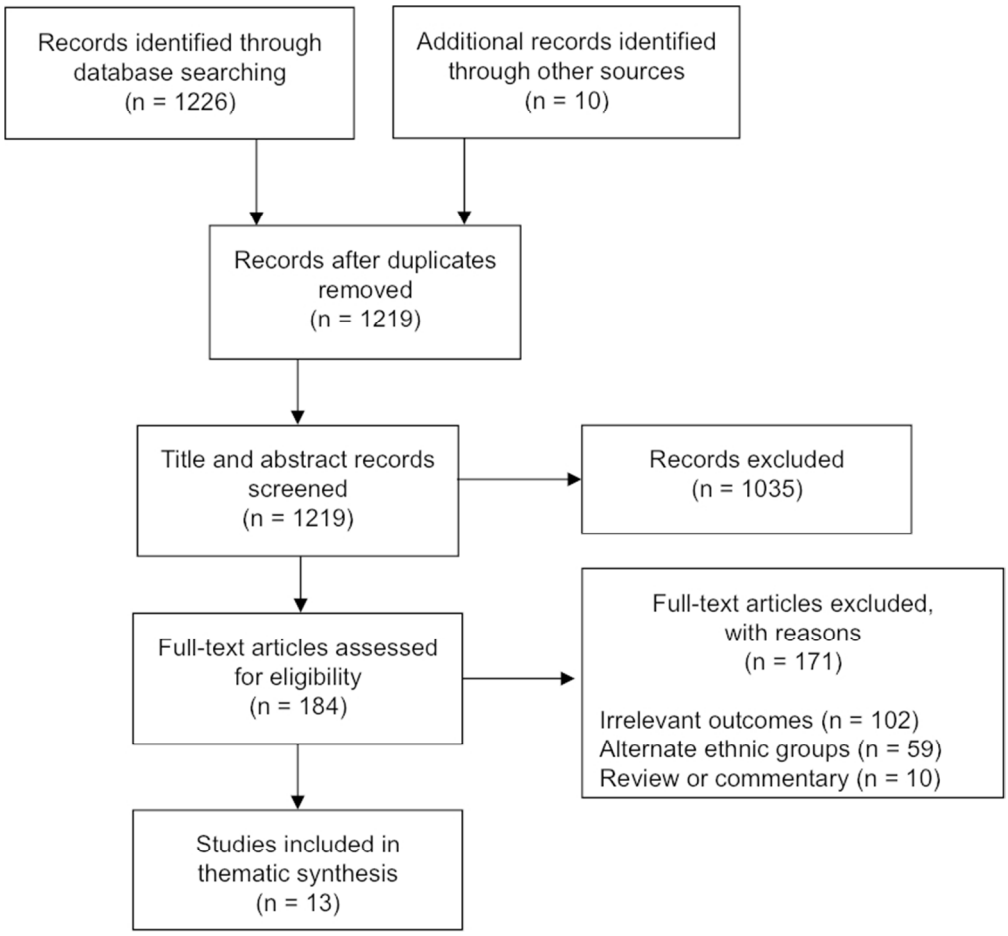

Figure 1: Flowchart of Included and Excluded Studies
Figure 1

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TITLE PAGE

Title

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, 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 summarized narratively.

Synthesis Of 1846 potentially relevant articles, 15 met the inclusion criteria and were included in the thematic synthesis. Multiple facilitators and barriers to enrollment 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. Understanding of these approaches and implementation during the grant funding stages may reduce the risk of poor recruitment and representation of South Asians.

ARTICLE SUMMARY

Strengths and Limitations of this Study

- First scoping review to summarize 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

INTRODUCTION

South Asians are the largest ethnic minority in Canada and the United Kingdom (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 (one quarter of the visible minority population, and 4.8% of the total population) and is projected to reach 3.2 to 4.1 million by 2031.[3] 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, South Asian ethnic groups had some of the largest population increases (0.4 million in each group) over the 2001 to 2011 time period (i.e., 0.4 million each in the Pakistani and Indian groups).[2]

South Asian populations face specific health challenges. An analysis of Canadian Community Health Survey data (2001 to 2013) concluded that South Asians are more likely to report poor self-rated health than Whites.[4] A higher proportion of South Asians suffer from health conditions including type 2 diabetes, cardiovascular disease, and asthma than people of European ethnicity,[5–9] and the rates of non-communicable disease are expected to rise.[10] South Asians are reported to develop non-communicable diseases at younger ages, despite fewer risk factors (e.g., at lower body mass index), than other ethnic groups.[5,11,12] Mental health is also an emerging area of concern, particularly in immigrant women who have been demonstrated to have a higher risk of post-partum depression.[13,14]

In the context of healthcare access, low socio-economic status,[15] racial and cultural discrimination,[16,17] geography (e.g., distance from research cenre, lack of access to transportation),[18] language barriers,[19] and traditional hierarchies within families[20] have been reported to obstruct optimal health care of South Asians, and in particular South Asian women.[20] Frequently, South Asians maintain traditional

religious, dietary, and healthcare practices, which may not align with modern western or allopathic medicine[21] and clinical research approaches.[22,23] Lack of support from families and communities in seeking healthcare and making healthcare decisions may discourage South Asians from engaging in risk-reducing health behaviors, including participation in research.[24] Lack of English language proficiency, unfamiliarity with local services, and lack of attention to cultural factors by health care providers may pose a particular challenge to healthcare service access for female South Asians.[14]

