

BMJ Open

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

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2016-014889
Article Type:	Research
Date Submitted by the Author:	26-Oct-2016
Complete List of Authors:	Quay, Teo; Canadian Agency for Drugs and Technologies in Health; University of British Columbia, Faculty of Land and Food Systems Frimer, Leora; McGill University Faculty of Medicine, Department of Epidemiology, Biostatistics and Occupational Health; University of British Columbia, School of Population and Public Health, Faculty of Medicine Janssen, Patricia; University of British Columbia, School of Population and Public Health, Faculty of Medicine; BC Children's Hospital Research Institute Lamers, Yvonne; University of British Columbia, Faculty of Land and Food Systems; BC Children's Hospital Research Institute
Primary Subject Heading:	Global health
Secondary Subject Heading:	Epidemiology
Keywords:	recruitment, South Asian, minority health, patient selection, scoping review

SCHOLARONE™
Manuscripts

Only

TITLE PAGE**Title**

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

Authors

Teo A W Quay,^{1,2} Leora Frimer,^{3,4} Patricia A Janssen,^{4,5,6} Yvonne Lamers^{2,5,6}

Affiliations

¹The Canadian Agency for Drugs and Technologies in Health, Ottawa, ON, Canada

²The University of British Columbia, Faculty of Land and Food Systems, Vancouver, BC, Canada

³Department of Epidemiology, Biostatistics and Occupational Health, McGill Faculty of Medicine, Montreal, QC, Canada

⁴School of Population and Public Health, Faculty of Medicine, University of British Columbia, Vancouver, BC, Canada

⁵BC Children's Hospital Research Institute, Vancouver, BC, Canada

⁶Women's Health Research Institute, Vancouver, BC, Canada

Corresponding Author Information

Yvonne Lamers
Canada Research Chair in Human Nutrition and Vitamin Metabolism
Assistant Professor, Food, Nutrition and Health
Email: yvonne.lamers@ubc.ca
Phone: +1 604-827-1776
Fax: +1 604-822-5143
FNH 245 - 2205 East Mall
Vancouver, BC V6T 1Z4
Canada

Word Count of Body of Text 3512

Number of Tables 4

Number of Figures 1

1
2
3 **Number of References 55**
4

5 **Word Count of Abstract 231**
6

7 **Keywords and MeSH Headings:** Recruitment, South Asian, Minority Health, Patient
8

9 Selection, Scoping Review
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

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

1
2
3 groups.[15,21,22] Mental health is also an emerging area of concern, particularly in
4
5 immigrant women who have been demonstrated to have a higher risk of post-partum
6
7 depression.[13,23]
8
9

10 Adequate ethnic minority representation in health research is important to
11
12 support generalizability of research findings and to enable tailored health care for ethnic
13
14 minorities.[24,25] However, South Asians are underrepresented in research, which
15
16 drives healthcare practice.[26,27] In general, there is a lack of representative population
17
18 health research comparing minority groups in Canada to European counterparts.[26]
19
20 This under-representation also occurs in other countries; a UK-based analysis reported
21
22 that while South Asians make up 4.5% of the total population, they represented on
23
24 average only 0.6% of participants in 6 multicenter randomized controlled trials.[2,28]
25
26 Another review noted that trials assessing cardiovascular outcomes in type 2 diabetes
27
28 patients had underrepresentation of South Asian populations compared to population
29
30 proportions in the UK, but overrepresentation in the United States.[29] Even studies with
31
32 sufficient numbers of South Asians may not be truly representative of the broad
33
34 heterogeneous population.[30]
35
36
37

38 To better understand the current knowledge and perspectives on this topic, a
39
40 scoping review of the evidence regarding barriers and facilitators to recruitment, and
41
42 strategies that have been employed or evaluated to improve representation of South
43
44 Asians was undertaken. A preliminary search of the literature did not yield sufficient
45
46 reports on the Canadian population, thus the review was expanded to include literature
47
48 regarding South Asian populations residing in other countries.
49
50
51
52
53
54
55
56
57
58
59
60

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	

1
2
3 The full search strategy is available upon request from the authors. The search dates
4 were restricted in the interest of identifying the most up-to-date evidence on the topic.
5
6 The search was supplemented by scanning reference lists of included studies, searching
7 clinicaltrials.gov and PROSPERO for ongoing work, and by a focused internet search.
8
9 Study selection was limited to English language articles or articles that could be
10 translated using Google Translate. No restriction was made by publication type. Results
11 from all searched were pooled and de-duplicated prior to screening.
12
13

14 **Study Selection**

15 All types of studies including primary randomized and non-randomized quantitative and
16 qualitative studies, and systematic reviews were included. Commentaries and narrative
17 reviews were excluded. We included studies involving South Asian individuals (e.g., Sri
18 Lankan, Bangladeshi, Pakistani, Nepalese, Bhutanese, Maldivian, Indian) in any setting,
19 or studies involving multiple ethnic groups where South Asians were a specified
20 subgroup or comprised the majority of participants. Studies assessing or reporting on
21 barriers and facilitators to recruitment, and recruitment strategies were included. This
22 includes studies determining, assessing the impact or effectiveness, or assessing the
23 comparative impact or effectiveness of barriers, facilitators, and recruitment strategies.
24
25 One reviewer (TQ) independently screened titles and abstracts against the pre-specified
26 eligibility criteria. A second reviewer (LF) then screened selected abstracts. Full text
27 articles were obtained and reviewed by both authors for studies that appeared to meet
28 the eligibility criteria or where eligibility could not be adequately judged. Disagreement
29 was resolved by discussion. Study authors were not contacted for further information.
30
31

32 **Data Abstraction**

33 Data abstraction was conducted by two authors (TQ and LF) using a structured and
34 piloted extraction form. Disagreement was resolved via discussion. Data including a)
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50

1
2
3 study classifiers (lead author, publication year, country), b) study characteristics (sample
4 size, study design, subject characteristics), and c) recruitment barriers, facilitators for
5 participation, and recruitment strategy data was extracted by a single reviewer. Specific
6 descriptions of recruitment barriers, facilitators, and strategies were recorded.
7
8

9
10
11 Barriers and facilitators, and recruitment strategies were grouped thematically into key
12 topics. Once established, these themes were presented and discussed narratively. No
13 formal data synthesis or assessment of intervention effectiveness was undertaken.
14
15 Quality appraisal of selected studies is outside the scope of this review, but general
16 limitations are discussed. In addition, no formal consultation exercise with stakeholders
17 was conducted.
18
19

20 21 22 23 24 **RESULTS**

25 26 27 **Literature Search**

28
29 The original search identified 1027 potentially relevant publications. After exclusion of
30 846 publications based on title and abstract, 181 full-texts were screened and 20 articles
31 selected for duplicate assessment (Figure 1). An updated search (to April 2016)
32 identified a further 199 potentially relevant articles, from which 3 studies were selected
33 for full-text review. Of the 23 studies included for full-text review, 13 articles met the
34 inclusion criteria and were included in this report.
35
36
37
38
39
40
41

42 43 **Study Characteristics**

44 The final thirteen articles included in this review focused on South Asian populations and
45 discussed barriers and motivations for participation in research, and potential strategies
46 for recruitment (Table 2).
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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

1
2
3 Study populations ranged in size from n=13 to n=1319. The majority of studies were
4
5 conducted in specific clinical populations. This included patients with depression,[33]
6
7 nutritional concerns,[34] asthma,[18,27,36,38] diabetes,[35,37,39] obesity,[37] in
8
9 hospital,[40] with reproductive health concerns,[41] and who were being recruited for
10
11 clinical trials.[25,30] Study designs included prospective cohort studies,[41] qualitative
12
13 interviews and focus groups,[18,25,27,30,36,38,39] literature reviews,[30,34] quantitative
14
15 surveys,[34,37] retrospective descriptive accounts of recruitment experiences,[35]
16
17 hermeneutic studies,[40] and mixed-methods syntheses.[33]
18
19

20
21 Most of the studies employed qualitative or survey-based techniques. As such,
22
23 most outcome data is sourced from direct interview statements and personal experience.
24
25 Limited empirical evidence on the effectiveness of the various recruitment strategies
26
27 discussed was available. Most of the included studies were conducted in the UK and
28
29 dealt with recruitment of clinical populations to clinical trials.
30
31

32 **Facilitators**

33
34 Three studies conducted in the UK [25,27,37] reported on facilitators of participation in
35
36 research. Subjects perceived participation in research to be a possible route to improved
37
38 treatment and health [25,27]. Participants also reported being motivated by the
39
40 importance of disease prevention and potential to contribute to scientific knowledge
41
42 [25,37], by the potential to help society through participation [25], and by a sense of
43
44 obligation to healthcare providers [25]. It was reported that higher social class and
45
46 education, and younger age influence the level of awareness of clinical trials in South
47
48 Asians.
49

50 **Barriers**

51
52 Potential barriers to recruitment of South Asians are outlined in Table 3.
53
54
55
56
57
58
59
60

Table 3. Barriers to Recruitment of South Asian Populations

Recruitment Barrier	First Author, Year of Publication								
	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		

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49

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

For peer review only

1
2
3 Treatment or participation related factors included perception of risk of adverse effects,
4
5 fear of finding out health status or experiencing the stigma of being labeled with a health
6
7 condition, previous poor experiences, mistrust of research, inability to participate due to
8
9 substance abuse or mental health issues, and fear of being reported to immigration.
10
11 Logistical concerns focused on cost of participating, time away from work, family and
12
13 other commitments, transportation and location, underrepresentation of South Asians at
14
15 recruitment sites, and lack of access to disease-specific services. Language- or culture-
16
17 specific barriers included religious or cultural conflicts, decisional hierarchies within
18
19 families, lack of understanding about the consent process, researcher stereotypes about
20
21 difficulties engaging with the South Asian population, inability to provide staff with
22
23 language and cultural competency training, inability to translate study materials, and
24
25 traditional gender roles. Some barriers related to general disinterest or lack of
26
27 awareness, including lack of interest due to previous treatment and the perception that
28
29 participation would not confer any further benefit, misgivings about the scientific
30
31 importance of the work, poor understanding of research intentions, perception of not
32
33 belonging to the society standing to benefit from research, simply not being approached
34
35 to participate, and researcher antipathy towards achieving proper representation of
36
37 South Asians. Finally, some study-specific issues included a lack of appropriate
38
39 assessment tools (e.g., translated or adapted tools) for South Asian populations, as well
40
41 as narrow entry criteria.
42
43
44
45

46 **Recruitment Strategies**

47
48 The most commonly reported strategy was involvement of the South Asian community
49
50 through mobilization of key community figures or community partnerships.[18,25,33–
51
52 35,37,41] The second most commonly reported strategies were incentives and
53
54 reciprocal benefits,[18,33,34,36,38] and demonstrated respect and knowledge of South
55
56
57
58
59
60

1
2
3 Asian culture, traditions, and ethics.[33,34,36,38,40] Multiple studies also mentioned the
4
5 development of trust and personal relationships,[33,36–38] the use of visual aids and
6
7 reduced reliance on verbal exchange,[27,34,39] providing language support and
8
9 translated materials,[33,34,37,38] personal versus written contact,[36,37,39] training for
10
11 staff in cultural competency,[18,25,33] conducting recruitment at places with high
12
13 concentrations of South Asian attendance or residence,[25,33,34] and improving
14
15 flexibility of appointment scheduling, location, childcare and transportation.[33,36,38]
16
17 Several additional strategies for recruiting South Asian populations reported by two or
18
19 fewer studies, as well as those previously discussed as outlined in Table 4.
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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					

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49

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

1
2
3 could be involved in participant engagement until the stage that it is necessary for
4
5
6 physicians to participate in the research process.

7
8 Many of the barriers to participation in research relate to cultural insensitivity,
9
10 lack of awareness of research or contact by researchers, and tangible issues like time
11
12 and cost of participating. Language was also a frequently cited issue. Language
13
14 compatibility has been reported to be of great importance to South Asian patients.[44]
15
16 Jolly *et al.* [8] observed a significantly higher proportion of South Asian individuals being
17
18 excluded from participation in research due to language barriers compared to 'White
19
20 Europeans' or those of 'Other' ethnicities. The use of multilingual research assistants, or
21
22 principal investigators from the same ethnic background, or with language and cultural
23
24 competency training has been proposed as a possible strategy to overcome language
25
26 barriers. This approach may also allow for larger recruitment pools if these staff are part
27
28 of or able to access networks within the South Asian community.[45] The effectiveness
29
30 of this strategy has been demonstrated in the successful recruitment and long-term
31
32 retention of pregnant South Asian women for a study involving sample collection from
33
34 the mother and baby in the UK.[46]
35
36

37
38 Other common barriers related to negative and discordant perceptions between
39
40 researchers and South Asian participants. Various stereotypes held by health
41
42 professionals conducting research on South Asian populations were highlighted as
43
44 recruitment deterrents. Specific examples include perceptions that South Asians are not
45
46 punctual, that they will have language limitations, generalizations that certain
47
48 subpopulations (e.g., seniors) would not have an interest in participating, perceived
49
50 issues with gender hierarchies (e.g., inability of women to make independent decisions),
51
52 the misconception that South Asians are not interested in disease prevention, and the
53
54 association of English speaking with intelligence and potentially greater trial
55
56
57
58
59
60

1
2
3 compatibility. On the other hand, South Asians reported that mistrust, mistreatment and
4
5 disrespectful behavior, sub-par care for non-English speakers, and previous poor
6
7 experiences participating in research would deter willingness to participate.[30] Cross-
8
9 cultural education of individuals working in research to dispel incorrect racial and cultural
10
11 stereotypes, as well as education of South Asian communities to dispel some
12
13 misconceptions about health research should be encouraged.[47]
14

15
16 From a logistical perspective, studies focused on South Asians may require
17
18 upfront budgeting for enhanced recruitment strategies to address the unique barriers
19
20 discussed. In particular, funds for multiple research sites, transportation of patients,
21
22 incentives, and childcare may need to be accounted for at the grant funding stages.
23
24 Support for minority recruitment may be better in the US where the National Institutes of
25
26 Health Revitalization Act of 1993 promotes opportunities for women and minorities to
27
28 participate in health research.[48,49] There is mandated support for gender
29
30 representation, but not for minority representation in Canada.[50] Government or
31
32 institutional regulations promoting minority representation may encourage researchers to
33
34 confront various barriers, despite the challenges involved.
35
36

37
38 There were some similarities and differences in the findings of this scoping
39
40 review compared to what has been reported for other ethnic groups. Congruent with our
41
42 findings, a systematic review of recruitment barriers and facilitators in African Americans,
43
44 Latinos, Asian Americans, and Pacific Islanders in the US reported that issues of
45
46 mistrust, competing demands, unintended outcomes, lack of access to research
47
48 information, stigma, health insurance coverage, and jeopardizing legal status in the US
49
50 were barriers to participation in research.[24] Facilitators included cultural congruence,
51
52 benefits to participation, altruism, convenience of participation, and low risks associated
53
54 with participation. They also found that there were issues specific to ethnic groups. For
55
56
57
58
59
60

1
2
3 instance, African Americans were disturbed by the legacy of the Tuskegee syphilis
4 study, and Asian Americans often required the endorsement from family members.
5
6 Another systematic review[51] that assessed barriers and facilitators in indigenous
7 populations in several countries including the US, Canada, Australia, and New Zealand,
8 reported that relationships and partnership, indigenous staff, indigenous knowledge
9 models, targeted recruitment, and adaptation of study material were associated with
10 improved recruitment, whereas factors such as distrust of research attributable to the
11 participants, study-centric issues such as trial design (no phone, travel costs), and lack
12 of incorporation of indigenous knowledge systems dissuaded individuals from
13 participating. While some barriers such as logistical issues may be common to multiple
14 ethnic groups, the strategies to address cultural factors may differ depending on
15 ethnicity. This highlights the importance of establishing targeted recruitment strategies
16 specific not only to an individual ethnic group, but also that address heterogeneity within
17 an ethnic group.
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32