Adequate ethnic minority representation in health research is important to support generalizability of research findings and to enable tailored health care for ethnic minorities.[25,26] However, South Asians are underrepresented in research, resulting in healthcare practice based on research with limited external validity for the South Asian context.[27,28] In general, there is a lack of representative population health research comparing minority groups in Canada to European counterparts.[27] 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 6 multicenter randomized controlled trials.[2,29] Another review noted that trials assessing cardiovascular outcomes in type 2 diabetes patients had underrepresentation of South Asian populations compared to population proportions in the UK, but overrepresentation in the United States.[30] Even studies with sufficient numbers of South Asians may not be truly representative of the broad heterogeneous population, as diets, lifestyles, and baseline health risk is noted to vary across South Asians of different origin.[31]

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.[32,33]. 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, summarizing and reporting the results; and an optional consultation with stakeholders to inform or validate the findings.[32] We followed this approach with the exception of the consultation stage and employed several suggestions made by Levac et al. including a focused research question, the conduct of thematic synthesis, duplicate study selection, and standardized and duplicate extraction.[33] This methodology was justified given that there is limited knowledge on this topic, and there was 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 (TQ). 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 Appendix 1.

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	

The full search strategy is available upon request from the authors. 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 included studies, searching 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. No restriction was made by publication type. Results from all searches were pooled and de-duplicated prior to screening.

Study Selection

All types of studies including primary randomized and non-randomized quantitative and qualitative studies, and systematic reviews were included. Commentaries and narrative reviews were excluded. We included studies involving South Asian individuals (e.g., Sri Lankan, Bangladeshi, Pakistani, Nepalese, Bhutanese, Maldivian, 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 determining, assessing the impact or effectiveness, or assessing the comparative impact or effectiveness of barriers, facilitators, and recruitment strategies. One reviewer (TQ) independently screened titles and abstracts against the pre-specified 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 (TQ 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 was extracted. Specific descriptions of recruitment barriers, facilitators, and strategies were recorded.

Barriers and facilitators, and recruitment strategies were grouped thematically into key topics. 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 is outside the scope of this review, 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 to 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 to April 2016) identified 645 more potentially relevant articles. In total, 1846 records were screened after duplicates were removed. 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 (i.e., irrelevant outcomes, study of alternate ethnic groups, review or commentary) and 15 articles met the inclusion criteria (n = 9 from original PubMed search; n = 4 from PubMed search update; n = 2 from CINAHL and PsycINFO) and were included in this report.

Study Characteristics

The final fifteen articles included in this review focused on South Asian populations and discussed barriers and motivations 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.

Table 2. Study Characteristics.

First Author, Year	Country	Research Area	Ethnic Populations	Sample Size	Study Design
Waheed, 2016[34]	UK	Mental Health (Depression)	South Asians	5 studies (n = 292)	Mixed-methods study
Brown, 2014[35]	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 [36]	UK	Diet and Nutrition	South Asians	n = 300 adults, n = 100 children	Literature review and dietary survey
Mac Neill, 2013 [28]	UK	Asthma, Clinical Trials	Multiple ethnic groups (primarily Bangladeshi)	n = 42 parents (n = 20 Bangladeshi, n = 22 other)	Qualitative Interviews
Douglas, 2011 [37]	UK	Diabetes	South Asians	n = 1319 potential recruits	Descriptive review of recruitment experiences
Rooney, 2011 [38]	UK	Asthma	South Asians	n = 58 people with asthma	Qualitative focus groups
Samsudeen, 2011 [39]	UK	Diabetes - Obesity	South Asians	n = 22 health professionals, n = 27 community workers	Quantitative survey
Stirland, 2011 [40]	US/UK	Asthma	South Asians	n = 36 researchers	Qualitative interviews
Sheikh, 2009 [8]	US/UK	Asthma	South Asians	n = 36 researchers (19 UK, 17 US), n = 10 community members)	Qualitative interviews
Lloyd, 2008 [41]	UK	Diabetes	South Asians (Sylheti and Mipuri peoples from Bangladesh)	n = 31 participants	Qualitative interviews
Mohammadi, 2008 [42]	Australia	Hospitalized Patients	Islamic South Asians	n = 13 participants enrolled	Interpretive hermeneutic study
Krupp, 2007 [43]	India	Reproductive Health Research	South Asian women	n = 918 enrolled participants	Prospective cohort study
Hussain-Gambles, 2006 [31]	UK	Clinical Trials	South Asian health professional and lay persons	25 health professionals, n = 60 lay persons	Qualitative interviews
Hussain-Gambles*, 2004* [26]	UK	Clinical Trials	South Asians	n = 25 health professionals, n = 60 lay persons, n = 15 trial participants	Literature review and qualitative interviews
Shelton, 2004 [44]	US	Spousal Abuse	South Asian women (Bangladeshi)	n = 2 researchers; number of participants NR	Qualitative survey

*Some common data between publications
NR = not reported; UK = United Kingdom; US = United States

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,[34,35] nutritional concerns,[36] asthma,[8,28,38,40] diabetes,[37,39,41] obesity,[39] in hospital (i.e., tertiary care),[42] with reproductive health concerns,[43] who were being recruited for clinical trials,[26,31] and for a study on spousal abuse.[44] Study designs included prospective cohort studies,[43] thematic analysis[35], qualitative surveys, interviews and focus groups,[8,26,28,31,38,40,41,44] literature reviews,[31,36] quantitative surveys,[36,39] retrospective descriptive accounts of recruitment experiences,[37] hermeneutic studies,[42] and mixed-methods syntheses.[34]

Most of the studies employed qualitative or survey-based techniques. As such, most outcome data is sourced from direct interview statements and personal experience. Limited empirical evidence on the effectiveness of the various recruitment strategies discussed was available.[34,36,39,43] Most of the included studies were conducted in the UK [8,26,28,31,34–41] and dealt with recruitment of clinical populations to clinical trials.[8,26,28,31,34,37–41]

Facilitators

Three studies conducted in the UK [26,28,39] reported on facilitators of participation in research. Subjects perceived participation in research to be a possible route to improved treatment and health [26,28]. Participants also reported being motivated by the importance of disease prevention and potential to contribute to scientific knowledge [26,39], by the potential to help society through participation [26], and by a sense of obligation to healthcare providers [26]. It was reported that higher social class and education, and younger age influence the level of awareness of clinical trials in South Asians.[26]

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.

Table 3. Barriers to Recruitment of South Asian Populations

Recruitment Barrier	First Author, Year of Publication										
	Waheed, 2016 [34]	Brown, 2014[35]	Mac Neill, 2013 [28]	Douglas, 2011 [37]	Rooney, 2011 [38]	Samsudeen, 2011 [39]	Sheikh, 2009 [8]	Lloyd, 2008 [41]	Hussain-Gambles, 2004[26]	Shelton, 2004[44]	Hussain-Gambles, 2006[31]
Participant-Related											
-Disinterest or Lack of Feeling of Belonging											
Immigrant perceptions of not belonging to society meant to benefit from research									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					
Utilization of disease-specific services (e.g., 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 labeled with a health condition	X				X						
Concerns about adverse effects*			X		X	X			X		
Fear of finding out health status						X					
Mistrust of research	X					X			X		
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 (e.g., lack of respect for gender segregation, religious practices)	X	X	X	X	X
-Logistics					
Underrepresentation of ethnic population at recruitment sites	X				
Costs associated with elevated recruitment requirements	X			X	
Limited time to recruit or requirement for repeated recruitment efforts	X	X	X		
Need for care-coordinator to be present		X			
-Study Design					
Lack of appropriate (i.e., South Asian specific or validated) assessment tools	X				
Narrow entry criteria			X		
-Awareness					
Stereotypes about difficulties of engaging with South Asian populations	X				X
Researchers attitudes (e.g. apathy)	X			X	

*Related to interventions in clinical trials

Treatment or participation related factors included perception of risk of adverse effects (e.g., treatment-related side effects),[26,28,38,39] fear of finding out health status[39] or experiencing the stigma of being labeled with a health condition,[34,38] previous poor experiences,[26] mistrust of research,[26,34,39] inability to participate due to substance abuse or mental health issues,[34] and fear of being reported to immigration.[34] Logistical concerns focused on cost of participating,[34,37] time away from work, family and other commitments,[8,26,31,34,35,37–39] transportation and location,[34] underrepresentation of South Asians at recruitment sites,[34] and lack of access to disease-specific services.[34] Language- or culture-specific barriers included religious or cultural conflicts,[31,34,35] decisional hierarchies within families,[26,34,35] lack of understanding about the consent process,[34] researcher stereotypes about difficulties engaging with the South Asian population,[34] inability to provide staff with language and cultural competency training, inability to translate study materials,[8,31,34,35,38] and traditional gender roles.[34,35] Some barriers related to general disinterest or lack of awareness,[8,35,39] including lack of interest due to previous treatment and the perception that participation would not confer any further benefit,[34,39] misgivings about the scientific importance of the work,[8,35,39] poor understanding of research intentions,[8] perception of not belonging to the society standing to benefit from research,[26,31] simply not being approached to participate,[26] and researcher apathy towards achieving proper representation of South Asians.[8,34] Finally, some study-specific issues included a lack of appropriate assessment tools (e.g., translated or adapted tools) for South Asian populations,[34,35] as well as narrow entry criteria (e.g., restrictions on age and waist circumference).[39]

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 mobilization of key community figures or community partnerships.[8,26,34,36,37,39,43] The second most commonly reported strategies were incentives and reciprocal benefits,[8,34–36,38,40,44] and demonstrated respect and knowledge of South Asian culture, traditions, and ethics.[34–36,38,40,42,44] Multiple studies also mentioned the development of trust and personal relationships,[34,35,38–40,44] the use of visual aids and reduced reliance on verbal exchange,[28,36,41] providing language support and translated materials,[34,36,39,40] personal versus written contact,[38,39,41] training for staff in cultural competency,[8,26,34] conducting recruitment at places with high concentrations of South Asian attendance or residence,[26,34,36] and improving flexibility of appointment scheduling, location, childcare and transportation.[34,38,40] 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.