33
34 A strength of this review is that a range of perspectives and ideas regarding
35 recruitment of South Asians have been summarized and grouped thematically.
36 Accordingly, this review represents a comprehensive in-depth overview of this subject
37 area, and provides a good estimate of the volume and characteristics of the published
38 literature. Further, this review highlights areas for future investigation such as evaluation
39 of the effectiveness of the proposed recruitment strategies in the Canadian setting.
40
41
42
43
44
45
46 There were several limitations to this review and the individual studies included.
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65
66
67
68
69
70
71
72
73
74
75
76
77
78
79
80
81
82
83
84
85
86
87
88
89
90
91
92
93
94
95
96
97
98
99
100
101
102
103
104
105
106
107
108
109
110
111
112
113
114
115
116
117
118
119
120
121
122
123
124
125
126
127
128
129
130
131
132
133
134
135
136
137
138
139
140
141
142
143
144
145
146
147
148
149
150
151
152
153
154
155
156
157
158
159
160
161
162
163
164
165
166
167
168
169
170
171
172
173
174
175
176
177
178
179
180
181
182
183
184
185
186
187
188
189
190
191
192
193
194
195
196
197
198
199
200
201
202
203
204
205
206
207
208
209
210
211
212
213
214
215
216
217
218
219
220
221
222
223
224
225
226
227
228
229
230
231
232
233
234
235
236
237
238
239
240
241
242
243
244
245
246
247
248
249
250
251
252
253
254
255
256
257
258
259
260
261
262
263
264
265
266
267
268
269
270
271
272
273
274
275
276
277
278
279
280
281
282
283
284
285
286
287
288
289
290
291
292
293
294
295
296
297
298
299
300
301
302
303
304
305
306
307
308
309
310
311
312
313
314
315
316
317
318
319
320
321
322
323
324
325
326
327
328
329
330
331
332
333
334
335
336
337
338
339
340
341
342
343
344
345
346
347
348
349
350
351
352
353
354
355
356
357
358
359
360
361
362
363
364
365
366
367
368
369
370
371
372
373
374
375
376
377
378
379
380
381
382
383
384
385
386
387
388
389
390
391
392
393
394
395
396
397
398
399
400
401
402
403
404
405
406
407
408
409
410
411
412
413
414
415
416
417
418
419
420
421
422
423
424
425
426
427
428
429
430
431
432
433
434
435
436
437
438
439
440
441
442
443
444
445
446
447
448
449
450
451
452
453
454
455
456
457
458
459
460
461
462
463
464
465
466
467
468
469
470
471
472
473
474
475
476
477
478
479
480
481
482
483
484
485
486
487
488
489
490
491
492
493
494
495
496
497
498
499
500
501
502
503
504
505
506
507
508
509
510
511
512
513
514
515
516
517
518
519
520
521
522
523
524
525
526
527
528
529
530
531
532
533
534
535
536
537
538
539
540
541
542
543
544
545
546
547
548
549
550
551
552
553
554
555
556
557
558
559
560
561
562
563
564
565
566
567
568
569
570
571
572
573
574
575
576
577
578
579
580
581
582
583
584
585
586
587
588
589
590
591
592
593
594
595
596
597
598
599
600
601
602
603
604
605
606
607
608
609
610
611
612
613
614
615
616
617
618
619
620
621
622
623
624
625
626
627
628
629
630
631
632
633
634
635
636
637
638
639
640
641
642
643
644
645
646
647
648
649
650
651
652
653
654
655
656
657
658
659
660
661
662
663
664
665
666
667
668
669
670
671
672
673
674
675
676
677
678
679
680
681
682
683
684
685
686
687
688
689
690
691
692
693
694
695
696
697
698
699
700
701
702
703
704
705
706
707
708
709
710
711
712
713
714
715
716
717
718
719
720
721
722
723
724
725
726
727
728
729
730
731
732
733
734
735
736
737
738
739
740
741
742
743
744
745
746
747
748
749
750
751
752
753
754
755
756
757
758
759
760
761
762
763
764
765
766
767
768
769
770
771
772
773
774
775
776
777
778
779
780
781
782
783
784
785
786
787
788
789
790
791
792
793
794
795
796
797
798
799
800
801
802
803
804
805
806
807
808
809
810
811
812
813
814
815
816
817
818
819
820
821
822
823
824
825
826
827
828
829
830
831
832
833
834
835
836
837
838
839
840
841
842
843
844
845
846
847
848
849
850
851
852
853
854
855
856
857
858
859
860
861
862
863
864
865
866
867
868
869
870
871
872
873
874
875
876
877
878
879
880
881
882
883
884
885
886
887
888
889
890
891
892
893
894
895
896
897
898
899
900
901
902
903
904
905
906
907
908
909
910
911
912
913
914
915
916
917
918
919
920
921
922
923
924
925
926
927
928
929
930
931
932
933
934
935
936
937
938
939
940
941
942
943
944
945
946
947
948
949
950
951
952
953
954
955
956
957
958
959
960
961
962
963
964
965
966
967
968
969
970
971
972
973
974
975
976
977
978
979
980
981
982
983
984
985
986
987
988
989
990
991
992
993
994
995
996
997
998
999
1000

1
2
3 recruitment strategies for South Asians in these studies, and the majority of the evidence
4
5 is in the context of clinical trials. The usefulness of the proposed recruitment strategies
6
7 outside of the clinical trial setting is unknown. The applicability of the strategies
8
9 presented may vary, as some proposed solutions are relatively straightforward, while
10
11 others are more complex and difficult to apply. As discussed by Waheed et al.,[33]
12
13 changing recruitment venues may be easy, but provision of appropriate incentives and
14
15 catering to specific health and cultural beliefs may be more difficult to execute. The
16
17 primary types of studies that have been used to investigate potential recruitment
18
19 strategies in South Asian populations include focus groups and interviews. These
20
21 studies provide valuable insight into participant and researcher perspectives, but do not
22
23 directly address the quantitative impact of barriers or facilitators or effectiveness of
24
25 recruitment strategies. Where empirical data exists, it is often limited to descriptive rates
26
27 of recruitment and retention based on the results of quantitative surveys or prospective
28
29 cohort studies. Documentation of barriers to recruitment in future studies including South
30
31 Asian participants via qualitative interviews during the recruitment process would help to
32
33 address this gap. As well, assessment tools, such as the Barriers to Research
34
35 Participation Questionnaire, may assist in determining hurdles to research participation
36
37 in specific populations in a structured manner [52]. Since this was a scoping review
38
39 aimed at mapping the current literature on this topic, we did not complete a quality
40
41 assessment of the data. The search date restrictions that were imposed may have
42
43 excluded studies with valuable historical perspectives. Also, we did not search
44
45 databases of qualitative research, which may have resulted in oversight of relevant
46
47 evidence. We attempted to overcome this to some extent with the grey literature search
48
49 strategies. However, we believe this review captures a relevant snapshot of the most up-
50
51 to-date research on this topic.
52
53
54
55
56
57
58
59
60

1
2
3 The evidence reviewed suggests that recruitment methods aimed at engaging
4 with the target population may have a positive impact. One such intervention that was
5 not discussed explicitly by the included studies is community based participatory
6 research, which employs strategies such as involving trusted community members as
7 study staff, which has been shown to be effective at mitigating ethical and cultural
8 challenges in research [53]. This approach may have the potential to mobilize individuals
9 to take ownership of their health and encourage education and participation within their
10 communities, and to ensure appropriate dissemination of findings [54,55]. The paucity of
11 evidence, particularly in the Canadian context, suggests that work is still needed to
12 determine context-specific barriers and facilitators to recruitment, and associated
13 strategies to increase the participation of South Asians in health research. A mixed-
14 methods synthesis from the Canadian perspective linking experiences of individuals and
15 groups to the evidence on effectiveness of recruitment strategies may shed some light
16 on potential approaches researchers could employ in future studies. Given the lack of
17 empirical data, proposed recruitment strategies should be quantitatively evaluated to
18 determine the relative effectiveness and value.
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36

37 **Conclusions**

38
39 Better representation of South Asians in health research may promote
40 development of tailored treatment, increased awareness and ownership of health, and
41 support the ultimate goals of improving the health of the South Asian population and
42 reducing healthcare spending. The information presented in this review can be used to
43 assist researchers when preparing to conduct research, and may help to inform a more
44 in-depth analysis of this issue from a Canadian perspective. Consideration of these
45 issues during the grant writing and protocol stages of research may decrease the risk of
46 encountering recruitment problems at latter stages.
47
48
49
50
51
52
53
54
55
56
57
58
59
60

ACKNOWLEDGEMENTS

YL acknowledges funding from the Canada Research Chair program of the Canadian Institutes of Health Research. PJ is supported by a Senior Scientist Salary Award from the BC Children's Hospital Research Institute.

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.

FUNDING STATEMENT

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

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.

REFERENCES

- 1 Government of Canada SC. National Household Survey: Immigration and Ethnocultural Diversity. 2014. <http://www5.statcan.gc.ca/olc-cel/olc.action?ObjId=99-010-X&ObjType=2&lang=en&limit=1> (accessed 27 May2015).
- 2 Ethnicity and National Identity in England and Wales - Office for National Statistics. <http://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/ethnicityandnationalidentityinenglandandwales/2012-12-11> (accessed 19 Jun2016).
- 3 Statistics Canada. Projections of the Diversity of the Canadian Population. 2013. <http://www12.statcan.gc.ca/census-recensement/2011/ref/92-135/surveys-enquetes/vismin-population-minvis-eng.cfm> (accessed 10 Jul2014).
- 4 Asanin J, Wilson K. "I spent nine years looking for a doctor": exploring access to health care among immigrants in Mississauga, Ontario, Canada. *Soc Sci Med* 1982 2008;**66**:1271–83. doi:10.1016/j.socscimed.2007.11.043
- 5 Hussain-Gambles M, Atkin K, Leese B. Why ethnic minority groups are under-represented in clinical trials: a review of the literature. *Health Soc Care Community* 2004;**12**:382–8. doi:10.1111/j.1365-2524.2004.00507.x
- 6 Hilton BA, Grewal S, Popatia N, *et al*. The desi ways: traditional health practices of South Asian women in Canada. *Health Care Women Int* 2001;**22**:553–67. doi:10.1080/07399330127195
- 7 Bhandari N, Taneja S, Rongsen T, *et al*. Implementation of the WHO Multicentre Growth Reference Study in India. *Food Nutr Bull* 2004;**25**:S66-71.
- 8 Jolly K, Lip GY, Taylor RS, *et al*. Recruitment of ethnic minority patients to a cardiac rehabilitation trial: the Birmingham Rehabilitation Uptake Maximisation (BRUM) study [ISRCTN72884263]. *BMC Med Res Methodol* 2005;**5**:18. doi:10.1186/1471-2288-5-18
- 9 Bajaj S, Jawad F, Islam N, *et al*. South Asian women with diabetes: Psychosocial challenges and management: Consensus statement. *Indian J Endocrinol Metab* 2013;**17**:548–62. doi:10.4103/2230-8210.113720
- 10 Statistics Canada. The South Asian Community in Canada. 2007. <http://www.statcan.gc.ca/pub/89-621-x/89-621-x2007006-eng.htm> (accessed 19 Aug2013).
- 11 Lucas A, Murray E, Kinra S. Heath beliefs of UK South Asians related to lifestyle diseases: a review of qualitative literature. *J Obes* 2013;**2013**:827674. doi:10.1155/2013/827674
- 12 Grewal K, Stewart DE, Grace SL. Differences in social support and illness perceptions among South Asian and Caucasian patients with coronary artery disease. *Heart Lung J Crit Care* 2010;**39**:180–7. doi:10.1016/j.hrtlng.2009.06.016

- 1
2
3 13 Nilaweera I, Doran F, Fisher J. Prevalence, nature and determinants of postpartum
4 mental health problems among women who have migrated from South Asian to high-
5 income countries: a systematic review of the evidence. *J Affect Disord*
6 2014;**166**:213–26. doi:10.1016/j.jad.2014.05.021
7
- 8
9 14 Veenstra G, Patterson AC. South Asian-White health inequalities in Canada:
10 intersections with gender and immigrant status. *Ethn Health* 2016;:1–10.
11 doi:10.1080/13557858.2016.1179725
12
- 13 15 Gupta M, Singh N, Verma S. South Asians and Cardiovascular Risk What Clinicians
14 Should Know. *Circulation* 2006;**113**:e924–9.
15 doi:10.1161/CIRCULATIONAHA.105.583815
16
- 17 16 Anand SS, Yusuf S, Vuksan V, *et al.* Differences in risk factors, atherosclerosis, and
18 cardiovascular disease between ethnic groups in Canada: the Study of Health
19 Assessment and Risk in Ethnic groups (SHARE). *Lancet* 2000;**356**:279–84.
20
- 21 17 Rana A, Souza RJ de, Kandasamy S, *et al.* Cardiovascular risk among South Asians
22 living in Canada: a systematic review and meta-analysis. *Can Med Assoc Open*
23 *Access J* 2014;**2**:E183–91. doi:10.9778/cmajo.20130064
24
- 25 18 Sheikh A, Halani L, Bhopal R, *et al.* Facilitating the Recruitment of Minority Ethnic
26 People into Research: Qualitative Case Study of South Asians and Asthma. *PLoS*
27 *Med* 2009;**6**:e1000148. doi:10.1371/journal.pmed.1000148
28
- 29 19 Razak F, Anand SS, Shannon H, *et al.* Defining obesity cut points in a multiethnic
30 population. *Circulation* 2007;**115**:2111–8.
31 doi:10.1161/CIRCULATIONAHA.106.635011
32
- 33 20 Twells LK, Gregory DM, Reddigan J, *et al.* Current and predicted prevalence of
34 obesity in Canada: a trend analysis. *CMAJ Open* 2014;**2**:E18–26.
35 doi:10.9778/cmajo.20130016
36
- 37 21 Chiu M, Austin PC, Manuel DG, *et al.* Deriving Ethnic-Specific BMI Cutoff Points for
38 Assessing Diabetes Risk. *Diabetes Care* 2011;**34**:1741–8. doi:10.2337/dc10-2300
39
- 40 22 Nanditha A, Ma RCW, Ramachandran A, *et al.* Diabetes in Asia and the Pacific:
41 Implications for the Global Epidemic. *Diabetes Care* 2016;**39**:472–85.
42 doi:10.2337/dc15-1536
43
- 44 23 Sword W, Watt S, Krueger P. Postpartum health, service needs, and access to care
45 experiences of immigrant and Canadian-born women. *J Obstet Gynecol Neonatal*
46 *Nurs JOGNN NAACOG* 2006;**35**:717–27. doi:10.1111/j.1552-6909.2006.00092.x
47
- 48 24 George S, Duran N, Norris K. A systematic review of barriers and facilitators to
49 minority research participation among African Americans, Latinos, Asian Americans,
50 and Pacific Islanders. *Am J Public Health* 2014;**104**:e16–31.
51 doi:10.2105/AJPH.2013.301706
52
53
54
55
56
57
58
59
60