Table 4. Recruitment Strategies for South Asian Populations

Recruitment Strategy	First Author, Year: Waheed, 2016[34]	Brown, 2014[35]	Garduno-Diaz, 2014 [36]	Mac Neill, 2013 [28]	Douglas, 2011 [37]	Rooney, 2011 [38]	Samsudeen, 2011 [39]	Stirland, 2011 [40]	Sheikh, 2009 [8]	Lloyd, 2008 [41]	Mohammadi, 2008 [42]	Hussain-Gambles, 2004 [26]	Shelton, 2004[44]	Krupp, 2007 [43]
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	
Language knowledge or translators; employing staff with language and cultural similarities to participants; translated materials and interpreters	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		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
Involving family members in recruitment process	X	X											X	
Development of trust and personal relationships	X	X				X	X	X					X	
Constant communication and follow up, effective dissemination			X					X					X	
Recruitment at places of worship and community centers, 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										X
Personalized 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			
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	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 counseling or education on clinical condition of participants	X											

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 summarized 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 health care providers. Interest in health and research may vary according to social class and education.[26] Strategies that aim to capitalize on altruism and awareness[26,31] may systematically exclude individuals of lower socioeconomic status if there is a lack of perceived benefit to self. Benefit to self, including financial incentive, were factors associated with motivation to participate in research in Chinese patients in rural areas of lower socioeconomic status.[45] 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.[46] 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.[47] Recruitment involving senior physicians or researchers through partnerships between hospitals and academic centers is preferred to recruitment by individuals with perceived lesser hierarchical status by South Asians living in the UK [48]. 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 contact by researchers, 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.[49] Jolly *et al*. [19] observed a significantly higher proportion of South Asian individuals being excluded from participation in research due to language barriers compared to '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.[50] 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 the mother and baby in the UK.[51] The retention of study participants is another noted challenge for the South Asian population,[26,39] not addressed by this scoping review.

Other common barriers are related to negative perceptions of researchers toward South Asian participants and vice-versa. Various stereotypes held by health professionals conducting research on South Asian populations were highlighted as recruitment deterrents.[8,31,34] Specific examples include perceptions or

generalizations that South Asians are not punctual, that they have language limitations, and that certain subpopulations (e.g., seniors) would not have an interest in participating.[8,31] In addition, perceived issues with gender hierarchies (e.g., inability of women to make independent decisions),[26,34,35] the misconception that South Asians are less motivated about disease prevention,[23,52] and the association of English speaking with intelligence and potentially greater trial compatibility have been noted.[31] On the other hand, South Asians reported that mistrust, mistreatment and disrespectful behavior, sub-par care for non-English speakers, and previous poor experiences participating in research would deter willingness to participate.[31] 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.[53]

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 US where the National Institutes of Health Revitalization Act of 1993 promotes opportunities for women and minorities to participate in health research.[54,55] There is mandated support for gender representation, but not for minority representation in Canada.[56] In the UK and other European countries the Research Governance Framework encourages researchers to consider factors including race into research conduct when relevant, but it is not enforced.[57,58] 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 US reported that issues of mistrust, competing demands, unintended outcomes (e.g., 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 jeopardizing legal status in the US were barriers to participation in research.[25] 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 may discourage African Americans from participating in research, and Asian Americans often required the endorsement from family members. Another systematic review[59] that assessed barriers and facilitators in indigenous populations in several countries including the US, 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 specific not only to an individual ethnic group, but also that address heterogeneity within an ethnic group, such as exists in South Asians who as a group are multicultural, multilingual, and multiethnic.[60]

A strength of this review is that a range of perspectives and ideas regarding recruitment of South Asians have been summarized 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 included. Published evidence was only available from the UK, the US, 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 generalizable 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.,[34] 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 exists, 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 [61]. 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.[62] This approach employs strategies such as involving trusted community members as study staff, which may effectively mitigate ethical and cultural challenges in research [63]. This approach may have the potential to mobilize individuals to take ownership of their health and encourage education and participation within their communities, and to ensure appropriate dissemination of findings [64,65]. One study in South Asian women concluded that participatory action research provided a platform for the participants to “create and share knowledge”.[64] 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 the 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.[66,67] 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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COMPETING INTERESTS

We have read and understood BMJ policy on declaration of interests and declare the following interests: TQ is an employee of the Canadian Agency for Drugs and Technologies in Health.

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TQ, PJ, and YL were all involved in the conception of the review. TQ wrote the review protocol and TQ and LF were involved in conduct of the review. TQ wrote the initial draft. LF, PJ, and YL were involved in reviewing the manuscript and in critical revision of the manuscript. All authors read and approved the final manuscript.

DATA SHARING STATEMENT

A copy of the unpublished study protocol is available upon request from the corresponding author.