- 1
2
3 25 Hussain-Gambles M, Leese B, Atkin K, *et al.* Involving South Asian patients in
4 clinical trials. *Health Technol Assess Winch Engl* 2004;**8**:iii, 1-109.
5
6
7 26 Khan M, Kobayashi K, Lee SM, *et al.* (In)Visible Minorities in Canadian Health Data
8 and Research. *Popul Change Lifecourse Strateg Knowl Clust Discuss Pap Ser Un*
9 *Réseau Strat Connaiss Chang Popul Parcours Vie Doc Trav* 2015;**3**:5.
10
11 27 Macneill V, Nwokoro C, Griffiths C, *et al.* Recruiting ethnic minority participants to a
12 clinical trial: a qualitative study. *BMJ Open* 2013;**3**. doi:10.1136/bmjopen-2013-
13 002750
14
15 28 Mason S, Hussain-Gambles M, Leese B, *et al.* Representation of South Asian
16 people in randomised clinical trials: analysis of trials' data. *BMJ* 2003;**326**:1244–5.
17 doi:10.1136/bmj.326.7401.1244
18
19 29 Khunti K, Bellary S, Karamat MA, *et al.* Representation of people of South Asian
20 origin in cardiovascular outcome trials of glucose-lowering therapies in Type 2
21 diabetes. *Diabet Med J Br Diabet Assoc* Published Online First: 1 March 2016.
22 doi:10.1111/dme.13103
23
24 30 Hussain-Gambles M, Atkin K, Leese B. South Asian participation in clinical trials: the
25 views of lay people and health professionals. *Health Policy Amst Neth* 2006;**77**:149–
26 65. doi:10.1016/j.healthpol.2005.07.022
27
28 31 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J*
29 *Soc Res Methodol* 2005;**8**:19–32. doi:10.1080/1364557032000119616
30
31 32 Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology.
32 *Implement Sci* 2010;**5**:69. doi:10.1186/1748-5908-5-69
33
34 33 Waheed W, Husain N, Allen G, *et al.* Recruitment strategies for British South Asians
35 in 5 depression trials: A mixed method study. *J Affect Disord* 2015;**185**:195–203.
36 doi:10.1016/j.jad.2015.06.046
37
38 34 Garduño-Díaz SD, Husain W, Ashkanani F, *et al.* Meeting challenges related to the
39 dietary assessment of ethnic minority populations. *J Hum Nutr Diet Off J Br Diet*
40 *Assoc* 2014;**27**:358–66. doi:10.1111/jhn.12153
41
42 35 Douglas A, Bhopal RS, Bhopal R, *et al.* Recruiting South Asians to a lifestyle
43 intervention trial: experiences and lessons from PODOSA (Prevention of Diabetes &
44 Obesity in South Asians). *Trials* 2011;**12**:220. doi:10.1186/1745-6215-12-220
45
46 36 Rooney LK, Bhopal R, Halani L, *et al.* Promoting recruitment of minority ethnic
47 groups into research: qualitative study exploring the views of South Asian people
48 with asthma. *J Public Health Oxf Engl* 2011;**33**:604–15. doi:10.1093/pubmed/fdq100
49
50 37 Samsudeen BS, Douglas A, Bhopal RS. Challenges in recruiting South Asians into
51 prevention trials: health professional and community recruiters' perceptions on the
52 PODOSA trial. *Public Health* 2011;**125**:201–9. doi:10.1016/j.puhe.2011.01.013
53
54
55
56
57
58
59
60

- 1
2
3 38 Stirland L, Halani L, Raj B, *et al.* Recruitment of South Asians into asthma research:
4 qualitative study of UK and US researchers. *Prim Care Respir J J Gen Pract Airw*
5 *Group* 2011;**20**:282–290, 8 p following 290. doi:10.4104/pcrj.2011.00032
6
7
8 39 Lloyd CE, Johnson MR, Mughal S, *et al.* Securing recruitment and obtaining
9 informed consent in minority ethnic groups in the UK. *BMC Health Serv Res*
10 2008;**8**:68. doi:10.1186/1472-6963-8-68
11
12 40 Mohammadi N, Jones T, Evans D. Participant recruitment from minority religious
13 groups: the case of the Islamic population in South Australia. *Int Nurs Rev*
14 2008;**55**:393–8. doi:10.1111/j.1466-7657.2008.00647.x
15
16 41 Krupp K, Madhivanan P, Karat C, *et al.* Novel recruitment strategies to increase
17 participation of women in reproductive health research in India. *Glob Public Health*
18 2007;**2**:395–403. doi:10.1080/17441690701238031
19
20 42 Pratt B, Van C, Cong Y, *et al.* Perspectives from South and East Asia on Clinical and
21 Research Ethics: A Literature Review. *J Empir Res Hum Res Ethics* 2014;**9**:52–67.
22 doi:10.1525/jer.2014.9.2.52
23
24 43 Symonds RP, Lord K, Mitchell AJ, *et al.* Recruitment of ethnic minorities into cancer
25 clinical trials: experience from the front lines. *Br J Cancer* 2012;**107**:1017–21.
26 doi:10.1038/bjc.2012.240
27
28 44 Ahmad F, Gupta H, Rawlins J, *et al.* Preferences for gender of family physician
29 among Canadian European-descent and South-Asian immigrant women. *Fam Pract*
30 2002;**19**:146–53.
31
32 45 Lee SK, Sulaiman-Hill CR, Thompson SC. Overcoming language barriers in
33 community-based research with refugee and migrant populations: options for using
34 bilingual workers. *BMC Int Health Hum Rights* 2014;**14**:11. doi:10.1186/1472-698X-
35 14-11
36
37 46 Neelotpol S, Hay AWM, Jolly AJ, *et al.* Challenges in collecting clinical samples for
38 research from pregnant women of South Asian origin: evidence from a UK study.
39 *BMJ Open* 2016;**6**:e010554. doi:10.1136/bmjopen-2015-010554
40
41 47 Marshall A, Batten S. Researching Across Cultures: Issues of Ethics and Power.
42 *Forum Qual Sozialforschung Forum Qual Soc Res* 2004;**5**.[http://www.qualitative-](http://www.qualitative-research.net/index.php/fqs/article/view/572)
43 [research.net/index.php/fqs/article/view/572](http://www.qualitative-research.net/index.php/fqs/article/view/572) (accessed 13 Feb2015).
44
45 48 Inclusion: The Politics of Difference in Medical Research, Epstein.
46 <http://press.uchicago.edu/ucp/books/book/chicago/l/bo5414954.html> (accessed 20
47 Jun2016).
48
49 49 NIH Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical
50 Research - Amended, October, 2001.
51 https://grants.nih.gov/grants/funding/women_min/guidelines_amended_10_2001.htm
52 (accessed 20 Jun2016).
53
54
55
56
57
58
59
60

- 1
2
3 50 Report on governmental health research policies promoting gender or sex differences
4 sensitivity | Canadian Women's Health Network. <http://www.cwhn.ca/en/node/25386>
5 (accessed 20 Jun2016).
6
7
8 51 Glover M, Kira A, Johnston V, *et al.* A systematic review of barriers and facilitators to
9 participation in randomized controlled trials by Indigenous people from New Zealand,
10 Australia, Canada and the United States. *Glob Health Promot* 2015;**22**:21–31.
11 doi:10.1177/1757975914528961
12
13 52 Kibler JL, Brisco K. Evaluation of a brief questionnaire for assessing Barriers to
14 Research Participation. *Ethn Dis* 2006;**16**:547–50.
15
16 53 Minkler M. Community-based research partnerships: Challenges and opportunities. *J*
17 *Urban Health Bull N Y Acad Med* 2005;**82**:ii3-ii12. doi:10.1093/jurban/jti034
18
19 54 Choudhry U k., Jandu S, Mahal J, *et al.* Health Promotion and Participatory Action
20 Research with South Asian Women. *J Nurs Scholarsh* 2002;**34**:75–81.
21 doi:10.1111/j.1547-5069.2002.00075.x
22
23 55 Getrich CM, Sussman AL, Campbell-Voytal K, *et al.* Cultivating a cycle of trust with
24 diverse communities in practice-based research: a report from PRIME Net. *Ann Fam*
25 *Med* 2013;**11**:550–8. doi:10.1370/afm.1543
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

FIGURE LEGENDS

Figure 1: Flowchart of Included and Excluded Studies

For peer review only

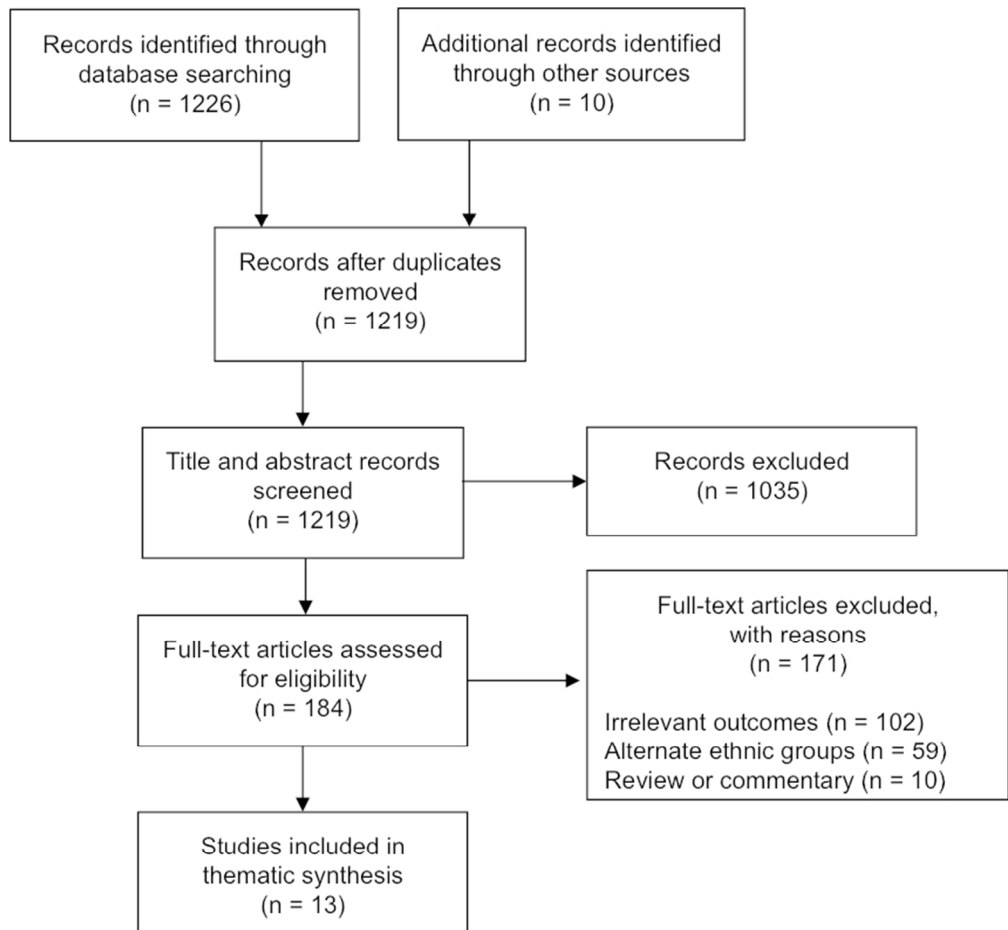


Figure 1: Flowchart of Included and Excluded Studies
Figure 1

only

BMJ Open

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

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2016-014889.R1
Article Type:	Research
Date Submitted by the Author:	08-Feb-2017
Complete List of Authors:	Quay, Teo; Canadian Agency for Drugs and Technologies in Health; University of British Columbia, Faculty of Land and Food Systems Frimer, Leora; McGill University Faculty of Medicine, Department of Epidemiology, Biostatistics and Occupational Health; University of British Columbia, School of Population and Public Health, Faculty of Medicine Janssen, Patricia; University of British Columbia, School of Population and Public Health, Faculty of Medicine; BC Children's Hospital Research Institute Lamers, Yvonne; University of British Columbia, Faculty of Land and Food Systems; BC Children's Hospital Research Institute
Primary Subject Heading:	Global health
Secondary Subject Heading:	Epidemiology
Keywords:	recruitment, South Asian, minority health, patient selection, scoping review

SCHOLARONE™
Manuscripts

Only

TITLE PAGE**Title**

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

Authors

Teo A W Quay,^{1,2} Leora Frimer,^{3,4} Patricia A Janssen,^{4,5,6} Yvonne Lamers^{2,5,6}

Affiliations

¹The Canadian Agency for Drugs and Technologies in Health, Ottawa, ON, Canada

²The University of British Columbia, Faculty of Land and Food Systems, Vancouver, BC, Canada

³Department of Epidemiology, Biostatistics and Occupational Health, McGill Faculty of Medicine, Montreal, QC, Canada

⁴School of Population and Public Health, Faculty of Medicine, University of British Columbia, Vancouver, BC, Canada

⁵BC Children's Hospital Research Institute, Vancouver, BC, Canada

⁶Women's Health Research Institute, Vancouver, BC, Canada

Corresponding Author Information

Yvonne Lamers
Canada Research Chair in Human Nutrition and Vitamin Metabolism
Assistant Professor, Food, Nutrition and Health
Email: yvonne.lamers@ubc.ca
Phone: +1 604-827-1776
Fax: +1 604-822-5143
FNH 245 - 2205 East Mall
Vancouver, BC V6T 1Z4
Canada

Word Count of Body of Text 4108

Number of Tables 4

Number of Figures 1

1
2
3 **Appendices: 1**

4
5 **Number of References 67**

6
7 **Word Count of Abstract 234**

8
9 **Keywords and MeSH Headings:** Recruitment, South Asian, Minority Health, Patient
10
11 Selection, Scoping Review
12
13

14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

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 centre, 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

1
2
3 religious, dietary, and healthcare practices, which may not align with modern western or
4 allopathic medicine[21] and clinical research approaches.[22,23] Lack of support from
5 families and communities in seeking healthcare and making healthcare decisions may
6 discourage South Asians from engaging in risk-reducing health behaviors, including
7 participation in research.[24] Lack of English language proficiency, unfamiliarity with
8 local services, and lack of attention to cultural factors by health care providers may pose
9 a particular challenge to healthcare service access for female South Asians.[14]

10
11 Adequate ethnic minority representation in health research is important to
12 support generalizability of research findings and to enable tailored health care for ethnic
13 minorities.[25,26] However, South Asians are underrepresented in research, resulting in
14 healthcare practice based on research with limited external validity for the South Asian
15 context.[27,28] In general, there is a lack of representative population health research
16 comparing minority groups in Canada to European counterparts.[27] This under-
17 representation also occurs elsewhere; a UK-based analysis reported that while South
18 Asians make up 4.5% of the total population, they represented on average only 0.6% of
19 participants in 6 multicenter randomized controlled trials.[2,29] Another review noted that
20 trials assessing cardiovascular outcomes in type 2 diabetes patients had
21 underrepresentation of South Asian populations compared to population proportions in
22 the UK, but overrepresentation in the United States.[30] Even studies with sufficient
23 numbers of South Asians may not be truly representative of the broad heterogeneous
24 population, as diets, lifestyles, and baseline health risk is noted to vary across South
25 Asians of different origin.[31]

26
27 To better understand the current knowledge and perspectives on this topic, a
28 scoping review of the evidence regarding barriers and facilitators to recruitment, and
29 strategies that have been employed or evaluated to improve representation of South
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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.