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FIGURE LEGENDS

Figure 1: Flowchart of Included and Excluded Studies

APPENDIX 1: LITERATURE SEARCH

Multi-database Strategy	
#	South Asian or South Asia
1	minority groups[MeSH term]
2	minority health[MeSH term]
3	Sri Lankan or Sri Lanka
4	Bangladeshi or Bangladesh
5	Pakistani or Pakistan
6	Nepalese or Nepal
7	Bhutanese or Bhutan
8	Maldivian or Maldives
9	Indian or India
10	or/1-9
11	patient selection[MeSH term]
12	recruitment
13	Enrolment or enrollment
14	recruitment strategies
15	or/10-14
16	10 and 16
17	Limit 16 to yr="2004 –Current"
18	remove duplicates from 17

Search String:

((((((patient selection[MeSH Terms]) OR recruitment) OR enrollment) OR recruitment strategies)) AND ((((((((((south asian) OR south asia)) OR ((sri lankan) OR sri lanka)) OR ((bangladeshi) OR bangladesh)) OR ((pakistani) OR pakistan)) OR minority groups[MeSH Terms]) OR minority health[MeSH Terms]) OR ((nepalese) OR nepal)) OR ((bhutanese) OR bhutan)) OR ((maldivian) OR maldives)) OR ((indian) OR india))) Sort by: PublicationDate Filters: Publication date from 2004/01/01 to 2016/04/01

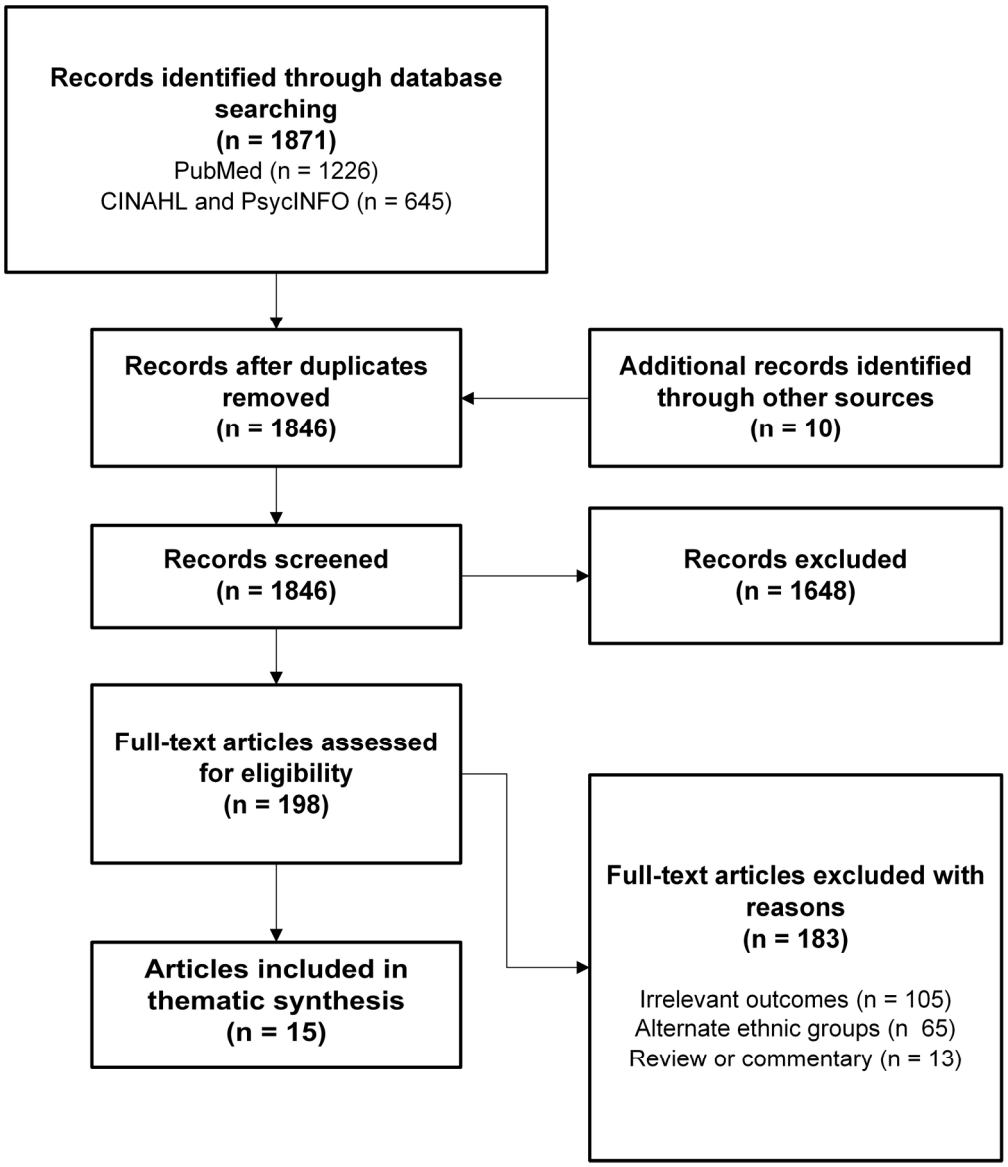

Figure 1: Flowchart of Included and Excluded Studies
Figure 1
188x217mm (300 x 300 DPI)

BMJ Open

Barriers and Facilitators to Recruitment of South Asians to Health Research: A Scoping Review

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Primary Subject Heading:	Global health
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TITLE PAGE

Title

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, 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 summarized narratively.

Synthesis Of 1846 potentially relevant articles, 15 met the inclusion criteria and were included in the thematic synthesis. Multiple facilitators and barriers to enrollment 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.

ARTICLE SUMMARY

Strengths and Limitations of this Study

- First scoping review to summarize 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

INTRODUCTION

South Asians are the largest ethnic minority in Canada and the United Kingdom (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; one quarter of the visible minority population (i.e., “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 reach 3.2 to 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 to 2011 time period (i.e., 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 to 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 (e.g., 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 post-partum depression has been reported.[14,15]

In the context of healthcare access, low socio-economic status,[16] racial and cultural discrimination,[17,18] geography (e.g., distance from research centre, lack of access to transportation),[19] language barriers,[20] and traditional hierarchies within

families[21] have been reported to obstruct optimal health care 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 medicine[22] 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 behaviors, including participation in research.[25] Lack of English language proficiency, unfamiliarity with local services, and lack of attention to cultural factors by health care 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 generalizability of research findings and to enable tailored health care for ethnic minorities.[26,27] However, South Asians are underrepresented 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 to 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 6 multicenter randomized controlled trials.[2,30] Another review noted that trials assessing cardiovascular outcomes in type 2 diabetes patients had underrepresentation of the South Asian population compared to the population proportion in the UK, but overrepresentation in the United States.[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 is 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, summarizing 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 standardized and duplicate extraction.[34] This methodology was justified given that there is limited knowledge on this topic, and there was 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 (TQ). 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 Appendix 1.

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	

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 included studies, searching 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. Results from all searches were pooled and de-duplicated prior to screening.

Study Selection

All types of studies including primary randomized and non-randomized quantitative and 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 (e.g., Sri Lankan, Bangladeshi, Pakistani, Nepalese, Bhutanese, Maldivian, 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 determining, assessing the impact or effectiveness, or assessing the comparative impact or effectiveness of barriers, facilitators, and recruitment strategies.

One reviewer (TQ) independently screened titles and abstracts against the pre-specified 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 (TQ 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 was 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 upon 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 to 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 to April 2016) identified 645 more potentially relevant articles. In total, 1846 records were screened after duplicates were removed. 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 (i.e., irrelevant outcomes, study of alternate ethnic groups, review or commentary) and 15 articles met the inclusion criteria (n = 9 from original PubMed search; n = 4 from PubMed search update; n = 2 from CINAHL and PsycINFO) and were included in this report.

Study Characteristics

The final fifteen articles included in this review focused on South Asian populations and discussed barriers and motivations 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.

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	5 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 [39]	UK	Diabetes	South Asians	n = 1319 potential recruits	Descriptive review of recruitment experiences
Rooney, 2011 [40]	UK	Asthma	South Asians	n = 58 people with asthma	Qualitative focus groups
Samsudeen, 2011 [41]	UK	Diabetes - Obesity	South Asians	n = 22 health professionals, n = 27 community workers	Quantitative survey
Stirland, 2011 [42]	US/UK	Asthma	South Asians	n = 36 researchers	Qualitative interviews
Sheikh, 2009 [9]	US/UK	Asthma	South Asians	n = 36 researchers (19 UK, 17 US), n = 10 community members)	Qualitative interviews
Lloyd, 2008 [43]	UK	Diabetes	South Asians (Sylheti and Mipuri peoples from Bangladesh)	n = 31 participants	Qualitative interviews
Mohammadi, 2008 [44]	Australia	Hospitalized 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	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]	US	Spousal Abuse	South Asian women (Bangladeshi)	n = 2 researchers; number of participants NR	Qualitative survey

*Some common data between publications
NR = not reported; UK = United Kingdom; US = United States

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,[9,29,40,42] diabetes,[39,41,43] obesity,[41] in hospital (i.e., 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,[9,27,29,32,40,42,43,46] literature reviews,[32,38] quantitative surveys,[38,41] retrospective descriptive accounts of recruitment experiences,[39] hermeneutic studies,[44] and mixed-methods syntheses.[36]

Most of the studies employed qualitative or survey-based techniques. As such, most outcome data is sourced from direct interview statements and personal experience. Limited empirical evidence on the effectiveness of the various recruitment strategies discussed was available.[36,38,41,45] 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 [27,29,41] reported on facilitators of participation in research. Subjects perceived participation in research to be a possible route 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 [27,41], by the potential to help society through participation [27], 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.

Table 3. Barriers to Recruitment of South Asian Populations

Recruitment Barrier	First Author, Year of Publication										
	Waheed, 2016 [36]	Brown, 2014[37]	Mac Neill, 2013 [29]	Douglas, 2011 [39]	Rooney, 2011 [40]	Samsudeen, 2011 [41]	Sheikh, 2009 [9]	Lloyd, 2008 [43]	Hussain-Gambles, 2004[27]	Shelton, 2004[46]	Hussain-Gambles, 2006[32]
Participant-Related											
-Disinterest or Lack of Feeling of Belonging											
Immigrant perceptions of not belonging to society meant to benefit from research									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					
Utilization of disease-specific services (e.g., 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 labeled with a health condition	X				X						
Concerns about adverse effects*			X		X	X			X		
Fear of finding out health status						X					
Mistrust of research	X					X			X		
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 (e.g., lack of respect for gender segregation, religious practices)	X	X	X	X	X
-Logistics					
Underrepresentation of ethnic population at recruitment sites	X				
Costs associated with elevated recruitment requirements	X			X	
Limited time to recruit or requirement for repeated recruitment efforts	X	X	X		
Need for care-coordinator to be present		X			
-Study Design					
Lack of appropriate (i.e., South Asian specific or validated) assessment tools	X				
Narrow entry criteria			X		
-Awareness					
Stereotypes about difficulties of engaging with South Asian populations	X				X
Researchers attitudes (e.g. apathy)	X			X	