For peer review only

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

1
2
3 includes studies determining, assessing the impact or effectiveness, or assessing the
4 comparative impact or effectiveness of barriers, facilitators, and recruitment strategies.
5
6 One reviewer (TQ) independently screened titles and abstracts against the pre-specified
7 eligibility criteria. A second reviewer (LF) then screened selected abstracts. Full text
8 articles were obtained and reviewed by both authors for studies that appeared to meet
9 the eligibility criteria or where eligibility could not be adequately judged. Disagreement
10 was resolved by discussion among the two reviewers with a third reviewer consulted if
11 deemed necessary. Study authors were not contacted for further information.
12
13
14
15
16
17
18
19

20 **Data Abstraction**

21
22 Data abstraction was conducted in duplicate by two authors (TQ and LF) using a
23 structured extraction form piloted on two studies. Disagreement was resolved via
24 discussion. Data including a) study classifiers (lead author, publication year, country), b)
25 study characteristics (sample size, study design, subject characteristics), and c)
26 recruitment barriers, facilitators for participation, and recruitment strategy data was
27 extracted. Specific descriptions of recruitment barriers, facilitators, and strategies were
28 recorded.
29
30
31
32
33
34
35
36

37 Barriers and facilitators, and recruitment strategies were grouped thematically into key
38 topics. Once established, these themes were presented and discussed narratively. No
39 formal data synthesis or assessment of intervention effectiveness was undertaken.
40
41
42

43 Quality appraisal of selected studies is outside the scope of this review, but general
44 limitations are discussed. In addition, no formal consultation exercise with stakeholders
45 was conducted.
46
47
48
49

50 **RESULTS**

51 **Literature Search**

1
2
3 The original search on PubMed and Cochrane (2004 to October 2014) identified 1027
4 potentially relevant publications. A further 10 studies were identified from grey literature
5 sources. The original search was updated in April 2016 and 199 more potentially
6 relevant articles were identified. Also, the databases CINAHL and PsycINFO were added
7 and these searches (2004 to April 2016) identified 645 more potentially relevant articles.
8 In total, 1846 records were screened after duplicates were removed. Based on title and
9 abstract 1648 records were excluded and 198 full-texts were screened (Figure 1). Of the
10 198 studies included for full-text review, 183 were excluded for various reasons (i.e.,
11 irrelevant outcomes, study of alternate ethnic groups, review or commentary) and 15
12 articles met the inclusion criteria (n = 9 from original PubMed search; n = 4 from PubMed
13 search update; n = 2 from CINAHL and PsycINFO) and were included in this report.

24 25 26 27 **Study Characteristics**

28 The final fifteen articles included in this review focused on South Asian populations and
29 discussed barriers and motivations for participation in research, and potential strategies
30 for recruitment. Primary study characteristics including research area, study populations,
31 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

1
2
3 Study populations ranged in size from n=2 to n=1319. The majority of studies were
4 conducted in specific clinical populations. This included patients with mental health
5 issues,[34,35] nutritional concerns,[36] asthma,[8,28,38,40] diabetes,[37,39,41]
6 obesity,[39] in hospital (i.e., tertiary care),[42] with reproductive health concerns,[43] who
7 were being recruited for clinical trials,[26,31] and for a study on spousal abuse.[44]
8
9 Study designs included prospective cohort studies,[43] thematic analysis[35], qualitative
10 surveys, interviews and focus groups,[8,26,28,31,38,40,41,44] literature reviews,[31,36]
11 quantitative surveys,[36,39] retrospective descriptive accounts of recruitment
12 experiences,[37] hermeneutic studies,[42] and mixed-methods syntheses.[34]
13
14

15
16 Most of the studies employed qualitative or survey-based techniques. As such,
17 most outcome data is sourced from direct interview statements and personal experience.
18 Limited empirical evidence on the effectiveness of the various recruitment strategies
19 discussed was available.[34,36,39,43] Most of the included studies were conducted in
20 the UK [8,26,28,31,34–41] and dealt with recruitment of clinical populations to clinical
21 trials.[8,26,28,31,34,37–41]
22
23

24 **Facilitators**

25
26 Three studies conducted in the UK [26,28,39] reported on facilitators of participation in
27 research. Subjects perceived participation in research to be a possible route to improved
28 treatment and health [26,28]. Participants also reported being motivated by the
29 importance of disease prevention and potential to contribute to scientific knowledge
30 [26,39], by the potential to help society through participation [26], and by a sense of
31 obligation to healthcare providers [26]. It was reported that higher social class and
32 education, and younger age influence the level of awareness of clinical trials in South
33 Asians.[26]
34
35

36 **Barriers**

1
2
3 Potential barriers to recruitment of South Asians are outlined in Table 3. Participant-
4 related factors followed themes of disinterest or lacking a feeling of belonging, conflicts,
5 education or training-related deficits, logistical issues or opportunity cost, and factors
6 related to fear or inhibition. Factors attributed to the researcher or research process
7 followed themes of culture or language related issues, logistical issues, issues related to
8 study design, and lack of awareness.
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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											
<i>-Disinterest or Lack of Feeling of Belonging</i>											
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										
<i>-Conflicts</i>											
Decisional hierarchies and gender	X	X							X		
Substance abuse or mental health issues	X										
Religious or cultural conflicts	X	X									X
<i>-Education or Training-Related</i>											
Poor understanding of research intentions among community or religious leaders							X				
Lack of understanding about consent process	X										
<i>-Logistics or Opportunity Costs</i>											
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		
<i>-Fear or Inhibitions</i>											
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

1
2
3 Treatment or participation related factors included perception of risk of adverse effects
4 (e.g., treatment-related side effects),[26,28,38,39] fear of finding out health status[39] or
5
6 (e.g., treatment-related side effects),[26,28,38,39] fear of finding out health status[39] or
7
8 experiencing the stigma of being labeled with a health condition,[34,38] previous poor
9
10 experiences,[26] mistrust of research,[26,34,39] inability to participate due to substance
11
12 abuse or mental health issues,[34] and fear of being reported to immigration.[34]
13
14 Logistical concerns focused on cost of participating,[34,37] time away from work, family
15
16 and other commitments,[8,26,31,34,35,37–39] transportation and location,[34]
17
18 underrepresentation of South Asians at recruitment sites,[34] and lack of access to
19
20 disease-specific services.[34] Language- or culture-specific barriers included religious or
21
22 cultural conflicts,[31,34,35] decisional hierarchies within families,[26,34,35] lack of
23
24 understanding about the consent process,[34] researcher stereotypes about difficulties
25
26 engaging with the South Asian population,[34] inability to provide staff with language and
27
28 cultural competency training, inability to translate study materials,[8,31,34,35,38] and
29
30 traditional gender roles.[34,35] Some barriers related to general disinterest or lack of
31
32 awareness,[8,35,39] including lack of interest due to previous treatment and the
33
34 perception that participation would not confer any further benefit,[34,39] misgivings
35
36 about the scientific importance of the work,[8,35,39] poor understanding of research
37
38 intentions,[8] perception of not belonging to the society standing to benefit from
39
40 research,[26,31] simply not being approached to participate,[26] and researcher apathy
41
42 towards achieving proper representation of South Asians.[8,34] Finally, some study-
43
44 specific issues included a lack of appropriate assessment tools (e.g., translated or
45
46 adapted tools) for South Asian populations,[34,35] as well as narrow entry criteria (e.g.,
47
48 restrictions on age and waist circumference).[39]
49
50
51
52

53 **Recruitment Strategies**

54
55
56
57
58
59
60

1
2
3 Themes that emerged for recruitment strategies included language and culture driven
4
5 methods, communication and engagement strategies, logistical changes and
6
7 accommodations, policy and study design measures, and compensation and incentives.
8
9 The most commonly reported strategy was involvement of the South Asian community
10
11 through mobilization of key community figures or community
12
13 partnerships.[8,26,34,36,37,39,43] The second most commonly reported strategies were
14
15 incentives and reciprocal benefits,[8,34–36,38,40,44] and demonstrated respect and
16
17 knowledge of South Asian culture, traditions, and ethics.[34–36,38,40,42,44] Multiple
18
19 studies also mentioned the development of trust and personal relationships,[34,35,38–
20
21 40,44] the use of visual aids and reduced reliance on verbal exchange,[28,36,41]
22
23 providing language support and translated materials,[34,36,39,40] personal versus
24
25 written contact,[38,39,41] training for staff in cultural competency,[8,26,34] conducting
26
27 recruitment at places with high concentrations of South Asian attendance or
28
29 residence,[26,34,36] and improving flexibility of appointment scheduling, location,
30
31 childcare and transportation.[34,38,40] Several additional strategies for recruiting South
32
33 Asian populations reported by two or fewer studies, as well as those previously
34
35 discussed are outlined in Table 4.
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1 **Table 4. Recruitment Strategies for South Asian Populations**

	First Author, Year													
Recruitment Strategy	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

1
2
3 abuse of this power dynamic may be detrimental. It may be necessary to have systems
4
5 in place to limit exploitation of this relationship in the interest of reducing selection and
6
7 performance bias. For instance, junior research staff could be involved in participant
8
9 engagement until the stage that it is necessary for physicians to participate in the
10
11 research process. Alternative methods of improving recruitment may be required where
12
13 physician involvement is either not necessary or inappropriate.
14
15

16 Many of the barriers to participation in research relate to cultural insensitivity, lack
17
18 of awareness of research or contact by researchers, and tangible issues like time and
19
20 cost of participating (Table 3). Language was also a frequently cited issue. Language
21
22 compatibility is reported to be of great importance to South Asian patients.[49] Jolly *et al.*
23
24 [19] observed a significantly higher proportion of South Asian individuals being excluded
25
26 from participation in research due to language barriers compared to 'White Europeans'
27
28 or those of 'Other' ethnicities. The use of multilingual research assistants, or principal
29
30 investigators from the same ethnic background, or with language and cultural
31
32 competency training is proposed as a possible strategy to overcome language barriers.
33
34 This approach may also allow for larger recruitment pools if these staff are part of or able
35
36 to access networks within the South Asian community.[50] The effectiveness of this
37
38 strategy was demonstrated in the successful recruitment and long-term retention of
39
40 pregnant South Asian women for a study involving sample collection from the mother
41
42 and baby in the UK.[51] The retention of study participants is another noted challenge for
43
44 the South Asian population,[26,39] not addressed by this scoping review.
45
46
47
48

49 Other common barriers are related to negative perceptions of researchers toward
50
51 South Asian participants and vice-versa. Various stereotypes held by health
52
53 professionals conducting research on South Asian populations were highlighted as
54
55 recruitment deterrents.[8,31,34] Specific examples include perceptions or
56
57
58
59
60

1
2
3 generalizations that South Asians are not punctual, that they have language limitations,
4
5 and that certain subpopulations (e.g., seniors) would not have an interest in
6
7 participating.[8,31] In addition, perceived issues with gender hierarchies (e.g., inability of
8
9 women to make independent decisions),[26,34,35] the misconception that South Asians
10
11 are less motivated about disease prevention,[23,52] and the association of English
12
13 speaking with intelligence and potentially greater trial compatibility have been noted.[31]
14
15 On the other hand, South Asians reported that mistrust, mistreatment and disrespectful
16
17 behavior, sub-par care for non-English speakers, and previous poor experiences
18
19 participating in research would deter willingness to participate.[31] Cross-cultural
20
21 education of individuals working in research to dispel incorrect racial and cultural
22
23 stereotypes, as well as education of South Asian communities to dispel some
24
25 misconceptions about health research should be encouraged.[53]
26
27
28

29 From a logistical perspective, studies focused on South Asians may require
30
31 upfront budgeting for enhanced recruitment strategies to address the unique barriers
32
33 discussed. In particular, funds for multiple research sites, transportation of patients,
34
35 incentives, and childcare may need to be accounted for at the grant funding stages.
36
37 Support for minority recruitment may be better in the US where the National Institutes of
38
39 Health Revitalization Act of 1993 promotes opportunities for women and minorities to
40
41 participate in health research.[54,55] There is mandated support for gender
42
43 representation, but not for minority representation in Canada.[56] In the UK and other
44
45 European countries the Research Governance Framework encourages researchers to
46
47 consider factors including race into research conduct when relevant, but it is not
48
49 enforced.[57,58] Government or institutional regulations promoting minority
50
51 representation may encourage researchers to confront various barriers, despite the
52
53 challenges involved.
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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]

1
2
3 A strength of this review is that a range of perspectives and ideas regarding
4 recruitment of South Asians have been summarized and grouped thematically.
5
6 Accordingly, this review represents a comprehensive in-depth overview of this subject
7 area, and provides a good estimate of the volume and characteristics of the published
8 literature. Further, this review highlights areas for future investigation such as evaluation
9 of the effectiveness of the proposed recruitment strategies in settings with large South
10 Asian populations. There were several limitations to this review and the individual
11 studies included. Published evidence was only available from the UK, the US, India and
12 Australia; therefore, transferability to the Canadian context may be limited. Also, the
13 variable patient populations and sample sizes suggest that results may not be
14 generalizable to all South Asian populations. In addition, there was a relative paucity of
15 evidence regarding recruitment strategies for South Asians in these studies, and the
16 majority of the evidence is in the context of clinical trials. The usefulness of the proposed
17 recruitment strategies outside of the clinical trial setting is unknown. The applicability of
18 the strategies presented may vary, as some proposed solutions are relatively
19 straightforward, while others are more complex and difficult to apply. As discussed by
20 Waheed et al.,[34] changing recruitment venues may be easy, but provision of
21 appropriate incentives and catering to specific health and cultural beliefs may be more
22 difficult to execute. The primary types of studies that have been used to investigate
23 potential recruitment strategies in South Asian populations include focus groups and
24 interviews. These studies provide valuable insight into participant and researcher
25 perspectives, but do not directly address the quantitative impact of barriers or facilitators
26 or effectiveness of recruitment strategies. Where empirical data exists, it is often limited
27 to descriptive rates of recruitment and retention based on the results of quantitative
28 surveys or prospective cohort studies. Documentation of barriers to recruitment in future
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 studies including South Asian participants via qualitative interviews during the
4
5 recruitment process would help to address this gap. As well, assessment tools, such as
6
7 the Barriers to Research Participation Questionnaire, may assist in determining hurdles
8
9 to research participation in specific populations in a structured manner [61]. Since this
10
11 was a scoping review aimed at mapping the current literature on this topic, we did not
12
13 complete a quality assessment of the data. The search date restrictions that were
14
15 imposed may have excluded studies with valuable historical perspectives. However, we
16
17 believe this review captures a relevant snapshot of the most up-to-date research on this
18
19 topic.
20
21

22
23 The evidence reviewed suggests that recruitment methods aimed at engaging
24
25 with the target population may have a positive impact. One such intervention that was
26
27 not discussed explicitly by the included studies is community based participatory
28
29 research. This research method aims to increase the mutual value of the research
30
31 initiative for the researchers and the community.[62] This approach employs strategies
32
33 such as involving trusted community members as study staff, which may effectively
34
35 mitigate ethical and cultural challenges in research [63]. This approach may have the
36
37 potential to mobilize individuals to take ownership of their health and encourage
38
39 education and participation within their communities, and to ensure appropriate
40
41 dissemination of findings [64,65]. One study in South Asian women concluded that
42
43 participatory action research provided a platform for the participants to “create and share
44
45 knowledge”. [64] The overall paucity of evidence, particularly in the Canadian context,
46
47 suggests that work is still needed to determine context-specific barriers and facilitators to
48
49 recruitment, and associated strategies to increase the participation of South Asians in
50
51 health research. A mixed-methods synthesis from the Canadian perspective linking
52
53 experiences of individuals and groups to the evidence on effectiveness of recruitment
54
55
56
57
58
59
60

1
2
3 strategies may shed some light on potential approaches researchers could employ in
4
5 future studies. Given the lack of empirical data, proposed recruitment strategies should
6
7 be quantitatively evaluated, ideally using prospective experimental methods, to
8
9 determine the relative effectiveness and value. Further, adequate representation of
10
11 South Asians in research also relies heavily on the retention of participants, which has
12
13 been reported to be variable in South Asians.[66,67] The identification and investigation
14
15 of retention strategies that ensure the successful recruitment is not undone should be of
16
17 highest priority.
18
19

20 **Conclusions**

21
22 Better representation of South Asians in health research may promote
23
24 development of tailored treatment, and increased awareness and ownership of health.
25
26 This would support the ultimate goals of improving the health of the South Asian
27
28 population, reducing healthcare spending and addressing health inequity. The
29
30 information presented in this review can be used to assist researchers when preparing to
31
32 conduct research, and may help to inform a more in-depth analysis of this issue from a
33
34 Canadian perspective. Consideration of these issues during the grant writing and
35
36 protocol stages of research may decrease the risk of encountering recruitment problems
37
38 at latter stages.
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

ACKNOWLEDGEMENTS

YL acknowledges funding from the Canada Research Chair program of the Canadian Institutes of Health Research. PJ is supported by a Senior Scientist Salary Award from the BC Children's Hospital Research Institute.