*Related to interventions in clinical trials

Treatment or participation related factors included perception of risk of adverse effects (e.g., treatment-related side effects),[27,29,40,41] fear of finding out health status[41] or experiencing the stigma of being labeled with a health condition,[36,40] previous poor experiences,[27] mistrust of research,[27,36,41] inability to participate due to substance abuse or mental health issues,[36] and fear of being reported to immigration.[36] Logistical concerns focused on cost of participating,[36,39] time away from work, family and other commitments,[9,27,32,36,37,39–41] transportation and location,[36] underrepresentation of South Asians at recruitment sites,[36] and lack of access to disease-specific services.[36] Language- 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 materials,[9,32,36,37,40] and traditional gender roles.[36,37] Some barriers related to general disinterest or lack of awareness,[9,37,41] including lack of interest due to previous treatment and the perception that participation would not confer any further benefit,[36,41] misgivings about the scientific importance of the work,[9,37,41] 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 participate,[27] and researcher apathy towards achieving proper representation of South Asians.[9,36] Finally, some study-specific issues included a lack of appropriate assessment tools (e.g., translated or adapted tools) for South Asian populations,[36,37] as well as narrow entry criteria (e.g., restrictions on age and waist circumference).[41]

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 mobilization of key community figures or community partnerships.[9,27,36,38,39,41,45] The second most commonly reported strategies were incentives and reciprocal benefits,[9,36–38,40,42,46] and demonstrated respect and knowledge of South Asian culture, traditions, and ethics.[36–38,40,42,44,46] Multiple studies also mentioned the development of trust and personal relationships,[36,37,40–42,46] the use of visual aids and reduced reliance on verbal exchange,[29,38,43] providing language support and translated materials,[36,38,41,42] personal versus written contact,[40,41,43] 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.[36,40,42] 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.

Table 4. Recruitment Strategies for South Asian Populations

Recruitment Strategy	First Author, Year: Waheed, 2016[36]	Brown, 2014[37]	Garduno-Diaz, 2014 [38]	Mac Neill, 2013 [29]	Douglas, 2011 [39]	Rooney, 2011 [40]	Samsudeen, 2011 [41]	Stirland, 2011 [42]	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	
Language knowledge or translators; employing staff with language and cultural similarities to participants; translated materials and interpreters	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		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
Involving family members in recruitment process	X	X											X	
Development of trust and personal relationships	X	X				X	X	X					X	
Constant communication and follow up, effective dissemination			X					X					X	
Recruitment at places of worship and community centers, 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										X
Personalized 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			
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	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 counseling or education on clinical condition of participants	X											

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 summarized 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 health care providers. Interest in health and research may vary according to social class and education.[27] Strategies that aim to capitalize 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. Benefit to self, including financial incentive, 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 centers 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 contact by researchers, 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 to '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 the mother and baby in the UK.[53] The retention of study participants is another noted challenge for the South Asian population,[27,41] not addressed by this scoping review.

Other common barriers are related to negative perceptions of researchers toward 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 generalizations that South Asians are not punctual, that they have language limitations, and that certain subpopulations (e.g., seniors) would not have an interest in participating.[9,32] In addition, perceived issues with gender hierarchies (e.g., 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 behavior, 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 US 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 for minority representation in Canada.[58] In the UK and other European countries the Research Governance Framework encourages researchers to consider factors including race into 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 US reported that issues of mistrust, competing demands, unintended outcomes (e.g., 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 jeopardizing legal status in the US 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 review[61] that assessed barriers and facilitators in indigenous populations in several countries including the US, 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

specific not only to an individual ethnic group, but also that address heterogeneity within an ethnic group, such as exists in 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 summarized 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 included. Published evidence was only available from the UK, the US, 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 generalizable 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 exists, 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 mobilize 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 the 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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COMPETING INTERESTS

We have read and understood BMJ policy on declaration of interests and declare the following interests: TQ is an employee of the Canadian Agency for Drugs and Technologies in Health.

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AUTHOR CONTRIBUTIONS

TQ, PJ, and YL were all involved in the conception of the review. TQ wrote the review protocol and TQ and LF were involved in conduct of the review. TQ wrote the initial draft. LF, PJ, and YL were involved in reviewing the manuscript and in critical revision of the manuscript. All authors read and approved the final manuscript.

DATA SHARING STATEMENT

A copy of the unpublished study protocol is available upon request from the corresponding author.