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.

FUNDING STATEMENT

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

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.

REFERENCES

- 1 Government of Canada SC. National Household Survey: Immigration and Ethnocultural Diversity. 2014. <http://www5.statcan.gc.ca/olc-cel/olc.action?ObjId=99-010-X&ObjType=2&lang=en&limit=1> (accessed 27 May2015).
- 2 Ethnicity and National Identity in England and Wales - Office for National Statistics. <http://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/ethnicityandnationalidentityinenglandandwales/2012-12-11> (accessed 19 Jun2016).
- 3 Statistics Canada. Projections of the Diversity of the Canadian Population. 2013. <http://www12.statcan.gc.ca/census-recensement/2011/ref/92-135/surveys-enquetes/vismin-population-minvis-eng.cfm> (accessed 10 Jul2014).
- 4 Veenstra G, Patterson AC. South Asian-White health inequalities in Canada: intersections with gender and immigrant status. *Ethn Health* 2016;:1–10. doi:10.1080/13557858.2016.1179725
- 5 Gupta M, Singh N, Verma S. South Asians and Cardiovascular Risk What Clinicians Should Know. *Circulation* 2006;113:e924–9. doi:10.1161/CIRCULATIONAHA.105.583815
- 6 Anand SS, Yusuf S, Vuksan V, *et al.* Differences in risk factors, atherosclerosis, and cardiovascular disease between ethnic groups in Canada: the Study of Health Assessment and Risk in Ethnic groups (SHARE). *Lancet* 2000;356:279–84.
- 7 Rana A, Souza RJ de, Kandasamy S, *et al.* Cardiovascular risk among South Asians living in Canada: a systematic review and meta-analysis. *Can Med Assoc Open Access J* 2014;2:E183–91. doi:10.9778/cmajo.20130064
- 8 Sheikh A, Halani L, Bhopal R, *et al.* Facilitating the Recruitment of Minority Ethnic People into Research: Qualitative Case Study of South Asians and Asthma. *PLoS Med* 2009;6:e1000148. doi:10.1371/journal.pmed.1000148
- 9 Razak F, Anand SS, Shannon H, *et al.* Defining obesity cut points in a multiethnic population. *Circulation* 2007;115:2111–8. doi:10.1161/CIRCULATIONAHA.106.635011
- 10 Twells LK, Gregory DM, Reddigan J, *et al.* Current and predicted prevalence of obesity in Canada: a trend analysis. *CMAJ Open* 2014;2:E18–26. doi:10.9778/cmajo.20130016
- 11 Chiu M, Austin PC, Manuel DG, *et al.* Deriving Ethnic-Specific BMI Cutoff Points for Assessing Diabetes Risk. *Diabetes Care* 2011;34:1741–8. doi:10.2337/dc10-2300
- 12 Nanditha A, Ma RCW, Ramachandran A, *et al.* Diabetes in Asia and the Pacific: Implications for the Global Epidemic. *Diabetes Care* 2016;39:472–85. doi:10.2337/dc15-1536

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
- 13 Sword W, Watt S, Krueger P. Postpartum health, service needs, and access to care experiences of immigrant and Canadian-born women. *J Obstet Gynecol Neonatal Nurs JOGNN NAACOG* 2006;**35**:717–27. doi:10.1111/j.1552-6909.2006.00092.x
 - 14 Nilaweera I, Doran F, Fisher J. Prevalence, nature and determinants of postpartum mental health problems among women who have migrated from South Asian to high-income countries: a systematic review of the evidence. *J Affect Disord* 2014;**166**:213–26. doi:10.1016/j.jad.2014.05.021
 - 15 Asanin J, Wilson K. “I spent nine years looking for a doctor”: exploring access to health care among immigrants in Mississauga, Ontario, Canada. *Soc Sci Med* 1982 2008;**66**:1271–83. doi:10.1016/j.socscimed.2007.11.043
 - 16 Hussain-Gambles M, Atkin K, Leese B. Why ethnic minority groups are under-represented in clinical trials: a review of the literature. *Health Soc Care Community* 2004;**12**:382–8. doi:10.1111/j.1365-2524.2004.00507.x
 - 17 Hilton BA, Grewal S, Popatia N, *et al*. The desi ways: traditional health practices of South Asian women in Canada. *Health Care Women Int* 2001;**22**:553–67. doi:10.1080/07399330127195
 - 18 Bhandari N, Taneja S, Rongsen T, *et al*. Implementation of the WHO Multicentre Growth Reference Study in India. *Food Nutr Bull* 2004;**25**:S66-71.
 - 19 Jolly K, Lip GY, Taylor RS, *et al*. Recruitment of ethnic minority patients to a cardiac rehabilitation trial: the Birmingham Rehabilitation Uptake Maximisation (BRUM) study [ISRCTN72884263]. *BMC Med Res Methodol* 2005;**5**:18. doi:10.1186/1471-2288-5-18
 - 20 Bajaj S, Jawad F, Islam N, *et al*. South Asian women with diabetes: Psychosocial challenges and management: Consensus statement. *Indian J Endocrinol Metab* 2013;**17**:548–62. doi:10.4103/2230-8210.113720
 - 21 Wiseman N. Designations of Medicines. *Evid Based Complement Alternat Med* 2004;**1**:327–9. doi:10.1093/ecam/neh053
 - 22 Statistics Canada. The South Asian Community in Canada. 2007. <http://www.statcan.gc.ca/pub/89-621-x/89-621-x2007006-eng.htm> (accessed 19 Aug2013).
 - 23 Lucas A, Murray E, Kinra S. Heath beliefs of UK South Asians related to lifestyle diseases: a review of qualitative literature. *J Obes* 2013;**2013**:827674. doi:10.1155/2013/827674
 - 24 Grewal K, Stewart DE, Grace SL. Differences in social support and illness perceptions among South Asian and Caucasian patients with coronary artery disease. *Heart Lung J Crit Care* 2010;**39**:180–7. doi:10.1016/j.hrtlng.2009.06.016
 - 25 George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans,

and Pacific Islanders. *Am J Public Health* 2014;**104**:e16-31.
doi:10.2105/AJPH.2013.301706

- 26 Hussain-Gambles M, Leese B, Atkin K, *et al.* Involving South Asian patients in clinical trials. *Health Technol Assess Winch Engl* 2004;**8**:iii, 1-109.
- 27 Khan M, Kobayashi K, Lee SM, *et al.* (In)Visible Minorities in Canadian Health Data and Research. *Popul Change Lifecourse Strateg Knowl Clust Discuss Pap Ser Un Réseau Strat Connaiss Chang Popul Parcours Vie Doc Trav* 2015;**3**:5.
- 28 Macneill V, Nwokoro C, Griffiths C, *et al.* Recruiting ethnic minority participants to a clinical trial: a qualitative study. *BMJ Open* 2013;**3**. doi:10.1136/bmjopen-2013-002750
- 29 Mason S, Hussain-Gambles M, Leese B, *et al.* Representation of South Asian people in randomised clinical trials: analysis of trials' data. *BMJ* 2003;**326**:1244–5. doi:10.1136/bmj.326.7401.1244
- 30 Khunti K, Bellary S, Karamat MA, *et al.* Representation of people of South Asian origin in cardiovascular outcome trials of glucose-lowering therapies in Type 2 diabetes. *Diabet Med J Br Diabet Assoc* Published Online First: 1 March 2016. doi:10.1111/dme.13103
- 31 Hussain-Gambles M, Atkin K, Leese B. South Asian participation in clinical trials: the views of lay people and health professionals. *Health Policy Amst Neth* 2006;**77**:149–65. doi:10.1016/j.healthpol.2005.07.022
- 32 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;**8**:19–32. doi:10.1080/1364557032000119616
- 33 Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci* 2010;**5**:69. doi:10.1186/1748-5908-5-69
- 34 Waheed W, Husain N, Allen G, *et al.* Recruitment strategies for British South Asians in 5 depression trials: A mixed method study. *J Affect Disord* 2015;**185**:195–203. doi:10.1016/j.jad.2015.06.046
- 35 Brown GE, Woodham A, Marshall M, *et al.* Recruiting South Asians into a UK Mental Health Randomised Controlled Trial: Experiences of Field Researchers. *J Racial Ethn Health Disparities* 2014;**1**:181–93. doi:10.1007/s40615-014-0024-4
- 36 Garduño-Díaz SD, Husain W, Ashkanani F, *et al.* Meeting challenges related to the dietary assessment of ethnic minority populations. *J Hum Nutr Diet Off J Br Diet Assoc* 2014;**27**:358–66. doi:10.1111/jhn.12153
- 37 Douglas A, Bhopal RS, Bhopal R, *et al.* Recruiting South Asians to a lifestyle intervention trial: experiences and lessons from PODOSA (Prevention of Diabetes & Obesity in South Asians). *Trials* 2011;**12**:220. doi:10.1186/1745-6215-12-220

- 1
2
3 38 Rooney LK, Bhopal R, Halani L, *et al*. Promoting recruitment of minority ethnic
4 groups into research: qualitative study exploring the views of South Asian people
5 with asthma. *J Public Health Oxf Engl* 2011;**33**:604–15. doi:10.1093/pubmed/fdq100
6
7
8 39 Samsudeen BS, Douglas A, Bhopal RS. Challenges in recruiting South Asians into
9 prevention trials: health professional and community recruiters' perceptions on the
10 PODOSA trial. *Public Health* 2011;**125**:201–9. doi:10.1016/j.puhe.2011.01.013
11
12 40 Stirland L, Halani L, Raj B, *et al*. Recruitment of South Asians into asthma research:
13 qualitative study of UK and US researchers. *Prim Care Respir J J Gen Pract Airw*
14 *Group* 2011;**20**:282–290, 8 p following 290. doi:10.4104/pcrj.2011.00032
15
16 41 Lloyd CE, Johnson MR, Mughal S, *et al*. Securing recruitment and obtaining
17 informed consent in minority ethnic groups in the UK. *BMC Health Serv Res*
18 2008;**8**:68. doi:10.1186/1472-6963-8-68
19
20 42 Mohammadi N, Jones T, Evans D. Participant recruitment from minority religious
21 groups: the case of the Islamic population in South Australia. *Int Nurs Rev*
22 2008;**55**:393–8. doi:10.1111/j.1466-7657.2008.00647.x
23
24 43 Krupp K, Madhivanan P, Karat C, *et al*. Novel recruitment strategies to increase
25 participation of women in reproductive health research in India. *Glob Public Health*
26 2007;**2**:395–403. doi:10.1080/17441690701238031
27
28 44 Shelton AJ, Rianon NJ. Recruiting participants from a community of Bangladeshi
29 immigrants for a study of spousal abuse: an appropriate cultural approach. *Qual*
30 *Health Res* 2004;**14**:369–80. doi:10.1177/1049732303261957
31
32 45 A comparative study of patients' attitudes toward clinical research in the United
33 States and urban and rural China. - PubMed - NCBI.
34 <https://www.ncbi.nlm.nih.gov/pubmed/25588611> (accessed 2 Feb2017).
35
36 46 Yancey AK, Ortega AN, Kumanyika SK. Effective recruitment and retention of
37 minority research participants. *Annu Rev Public Health* 2006;**27**:1–28.
38 doi:10.1146/annurev.publhealth.27.021405.102113
39
40 47 Pratt B, Van C, Cong Y, *et al*. Perspectives from South and East Asia on Clinical and
41 Research Ethics: A Literature Review. *J Empir Res Hum Res Ethics* 2014;**9**:52–67.
42 doi:10.1525/jer.2014.9.2.52
43
44 48 Symonds RP, Lord K, Mitchell AJ, *et al*. Recruitment of ethnic minorities into cancer
45 clinical trials: experience from the front lines. *Br J Cancer* 2012;**107**:1017–21.
46 doi:10.1038/bjc.2012.240
47
48 49 Ahmad F, Gupta H, Rawlins J, *et al*. Preferences for gender of family physician
49 among Canadian European-descent and South-Asian immigrant women. *Fam Pract*
50 2002;**19**:146–53.
51
52 50 Lee SK, Sulaiman-Hill CR, Thompson SC. Overcoming language barriers in
53 community-based research with refugee and migrant populations: options for using
54
55
56
57
58
59
60

1
2
3 bilingual workers. *BMC Int Health Hum Rights* 2014;**14**:11. doi:10.1186/1472-698X-
4 14-11
5

- 6
7 51 Neelotpol S, Hay AWM, Jolly AJ, *et al*. Challenges in collecting clinical samples for
8 research from pregnant women of South Asian origin: evidence from a UK study.
9 *BMJ Open* 2016;**6**:e010554. doi:10.1136/bmjopen-2015-010554
10
11 52 Patel M, Phillips-Caesar E, Boutin-Foster C. Barriers to Lifestyle Behavioral Change
12 in Migrant South Asian Populations. *J Immigr Minor Health Cent Minor Public Health*
13 2012;**14**:774–85. doi:10.1007/s10903-011-9550-x
14
15 53 Marshall A, Batten S. Researching Across Cultures: Issues of Ethics and Power.
16 *Forum Qual Sozialforschung Forum Qual Soc Res* 2004;**5**.[http://www.qualitative-](http://www.qualitative-research.net/index.php/fqs/article/view/572)
17 [research.net/index.php/fqs/article/view/572](http://www.qualitative-research.net/index.php/fqs/article/view/572) (accessed 13 Feb2015).
18
19 54 Inclusion: The Politics of Difference in Medical Research, Epstein.
20 <http://press.uchicago.edu/ucp/books/book/chicago/l/bo5414954.html> (accessed 20
21 Jun2016).
22
23 55 NIH Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical
24 Research - Amended, October, 2001.
25 https://grants.nih.gov/grants/funding/women_min/guidelines_amended_10_2001.htm
26 (accessed 20 Jun2016).
27
28 56 Report on governmental health research policies promoting gender or sex differences
29 sensitivity | Canadian Women’s Health Network. <http://www.cwhn.ca/en/node/25386>
30 (accessed 20 Jun2016).
31
32 57 Research governance framework for health and social care: second edition -
33 Publications - GOV.UK. [https://www.gov.uk/government/publications/research-](https://www.gov.uk/government/publications/research-governance-framework-for-health-and-social-care-second-edition)
34 [governance-framework-for-health-and-social-care-second-edition](https://www.gov.uk/government/publications/research-governance-framework-for-health-and-social-care-second-edition) (accessed 31
35 Jan2017).
36
37 58 Redwood S, Gill PS. Under-representation of minority ethnic groups in research —
38 call for action. *Br J Gen Pract* 2013;**63**:342. doi:10.3399/bjgp13X668456
39
40 59 Glover M, Kira A, Johnston V, *et al*. A systematic review of barriers and facilitators to
41 participation in randomized controlled trials by Indigenous people from New Zealand,
42 Australia, Canada and the United States. *Glob Health Promot* 2015;**22**:21–31.
43 doi:10.1177/1757975914528961
44
45 60 Kallivayalil RA, Chadda RK. Culture, Ethics and Medicine in South Asia. *Int J Pers*
46 *Centered Med* 2011;**1**:56–61.
47
48 61 Kibler JL, Brisco K. Evaluation of a brief questionnaire for assessing Barriers to
49 Research Participation. *Ethn Dis* 2006;**16**:547–50.
50
51 62 Viswanathan M, Ammerman A, Eng E, *et al*. *Community-Based Participatory*
52 *Research: Assessing the Evidence: Summary*. Agency for Healthcare Research and
53
54
55
56
57
58
59
60

1
2
3 Quality (US) 2004. <https://www.ncbi.nlm.nih.gov/books/NBK11852/> (accessed 31
4 Jan2017).

- 5
6
7 63 Minkler M. Community-based research partnerships: Challenges and opportunities. *J*
8 *Urban Health Bull N Y Acad Med* 2005;**82**:ii3-ii12. doi:10.1093/jurban/jti034
- 9
10 64 Choudhry U k., Jandu S, Mahal J, *et al.* Health Promotion and Participatory Action
11 Research with South Asian Women. *J Nurs Scholarsh* 2002;**34**:75–81.
12 doi:10.1111/j.1547-5069.2002.00075.x
- 13
14 65 Getrich CM, Sussman AL, Campbell-Voytal K, *et al.* Cultivating a cycle of trust with
15 diverse communities in practice-based research: a report from PRIME Net. *Ann Fam*
16 *Med* 2013;**11**:550–8. doi:10.1370/afm.1543
- 17
18 66 Kandula NR, Dave S, De Chavez PJ, *et al.* Translating a heart disease lifestyle
19 intervention into the community: the South Asian Heart Lifestyle Intervention
20 (SAHELI) study; a randomized control trial. *BMC Public Health* 2015;**15**:1064.
21 doi:10.1186/s12889-015-2401-2
- 22
23 67 Vlaar EMA, van Valkengoed IGM, Nierkens V, *et al.* Feasibility and effectiveness of
24 a targeted diabetes prevention program for 18 to 60-year-old South Asian migrants:
25 design and methods of the DH!AAN study. *BMC Public Health* 2012;**12**:371.
26 doi:10.1186/1471-2458-12-371
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1 **FIGURE LEGENDS**

2 Figure 1: Flowchart of Included and Excluded Studies

3

For peer review only

4 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

5

6 Search String:

7 ((((((patient selection[MeSH Terms]) OR recruitment) OR enrollment) OR recruitment
8 strategies)) AND (((((((((((south asian) OR south asia)) OR ((sri lankan) OR sri lanka))
9 OR ((bangladeshi) OR bangladesh)) OR ((pakistani) OR pakistan)) OR minority
10 groups[MeSH Terms]) OR minority health[MeSH Terms]) OR ((nepalese) OR nepal)) OR
11 ((bhutanese) OR bhutan)) OR ((maldivian) OR maldives)) OR ((indian) OR india))) Sort
12 by: PublicationDate Filters: Publication date from 2004/01/01 to 2016/04/01
13

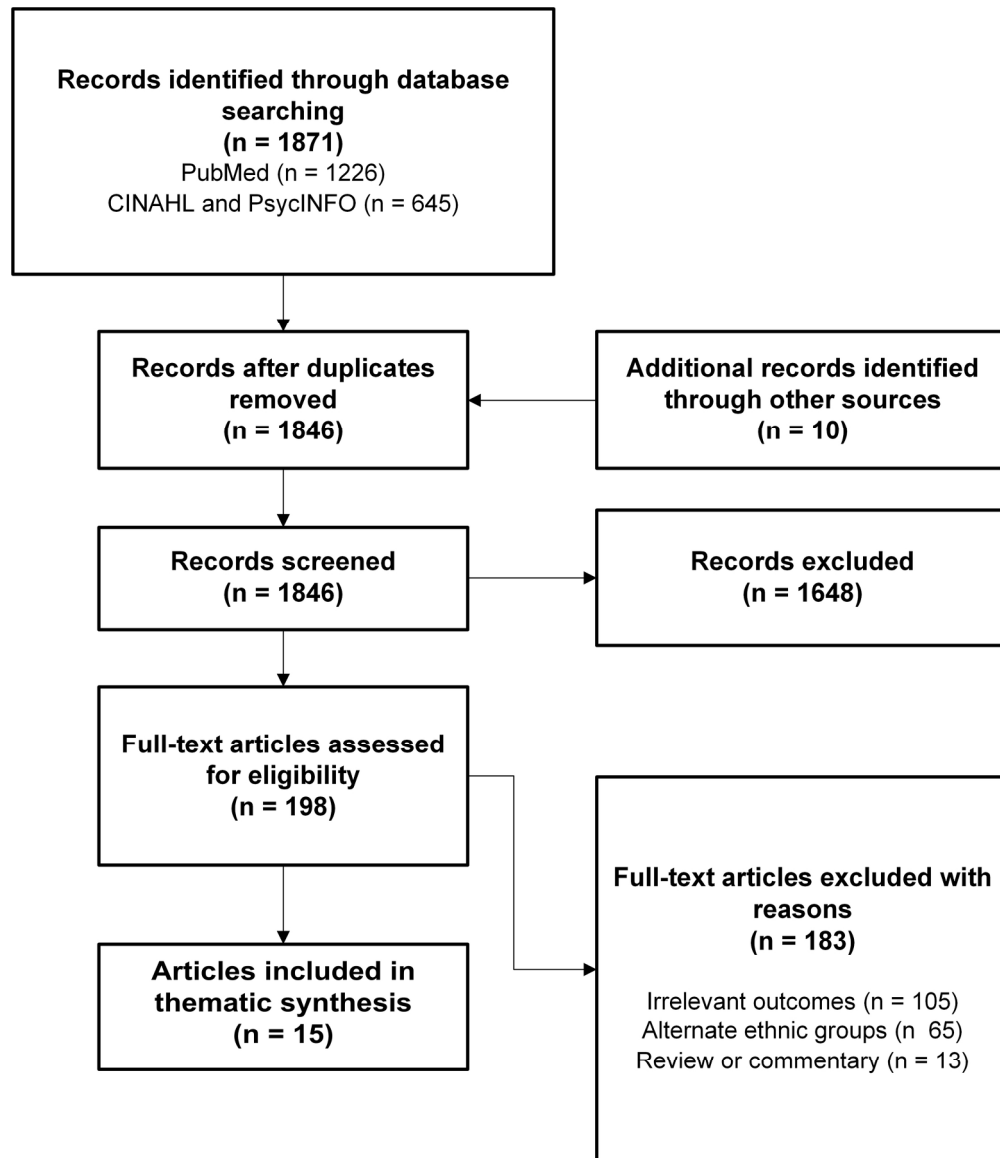


Figure 1: Flowchart of Included and Excluded Studies

Figure 1

188x217mm (300 x 300 DPI)

45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

BMJ Open

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

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2016-014889.R2
Article Type:	Research
Date Submitted by the Author:	17-Mar-2017
Complete List of Authors:	Quay, Teo; Canadian Agency for Drugs and Technologies in Health; University of British Columbia, Faculty of Land and Food Systems Frimer, Leora; McGill University Faculty of Medicine, Department of Epidemiology, Biostatistics and Occupational Health; University of British Columbia, School of Population and Public Health, Faculty of Medicine Janssen, Patricia; University of British Columbia, School of Population and Public Health, Faculty of Medicine; BC Children's Hospital Research Institute Lamers, Yvonne; University of British Columbia, Faculty of Land and Food Systems; BC Children's Hospital Research Institute
Primary Subject Heading:	Global health
Secondary Subject Heading:	Epidemiology
Keywords:	recruitment, South Asian, minority health, patient selection, scoping review

SCHOLARONE™
Manuscripts

only

TITLE PAGE**Title**

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

Authors

Teo A W Quay,^{1,2} Leora Frimer,^{3,4} Patricia A Janssen,^{4,5,6} Yvonne Lamers^{2,5,6}

Affiliations

¹The Canadian Agency for Drugs and Technologies in Health, Ottawa, ON, Canada

²The University of British Columbia, Faculty of Land and Food Systems, Vancouver, BC, Canada

³Department of Epidemiology, Biostatistics and Occupational Health, McGill Faculty of Medicine, Montreal, QC, Canada

⁴School of Population and Public Health, Faculty of Medicine, University of British Columbia, Vancouver, BC, Canada

⁵BC Children's Hospital Research Institute, Vancouver, BC, Canada

⁶Women's Health Research Institute, Vancouver, BC, Canada

Corresponding Author Information

Yvonne Lamers
Canada Research Chair in Human Nutrition and Vitamin Metabolism
Assistant Professor, Food, Nutrition and Health
Email: yvonne.lamers@ubc.ca
Phone: +1 604-827-1776
Fax: +1 604-822-5143
FNH 245 - 2205 East Mall
Vancouver, BC V6T 1Z4
Canada

Word Count of Body of Text 4216

Number of Tables 4

Number of Figures 1

1
2
3 **Appendices: 1**
4

5 **Number of References 69**
6

7 **Word Count of Abstract 235**
8

9 **Keywords and MeSH Headings:** Recruitment, South Asian, Minority Health, Patient
10
11 Selection, Scoping Review
12
13

14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

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

1
2
3 families[21] have been reported to obstruct optimal health care of South Asians, and in
4 particular South Asian women.[21] Frequently, South Asians maintain traditional
5 religious, dietary, and healthcare practices, which may not align with modern western or
6 allopathic medicine[22] and clinical research approaches.[23,24] Lack of support from
7 families and communities in seeking healthcare and making healthcare decisions may
8 discourage South Asians from engaging in risk-reducing health behaviors, including
9 participation in research.[25] Lack of English language proficiency, unfamiliarity with
10 local services, and lack of attention to cultural factors by health care providers may pose
11 a particular challenge to healthcare service access for female South Asians.[15]

12
13 Adequate ethnic minority representation in health research is important to
14 support generalizability of research findings and to enable tailored health care for ethnic
15 minorities.[26,27] However, South Asians are underrepresented in research, resulting in
16 healthcare practice based on research with limited external validity for the South Asian
17 context.[28,29] In general, there is a lack of representative population health research
18 comparing minority groups in Canada to European counterparts.[28] This under-
19 representation also occurs elsewhere; a UK-based analysis reported that while South
20 Asians make up 4.5% of the total population, they represented on average only 0.6% of
21 participants in 6 multicenter randomized controlled trials.[2,30] Another review noted that
22 trials assessing cardiovascular outcomes in type 2 diabetes patients had
23 underrepresentation of the South Asian population compared to the population
24 proportion in the UK, but overrepresentation in the United States.[31] Even studies with
25 sufficient numbers of South Asians may not be truly representative of the heterogeneous
26 subgroups that comprise the broader South Asian population. Diets, lifestyles, and
27 baseline health risk is noted to vary across South Asian subgroups based on differences
28 in origin, culture, and religion.[32]

1
2
3 To better understand the current knowledge and perspectives on this topic, a
4
5 scoping review of the evidence regarding barriers and facilitators to recruitment, and
6
7 strategies that have been employed or evaluated to improve representation of South
8
9 Asians was undertaken. A preliminary search of the literature did not yield sufficient
10
11 reports on the Canadian population, thus the review was expanded to include literature
12
13 regarding South Asian populations residing in other countries.
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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

1
2
3 multiple ethnic groups where South Asians were a specified subgroup or comprised the
4 majority of participants. Studies assessing or reporting on barriers and facilitators to
5 recruitment, and recruitment strategies were included. This includes studies determining,
6 assessing the impact or effectiveness, or assessing the comparative impact or
7 effectiveness of barriers, facilitators, and recruitment strategies.
8
9

10
11
12 One reviewer (TQ) independently screened titles and abstracts against the pre-specified
13 eligibility criteria. A second reviewer (LF) then screened selected abstracts. Full text
14 articles were obtained and reviewed by both authors for studies that appeared to meet
15 the eligibility criteria or where eligibility could not be adequately judged. Disagreement
16 was resolved by discussion among the two reviewers with a third reviewer consulted if
17 deemed necessary. Study authors were not contacted for further information.
18
19
20
21
22
23
24
25
26

27 **Data Abstraction**

28
29 Data abstraction was conducted in duplicate by two authors (TQ and LF) using a
30 structured extraction form piloted on two studies. Disagreement was resolved via
31 discussion. Data including a) study classifiers (lead author, publication year, country), b)
32 study characteristics (sample size, study design, subject characteristics), and c)
33 recruitment barriers, facilitators for participation, and recruitment strategy data was
34 extracted. Specific descriptions of recruitment barriers, facilitators, and strategies were
35 recorded.
36
37
38
39
40
41
42
43

44 Barriers and facilitators, and recruitment strategies were grouped thematically into key
45 topics that emerged upon review of the literature. Once established, these themes were
46 presented and discussed narratively. No formal data synthesis or assessment of
47 intervention effectiveness was undertaken. Quality appraisal of selected studies was not
48 conducted as this is not typical of scoping reviews,[33] but general limitations are
49 discussed. In addition, no formal consultation exercise with stakeholders was conducted.
50
51
52
53
54
55
56
57
58
59
60

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

1
2
3 Study populations ranged in size from n=2 to n=1319. The majority of studies were
4 conducted in specific clinical populations. This included patients with mental health
5 issues,[36,37] nutritional concerns,[38] asthma,[9,29,40,42] diabetes,[39,41,43]
6 obesity,[41] in hospital (i.e., tertiary care),[44] with reproductive health concerns,[45] who
7 were being recruited for clinical trials,[27,32] and for a study on spousal abuse.[46]
8
9 Study designs included prospective cohort studies,[45] thematic analysis[37], qualitative
10 surveys, interviews and focus groups,[9,27,29,32,40,42,43,46] literature reviews,[32,38]
11 quantitative surveys,[38,41] retrospective descriptive accounts of recruitment
12 experiences,[39] hermeneutic studies,[44] and mixed-methods syntheses.[36]
13
14

15
16 Most of the studies employed qualitative or survey-based techniques. As such,
17 most outcome data is sourced from direct interview statements and personal experience.
18 Limited empirical evidence on the effectiveness of the various recruitment strategies
19 discussed was available.[36,38,41,45] Most of the included studies were conducted in
20 the UK [9,27,29,32,36–43] and dealt with recruitment of clinical populations to clinical
21 trials.[9,27,29,32,36,39–43]
22

23 **Facilitators**

24
25 Three studies conducted in the UK [27,29,41] reported on facilitators of participation in
26 research. Subjects perceived participation in research to be a possible route to improved
27 treatment and health [27,29]. Participants also reported being motivated by the
28 importance of disease prevention and potential to contribute to scientific knowledge
29 [27,41], by the potential to help society through participation [27], and by a sense of
30 obligation to healthcare providers [27]. It was reported that higher social class and
31 education, and younger age influence the level of awareness of clinical trials in South
32 Asians.[27]
33
34

35 **Barriers**

1
2
3 Potential barriers to recruitment of South Asians are outlined in Table 3. Participant-
4 related factors followed themes of disinterest or lacking a feeling of belonging, conflicts,
5 education or training-related deficits, logistical issues or opportunity cost, and factors
6 related to fear or inhibition. Factors attributed to the researcher or research process
7 followed themes of culture or language related issues, logistical issues, issues related to
8 study design, and lack of awareness.
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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											
<i>-Disinterest or Lack of Feeling of Belonging</i>											
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										
<i>-Conflicts</i>											
Decisional hierarchies and gender	X	X							X		
Substance abuse or mental health issues	X										
Religious or cultural conflicts	X	X									X
<i>-Education or Training-Related</i>											
Poor understanding of research intentions among community or religious leaders							X				
Lack of understanding about consent process	X										
<i>-Logistics or Opportunity Costs</i>											
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		
<i>-Fear or Inhibitions</i>											
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