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FIGURE LEGENDS

Figure 1: Flowchart of Included and Excluded Studies

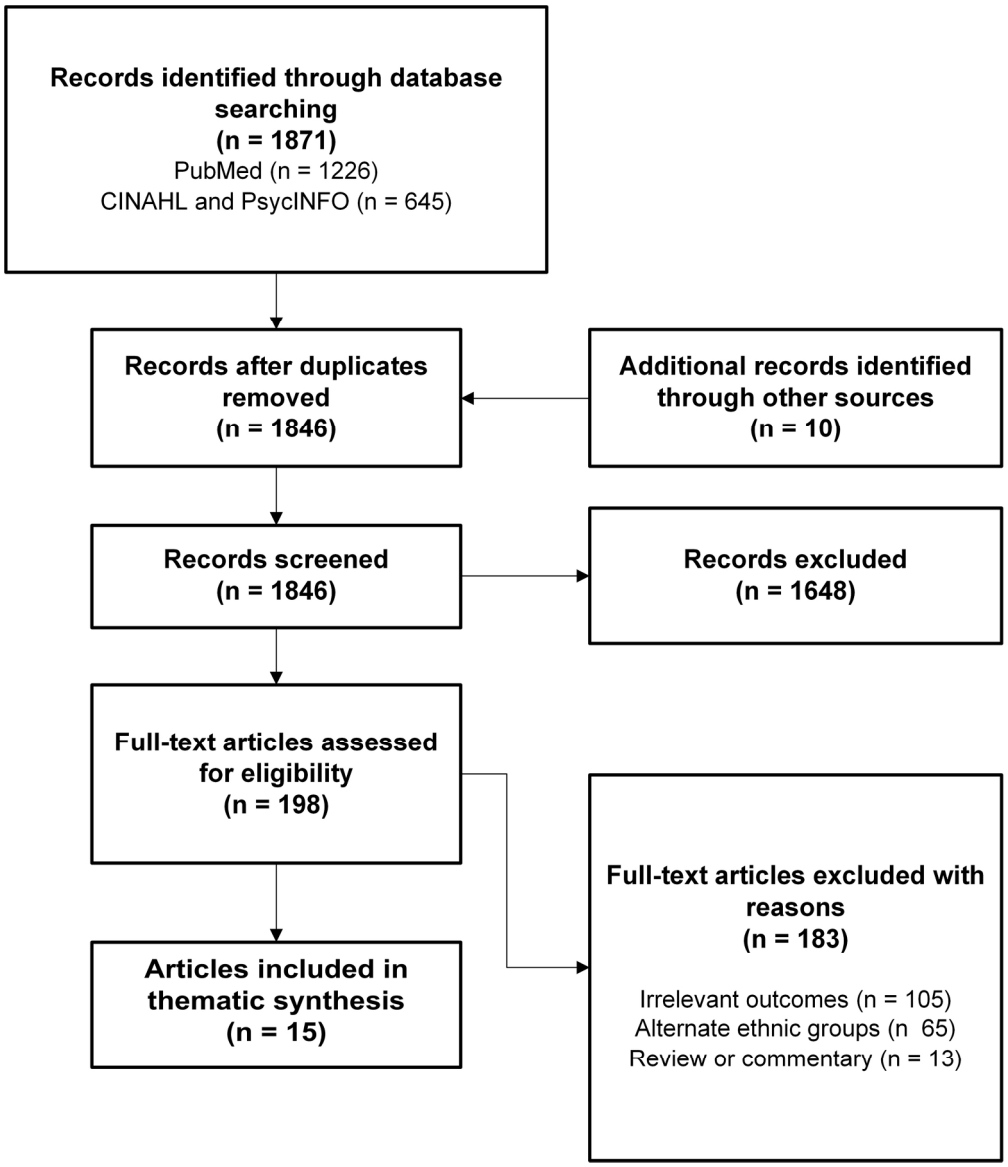

Figure 1: Flowchart of Included and Excluded Studies
Figure 1
188x217mm (300 x 300 DPI)

APPENDIX 1: LITERATURE SEARCH

Multi-database Strategy	
#	South Asian or South Asia
1	minority groups[MeSH term]
2	minority health[MeSH term]
3	Sri Lankan or Sri Lanka
4	Bangladeshi or Bangladesh
5	Pakistani or Pakistan
6	Nepalese or Nepal
7	Bhutanese or Bhutan
8	Maldivian or Maldives
9	Indian or India
10	or/1-9
11	patient selection[MeSH term]
12	recruitment
13	Enrolment or enrollment
14	recruitment strategies
15	or/10-14
16	10 and 16
17	Limit 16 to yr=”2004 –Current”
18	remove duplicates from 17

Search String:

((((((patient selection[MeSH Terms]) OR recruitment) OR enrollment) OR recruitment strategies)) AND ((((((((((south asian) OR south asia)) OR ((sri lankan) OR sri lanka)) OR ((bangladeshi) OR bangladesh)) OR ((pakistani) OR pakistan)) OR minority groups[MeSH Terms]) OR minority health[MeSH Terms]) OR ((nepalese) OR nepal)) OR ((bhutanese) OR bhutan)) OR ((maldivian) OR maldives)) OR ((indian) OR india))) Sort by: PublicationDate Filters: Publication date from 2004/01/01 to 2016/04/01

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	N/A
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	6
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	8
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	28
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	9
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	8-9
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	36
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	9-10
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	10
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	10
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	N/A
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	N/A

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	11
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	12
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	N/A
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	21-22
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	24
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	27
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	28

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