1
2
3 Treatment or participation related factors included perception of risk of adverse effects
4 (e.g., treatment-related side effects),[27,29,40,41] fear of finding out health status[41] or
5
6 (e.g., treatment-related side effects),[27,29,40,41] fear of finding out health status[41] or
7
8 experiencing the stigma of being labeled with a health condition,[36,40] previous poor
9
10 experiences,[27] mistrust of research,[27,36,41] inability to participate due to substance
11
12 abuse or mental health issues,[36] and fear of being reported to immigration.[36]
13
14 Logistical concerns focused on cost of participating,[36,39] time away from work, family
15
16 and other commitments,[9,27,32,36,37,39–41] transportation and location,[36]
17
18 underrepresentation of South Asians at recruitment sites,[36] and lack of access to
19
20 disease-specific services.[36] Language- or culture-specific barriers included religious or
21
22 cultural conflicts,[32,36,37] decisional hierarchies within families,[27,36,37] lack of
23
24 understanding about the consent process,[36] researcher stereotypes about difficulties
25
26 engaging with the South Asian population,[36] inability to provide staff with language and
27
28 cultural competency training, inability to translate study materials,[9,32,36,37,40] and
29
30 traditional gender roles.[36,37] Some barriers related to general disinterest or lack of
31
32 awareness,[9,37,41] including lack of interest due to previous treatment and the
33
34 perception that participation would not confer any further benefit,[36,41] misgivings
35
36 about the scientific importance of the work,[9,37,41] poor understanding of research
37
38 intentions,[9] perception of not belonging to the society standing to benefit from
39
40 research,[27,32] simply not being approached to participate,[27] and researcher apathy
41
42 towards achieving proper representation of South Asians.[9,36] Finally, some study-
43
44 specific issues included a lack of appropriate assessment tools (e.g., translated or
45
46 adapted tools) for South Asian populations,[36,37] as well as narrow entry criteria (e.g.,
47
48 restrictions on age and waist circumference).[41]
49
50
51

52 **Recruitment Strategies**

53
54
55
56
57
58
59
60

1
2
3 Themes that emerged for recruitment strategies included language and culture driven
4
5 methods, communication and engagement strategies, logistical changes and
6
7 accommodations, policy and study design measures, and compensation and incentives.
8
9 The most commonly reported strategy was involvement of the South Asian community
10
11 through mobilization of key community figures or community
12
13 partnerships.[9,27,36,38,39,41,45] The second most commonly reported strategies were
14
15 incentives and reciprocal benefits,[9,36–38,40,42,46] and demonstrated respect and
16
17 knowledge of South Asian culture, traditions, and ethics.[36–38,40,42,44,46] Multiple
18
19 studies also mentioned the development of trust and personal relationships,[36,37,40–
20
21 42,46] the use of visual aids and reduced reliance on verbal exchange,[29,38,43]
22
23 providing language support and translated materials,[36,38,41,42] personal versus
24
25 written contact,[40,41,43] training for staff in cultural competency,[9,27,36] conducting
26
27 recruitment at places with high concentrations of South Asian attendance or
28
29 residence,[27,36,38] and improving flexibility of appointment scheduling, location,
30
31 childcare and transportation.[36,40,42] Several additional strategies for recruiting South
32
33 Asian populations reported by two or fewer studies, as well as those previously
34
35 discussed are outlined in Table 4.
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1 **Table 4. Recruitment Strategies for South Asian Populations**

	First Author, Year													
Recruitment Strategy	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

1
2
3 physician recruitment is feasible, potential abuse of this power dynamic may be
4
5 detrimental. It may be necessary to have systems in place to limit exploitation of this
6
7 relationship in the interest of reducing selection and performance bias. For instance,
8
9 junior research staff could be involved in participant engagement until the stage that it is
10
11 necessary for physicians to participate in the research process. Alternative methods of
12
13 improving recruitment may be required where physician involvement is either not
14
15 necessary or inappropriate.
16
17

18
19 Many of the barriers to participation in research relate to cultural insensitivity, lack
20
21 of awareness of research or contact by researchers, and tangible issues like time and
22
23 cost of participating (Table 3). Language was also a frequently cited issue. Language
24
25 compatibility is reported to be of great importance to South Asian patients.[51] Jolly *et al.*
26
27 [20] observed a significantly higher proportion of South Asian individuals being excluded
28
29 from participation in research due to language barriers compared to 'White Europeans'
30
31 or those of 'Other' ethnicities. The use of multilingual research assistants, or principal
32
33 investigators from the same ethnic background, or with language and cultural
34
35 competency training is proposed as a possible strategy to overcome language barriers.
36
37 This approach may also allow for larger recruitment pools if these staff are part of or able
38
39 to access networks within the South Asian community.[52] The effectiveness of this
40
41 strategy was demonstrated in the successful recruitment and long-term retention of
42
43 pregnant South Asian women for a study involving sample collection from the mother
44
45 and baby in the UK.[53] The retention of study participants is another noted challenge for
46
47 the South Asian population,[27,41] not addressed by this scoping review.
48
49
50

51
52 Other common barriers are related to negative perceptions of researchers toward
53
54 South Asian participants and vice-versa. Various stereotypes held by health
55
56 professionals conducting research on South Asian populations were highlighted as
57
58
59
60

1
2
3 recruitment deterrents.[9,32,36] Specific examples include perceptions or
4
5 generalizations that South Asians are not punctual, that they have language limitations,
6
7 and that certain subpopulations (e.g., seniors) would not have an interest in
8
9 participating.[9,32] In addition, perceived issues with gender hierarchies (e.g., inability of
10
11 women to make independent decisions),[27,36,37] the misconception that South Asians
12
13 are less motivated about disease prevention,[24,54] and the association of English
14
15 speaking with intelligence and potentially greater trial compatibility have been noted.[32]
16
17 On the other hand, South Asians reported that mistrust, mistreatment and disrespectful
18
19 behavior, sub-par care for non-English speakers, and previous poor experiences
20
21 participating in research would deter willingness to participate.[32] Cross-cultural
22
23 education of individuals working in research to dispel incorrect racial and cultural
24
25 stereotypes, as well as education of South Asian communities to dispel some
26
27 misconceptions about health research should be encouraged.[55]
28
29
30

31
32 From a logistical perspective, studies focused on South Asians may require
33
34 upfront budgeting for enhanced recruitment strategies to address the unique barriers
35
36 discussed. In particular, funds for multiple research sites, transportation of patients,
37
38 incentives, and childcare may need to be accounted for at the grant funding stages.
39
40 Support for minority recruitment may be better in the US where the National Institutes of
41
42 Health Revitalization Act of 1993 promotes opportunities for women and minorities to
43
44 participate in health research.[56,57] There is mandated support for gender
45
46 representation, but not for minority representation in Canada.[58] In the UK and other
47
48 European countries the Research Governance Framework encourages researchers to
49
50 consider factors including race into research conduct when relevant, but it is not
51
52 enforced.[59,60] Government or institutional regulations promoting minority
53
54
55
56
57
58
59
60

1
2
3 representation may encourage researchers to confront various barriers, despite the
4
5 challenges involved.
6

7
8 There were similarities and differences in the findings of this scoping review in
9
10 contrast to what is reported for other ethnic groups. Congruent with our findings, a
11
12 systematic review of recruitment barriers and facilitators in African Americans, Latinos,
13
14 Asian Americans, and Pacific Islanders in the US reported that issues of mistrust,
15
16 competing demands, unintended outcomes (e.g., adverse effects of intervention, lack of
17
18 access to healthcare should injury or disease arise), lack of access to research
19
20 information, stigma, health insurance coverage, and jeopardizing legal status in the US
21
22 were barriers to participation in research.[26] Facilitators included cultural congruence,
23
24 benefits to participation, altruism, convenience of participation, and low risks associated
25
26 with participation. They also found that there were issues specific to ethnic groups. For
27
28 instance, the legacy of the Tuskegee Syphilis Study – an investigation noted for
29
30 unethical abuse against African Americans - may discourage African Americans from
31
32 participating in research, and Asian Americans often required the endorsement from
33
34 family members. Another systematic review[61] that assessed barriers and facilitators in
35
36 indigenous populations in several countries including the US, Canada, Australia, and
37
38 New Zealand, reported that relationships and partnership, indigenous staff, indigenous
39
40 knowledge models, targeted recruitment, and adaptation of study material were
41
42 associated with improved recruitment. Conversely, factors such as distrust of research
43
44 attributable to the participants, study-centric issues such as trial design (no phone, travel
45
46 costs), and lack of incorporation of indigenous knowledge systems dissuaded individuals
47
48 from participating. While some barriers such as logistical issues may be common to
49
50 multiple ethnic groups, the strategies to address cultural factors may differ depending on
51
52 ethnicity. This highlights the importance of establishing targeted recruitment strategies
53
54
55
56
57
58
59
60

1
2
3 specific not only to an individual ethnic group, but also that address heterogeneity within
4
5 an ethnic group, such as exists in South Asians who as a group are multicultural,
6
7 multilingual, and multiethnic.[62]
8
9

10 A strength of this review is that a range of perspectives and ideas regarding
11 recruitment of South Asians have been summarized and grouped thematically.
12
13 Accordingly, this review represents a comprehensive in-depth overview of this subject
14
15 area, and provides a good estimate of the volume and characteristics of the published
16
17 literature. Further, this review highlights areas for future investigation such as evaluation
18
19 of the effectiveness of the proposed recruitment strategies in settings with large South
20
21 Asian populations. There were several limitations to this review and the individual
22
23 studies included. Published evidence was only available from the UK, the US, India and
24
25 Australia; therefore, transferability to the Canadian context may be limited. Also, the
26
27 variable patient populations and sample sizes suggest that results may not be
28
29 generalizable to all South Asian populations. In addition, there was a relative paucity of
30
31 evidence regarding recruitment strategies for South Asians in these studies, and the
32
33 majority of the evidence is in the context of clinical trials. The usefulness of the proposed
34
35 recruitment strategies outside of the clinical trial setting is unknown. The applicability of
36
37 the strategies presented may vary, as some proposed solutions are relatively
38
39 straightforward, while others are more complex and difficult to apply. As discussed by
40
41 Waheed et al.,[36] changing recruitment venues may be easy, but provision of
42
43 appropriate incentives and catering to specific health and cultural beliefs may be more
44
45 difficult to execute. The primary types of studies that have been used to investigate
46
47 potential recruitment strategies in South Asian populations include focus groups and
48
49 interviews. These studies provide valuable insight into participant and researcher
50
51 perspectives, but do not directly address the quantitative impact of barriers or facilitators
52
53
54
55
56
57
58
59
60

1
2
3 or effectiveness of recruitment strategies. Where empirical data exists, it is often limited
4
5 to descriptive rates of recruitment and retention based on the results of quantitative
6
7 surveys or prospective cohort studies. Documentation of barriers to recruitment in future
8
9 studies including South Asian participants via qualitative interviews during the
10
11 recruitment process would help to address this gap. As well, assessment tools, such as
12
13 the Barriers to Research Participation Questionnaire, may assist in determining hurdles
14
15 to research participation in specific populations in a structured manner [63]. Since this
16
17 was a scoping review aimed at mapping the current literature on this topic, we did not
18
19 complete a quality assessment of the data. The search date restrictions that were
20
21 imposed may have excluded studies with valuable historical perspectives. However, we
22
23 believe this review captures a relevant snapshot of the most up-to-date research on this
24
25 topic.
26
27
28

29 The evidence reviewed suggests that recruitment methods aimed at engaging
30
31 with the target population may have a positive impact. One such intervention that was
32
33 not discussed explicitly by the included studies is community based participatory
34
35 research. This research method aims to increase the mutual value of the research
36
37 initiative for the researchers and the community.[64] This approach employs strategies
38
39 such as involving trusted community members as study staff, which may effectively
40
41 mitigate ethical and cultural challenges in research [65]. This approach may have the
42
43 potential to mobilize individuals to take ownership of their health and encourage
44
45 education and participation within their communities, and to ensure appropriate
46
47 dissemination of findings [66,67]. One study in South Asian women concluded that
48
49 participatory action research provided a platform for the participants to “create and share
50
51 knowledge”. [66] The overall paucity of evidence, particularly in the Canadian context,
52
53 suggests that work is still needed to determine context-specific barriers and facilitators to
54
55
56
57
58
59
60

1
2
3 recruitment, and associated strategies to increase the participation of South Asians in
4 health research. A mixed-methods synthesis from the Canadian perspective linking
5 experiences of individuals and groups to the evidence on effectiveness of recruitment
6 strategies may shed some light on potential approaches researchers could employ in
7 future studies. Given the lack of empirical data, proposed recruitment strategies should
8 be quantitatively evaluated, ideally using prospective experimental methods, to
9 determine the relative effectiveness and value. Further, adequate representation of
10 South Asians in research also relies heavily on the retention of participants, which has
11 been reported to be variable in South Asians.[68,69] The identification and investigation
12 of retention strategies that ensure the successful recruitment is not undone should be of
13 highest priority.

24 25 26 **Conclusions**

27
28
29 Better representation of South Asians in health research may promote
30 development of tailored treatment, and increased awareness and ownership of health.
31 This would support the ultimate goals of improving the health of the South Asian
32 population, reducing healthcare spending and addressing health inequity. The
33 information presented in this review can be used to assist researchers when preparing to
34 conduct research, and may help to inform a more in-depth analysis of this issue from a
35 Canadian perspective. Consideration of these issues during the grant writing and
36 protocol stages of research may decrease the risk of encountering recruitment problems
37 at latter stages.

ACKNOWLEDGEMENTS

YL acknowledges funding from the Canada Research Chair program of the Canadian Institutes of Health Research. PJ is supported by a Senior Scientist Salary Award from the BC Children's Hospital Research Institute.

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.

FUNDING STATEMENT

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

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.

REFERENCES

- 1 Government of Canada SC. National Household Survey: Immigration and Ethnocultural Diversity. 2014. <http://www5.statcan.gc.ca/olc-cel/olc.action?ObjId=99-010-X&ObjType=2&lang=en&limit=1> (accessed 27 May2015).
- 2 Ethnicity and National Identity in England and Wales - Office for National Statistics. <http://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/ethnicityandnationalidentityinenglandandwales/2012-12-11> (accessed 19 Jun2016).
- 3 Government of Canada SC. Classification of visible minority. 2009. <http://www.statcan.gc.ca/eng/concepts/definitions/minority01a> (accessed 17 Mar2017).
- 4 Statistics Canada. Projections of the Diversity of the Canadian Population. 2013. <http://www12.statcan.gc.ca/census-recensement/2011/ref/92-135/surveys-enquetes/vismin-population-minvis-eng.cfm> (accessed 10 Jul2014).
- 5 Veenstra G, Patterson AC. South Asian-White health inequalities in Canada: intersections with gender and immigrant status. *Ethn Health* 2016;**11**:1–10. doi:10.1080/13557858.2016.1179725
- 6 Gupta M, Singh N, Verma S. South Asians and Cardiovascular Risk What Clinicians Should Know. *Circulation* 2006;**113**:e924–9. doi:10.1161/CIRCULATIONAHA.105.583815
- 7 Anand SS, Yusuf S, Vuksan V, *et al*. Differences in risk factors, atherosclerosis, and cardiovascular disease between ethnic groups in Canada: the Study of Health Assessment and Risk in Ethnic groups (SHARE). *Lancet* 2000;**356**:279–84.
- 8 Rana A, Souza RJ de, Kandasamy S, *et al*. Cardiovascular risk among South Asians living in Canada: a systematic review and meta-analysis. *Can Med Assoc Open Access J* 2014;**2**:E183–91. doi:10.9778/cmajo.20130064
- 9 Sheikh A, Halani L, Bhopal R, *et al*. Facilitating the Recruitment of Minority Ethnic People into Research: Qualitative Case Study of South Asians and Asthma. *PLoS Med* 2009;**6**:e1000148. doi:10.1371/journal.pmed.1000148
- 10 Razak F, Anand SS, Shannon H, *et al*. Defining obesity cut points in a multiethnic population. *Circulation* 2007;**115**:2111–8. doi:10.1161/CIRCULATIONAHA.106.635011
- 11 Twells LK, Gregory DM, Reddigan J, *et al*. Current and predicted prevalence of obesity in Canada: a trend analysis. *CMAJ Open* 2014;**2**:E18-26. doi:10.9778/cmajo.20130016
- 12 Chiu M, Austin PC, Manuel DG, *et al*. Deriving Ethnic-Specific BMI Cutoff Points for Assessing Diabetes Risk. *Diabetes Care* 2011;**34**:1741–8. doi:10.2337/dc10-2300

- 1
2
3 13 Nanditha A, Ma RCW, Ramachandran A, *et al*. Diabetes in Asia and the Pacific:
4 Implications for the Global Epidemic. *Diabetes Care* 2016;**39**:472–85.
5 doi:10.2337/dc15-1536
6
- 7 14 Sword W, Watt S, Krueger P. Postpartum health, service needs, and access to care
8 experiences of immigrant and Canadian-born women. *J Obstet Gynecol Neonatal*
9 *Nurs JOGNN NAACOG* 2006;**35**:717–27. doi:10.1111/j.1552-6909.2006.00092.x
10
- 11 15 Nilaweera I, Doran F, Fisher J. Prevalence, nature and determinants of postpartum
12 mental health problems among women who have migrated from South Asian to high-
13 income countries: a systematic review of the evidence. *J Affect Disord*
14 2014;**166**:213–26. doi:10.1016/j.jad.2014.05.021
15
- 16 16 Asanin J, Wilson K. “I spent nine years looking for a doctor”: exploring access to
17 health care among immigrants in Mississauga, Ontario, Canada. *Soc Sci Med* 1982
18 2008;**66**:1271–83. doi:10.1016/j.socscimed.2007.11.043
19
- 20 17 Hussain-Gambles M, Atkin K, Leese B. Why ethnic minority groups are under-
21 represented in clinical trials: a review of the literature. *Health Soc Care Community*
22 2004;**12**:382–8. doi:10.1111/j.1365-2524.2004.00507.x
23
- 24 18 Hilton BA, Grewal S, Popatia N, *et al*. The desi ways: traditional health practices of
25 South Asian women in Canada. *Health Care Women Int* 2001;**22**:553–67.
26 doi:10.1080/07399330127195
27
- 28 19 Bhandari N, Taneja S, Rongsen T, *et al*. Implementation of the WHO Multicentre
29 Growth Reference Study in India. *Food Nutr Bull* 2004;**25**:S66-71.
30
- 31 20 Jolly K, Lip GY, Taylor RS, *et al*. Recruitment of ethnic minority patients to a cardiac
32 rehabilitation trial: the Birmingham Rehabilitation Uptake Maximisation (BRUM)
33 study [ISRCTN72884263]. *BMC Med Res Methodol* 2005;**5**:18. doi:10.1186/1471-
34 2288-5-18
35
- 36 21 Bajaj S, Jawad F, Islam N, *et al*. South Asian women with diabetes: Psychosocial
37 challenges and management: Consensus statement. *Indian J Endocrinol Metab*
38 2013;**17**:548–62. doi:10.4103/2230-8210.113720
39
- 40 22 Wiseman N. Designations of Medicines. *Evid Based Complement Alternat Med*
41 2004;**1**:327–9. doi:10.1093/ecam/neh053
42
- 43 23 Statistics Canada. The South Asian Community in Canada.
44 2007.<http://www.statcan.gc.ca/pub/89-621-x/89-621-x2007006-eng.htm> (accessed
45 19 Aug2013).
46
- 47 24 Lucas A, Murray E, Kinra S. Heath beliefs of UK South Asians related to lifestyle
48 diseases: a review of qualitative literature. *J Obes* 2013;**2013**:827674.
49 doi:10.1155/2013/827674
50
- 51
52
53
54
55
56
57
58
59
60

- 1
2
3
4 25 Grewal K, Stewart DE, Grace SL. Differences in social support and illness
5 perceptions among South Asian and Caucasian patients with coronary artery
6 disease. *Heart Lung J Crit Care* 2010;**39**:180–7. doi:10.1016/j.hrtlng.2009.06.016
7
8 26 George S, Duran N, Norris K. A systematic review of barriers and facilitators to
9 minority research participation among African Americans, Latinos, Asian Americans,
10 and Pacific Islanders. *Am J Public Health* 2014;**104**:e16-31.
11 doi:10.2105/AJPH.2013.301706
12
13 27 Hussain-Gambles M, Leese B, Atkin K, *et al.* Involving South Asian patients in
14 clinical trials. *Health Technol Assess Winch Engl* 2004;**8**:iii, 1-109.
15
16 28 Khan M, Kobayashi K, Lee SM, *et al.* (In)Visible Minorities in Canadian Health Data
17 and Research. *Popul Change Lifecourse Strateg Knowl Clust Discuss Pap Ser Un*
18 *Réseau Strat Connaiss Chang Popul Parcours Vie Doc Trav* 2015;**3**:5.
19
20 29 Macneill V, Nwokoro C, Griffiths C, *et al.* Recruiting ethnic minority participants to a
21 clinical trial: a qualitative study. *BMJ Open* 2013;**3**. doi:10.1136/bmjopen-2013-
22 002750
23
24 30 Mason S, Hussain-Gambles M, Leese B, *et al.* Representation of South Asian
25 people in randomised clinical trials: analysis of trials' data. *BMJ* 2003;**326**:1244–5.
26 doi:10.1136/bmj.326.7401.1244
27
28 31 Khunti K, Bellary S, Karamat MA, *et al.* Representation of people of South Asian
29 origin in cardiovascular outcome trials of glucose-lowering therapies in Type 2
30 diabetes. *Diabet Med J Br Diabet Assoc* Published Online First: 1 March 2016.
31 doi:10.1111/dme.13103
32
33 32 Hussain-Gambles M, Atkin K, Leese B. South Asian participation in clinical trials: the
34 views of lay people and health professionals. *Health Policy Amst Neth* 2006;**77**:149–
35 65. doi:10.1016/j.healthpol.2005.07.022
36
37 33 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J*
38 *Soc Res Methodol* 2005;**8**:19–32. doi:10.1080/1364557032000119616
39
40 34 Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology.
41 *Implement Sci* 2010;**5**:69. doi:10.1186/1748-5908-5-69
42
43 35 Balk EM, Chung M, Chen ML, *et al.* *Assessing the Accuracy of Google Translate to*
44 *Allow Data Extraction From Trials Published in Non-English Languages*. Rockville
45 (MD): : Agency for Healthcare Research and Quality (US) 2013.
46 http://www.ncbi.nlm.nih.gov/books/NBK121304/ (accessed 17 Mar2017).
47
48 36 Waheed W, Husain N, Allen G, *et al.* Recruitment strategies for British South Asians
49 in 5 depression trials: A mixed method study. *J Affect Disord* 2015;**185**:195–203.
50 doi:10.1016/j.jad.2015.06.046
51
52
53
54
55
56
57
58
59
60

- 1
2
3 37 Brown GE, Woodham A, Marshall M, *et al.* Recruiting South Asians into a UK Mental
4 Health Randomised Controlled Trial: Experiences of Field Researchers. *J Racial*
5 *Ethn Health Disparities* 2014;**1**:181–93. doi:10.1007/s40615-014-0024-4
6
7
8 38 Garduño-Díaz SD, Husain W, Ashkanani F, *et al.* Meeting challenges related to the
9 dietary assessment of ethnic minority populations. *J Hum Nutr Diet Off J Br Diet*
10 *Assoc* 2014;**27**:358–66. doi:10.1111/jhn.12153
11
12 39 Douglas A, Bhopal RS, Bhopal R, *et al.* Recruiting South Asians to a lifestyle
13 intervention trial: experiences and lessons from PODOSA (Prevention of Diabetes &
14 Obesity in South Asians). *Trials* 2011;**12**:220. doi:10.1186/1745-6215-12-220
15
16 40 Rooney LK, Bhopal R, Halani L, *et al.* Promoting recruitment of minority ethnic
17 groups into research: qualitative study exploring the views of South Asian people
18 with asthma. *J Public Health Oxf Engl* 2011;**33**:604–15. doi:10.1093/pubmed/fdq100
19
20 41 Samsudeen BS, Douglas A, Bhopal RS. Challenges in recruiting South Asians into
21 prevention trials: health professional and community recruiters' perceptions on the
22 PODOSA trial. *Public Health* 2011;**125**:201–9. doi:10.1016/j.puhe.2011.01.013
23
24 42 Stirland L, Halani L, Raj B, *et al.* Recruitment of South Asians into asthma research:
25 qualitative study of UK and US researchers. *Prim Care Respir J J Gen Pract Airw*
26 *Group* 2011;**20**:282–290, 8 p following 290. doi:10.4104/pcrj.2011.00032
27
28 43 Lloyd CE, Johnson MR, Mughal S, *et al.* Securing recruitment and obtaining
29 informed consent in minority ethnic groups in the UK. *BMC Health Serv Res*
30 2008;**8**:68. doi:10.1186/1472-6963-8-68
31
32 44 Mohammadi N, Jones T, Evans D. Participant recruitment from minority religious
33 groups: the case of the Islamic population in South Australia. *Int Nurs Rev*
34 2008;**55**:393–8. doi:10.1111/j.1466-7657.2008.00647.x
35
36 45 Krupp K, Madhivanan P, Karat C, *et al.* Novel recruitment strategies to increase
37 participation of women in reproductive health research in India. *Glob Public Health*
38 2007;**2**:395–403. doi:10.1080/17441690701238031
39
40 46 Shelton AJ, Rianon NJ. Recruiting participants from a community of Bangladeshi
41 immigrants for a study of spousal abuse: an appropriate cultural approach. *Qual*
42 *Health Res* 2004;**14**:369–80. doi:10.1177/1049732303261957
43
44 47 A comparative study of patients' attitudes toward clinical research in the United
45 States and urban and rural China. - PubMed - NCBI.
46 <https://www.ncbi.nlm.nih.gov/pubmed/25588611> (accessed 2 Feb2017).
47
48 48 Yancey AK, Ortega AN, Kumanyika SK. Effective recruitment and retention of
49 minority research participants. *Annu Rev Public Health* 2006;**27**:1–28.
50 doi:10.1146/annurev.publhealth.27.021405.102113
51
52
53
54
55
56
57
58
59
60

- 1
2
3 49 Pratt B, Van C, Cong Y, *et al.* Perspectives from South and East Asia on Clinical and
4 Research Ethics: A Literature Review. *J Empir Res Hum Res Ethics* 2014;**9**:52–67.
5 doi:10.1525/jer.2014.9.2.52
6
7
8 50 Symonds RP, Lord K, Mitchell AJ, *et al.* Recruitment of ethnic minorities into cancer
9 clinical trials: experience from the front lines. *Br J Cancer* 2012;**107**:1017–21.
10 doi:10.1038/bjc.2012.240
11
12 51 Ahmad F, Gupta H, Rawlins J, *et al.* Preferences for gender of family physician
13 among Canadian European-descent and South-Asian immigrant women. *Fam Pract*
14 2002;**19**:146–53.
15
16 52 Lee SK, Sulaiman-Hill CR, Thompson SC. Overcoming language barriers in
17 community-based research with refugee and migrant populations: options for using
18 bilingual workers. *BMC Int Health Hum Rights* 2014;**14**:11. doi:10.1186/1472-698X-
19 14-11
20
21 53 Neelotpol S, Hay AWM, Jolly AJ, *et al.* Challenges in collecting clinical samples for
22 research from pregnant women of South Asian origin: evidence from a UK study.
23 *BMJ Open* 2016;**6**:e010554. doi:10.1136/bmjopen-2015-010554
24
25
26 54 Patel M, Phillips-Caesar E, Boutin-Foster C. Barriers to Lifestyle Behavioral Change
27 in Migrant South Asian Populations. *J Immigr Minor Health Cent Minor Public Health*
28 2012;**14**:774–85. doi:10.1007/s10903-011-9550-x
29
30 55 Marshall A, Batten S. Researching Across Cultures: Issues of Ethics and Power.
31 *Forum Qual Sozialforschung Forum Qual Soc Res* 2004;**5**.[http://www.qualitative-](http://www.qualitative-research.net/index.php/fqs/article/view/572)
32 [research.net/index.php/fqs/article/view/572](http://www.qualitative-research.net/index.php/fqs/article/view/572) (accessed 13 Feb2015).
33
34 56 Inclusion: The Politics of Difference in Medical Research, Epstein.
35 <http://press.uchicago.edu/ucp/books/book/chicago/l/bo5414954.html> (accessed 20
36 Jun2016).
37
38 57 NIH Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical
39 Research - Amended, October, 2001.
40 https://grants.nih.gov/grants/funding/women_min/guidelines_amended_10_2001.htm
41 (accessed 20 Jun2016).
42
43 58 Report on governmental health research policies promoting gender or sex differences
44 sensitivity | Canadian Women’s Health Network. <http://www.cwhn.ca/en/node/25386>
45 (accessed 20 Jun2016).
46
47
48 59 Research governance framework for health and social care: second edition -
49 Publications - GOV.UK. [https://www.gov.uk/government/publications/research-](https://www.gov.uk/government/publications/research-governance-framework-for-health-and-social-care-second-edition)
50 [governance-framework-for-health-and-social-care-second-edition](https://www.gov.uk/government/publications/research-governance-framework-for-health-and-social-care-second-edition) (accessed 31
51 Jan2017).
52
53 60 Redwood S, Gill PS. Under-representation of minority ethnic groups in research —
54 call for action. *Br J Gen Pract* 2013;**63**:342. doi:10.3399/bjgp13X668456
55
56
57
58
59
60

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
- 61 Glover M, Kira A, Johnston V, *et al.* A systematic review of barriers and facilitators to participation in randomized controlled trials by Indigenous people from New Zealand, Australia, Canada and the United States. *Glob Health Promot* 2015;**22**:21–31. doi:10.1177/1757975914528961
- 62 Kallivayalil RA, Chadda RK. Culture, Ethics and Medicine in South Asia. *Int J Pers Centered Med* 2011;**1**:56–61.
- 63 Kibler JL, Brisco K. Evaluation of a brief questionnaire for assessing Barriers to Research Participation. *Ethn Dis* 2006;**16**:547–50.
- 64 Viswanathan M, Ammerman A, Eng E, *et al.* *Community-Based Participatory Research: Assessing the Evidence: Summary*. Agency for Healthcare Research and Quality (US) 2004. <https://www.ncbi.nlm.nih.gov/books/NBK11852/> (accessed 31 Jan2017).
- 65 Minkler M. Community-based research partnerships: Challenges and opportunities. *J Urban Health Bull N Y Acad Med* 2005;**82**:ii3-ii12. doi:10.1093/jurban/jti034
- 66 Choudhry U k., Jandu S, Mahal J, *et al.* Health Promotion and Participatory Action Research with South Asian Women. *J Nurs Scholarsh* 2002;**34**:75–81. doi:10.1111/j.1547-5069.2002.00075.x
- 67 Getrich CM, Sussman AL, Campbell-Voytal K, *et al.* Cultivating a cycle of trust with diverse communities in practice-based research: a report from PRIME Net. *Ann Fam Med* 2013;**11**:550–8. doi:10.1370/afm.1543
- 68 Kandula NR, Dave S, De Chavez PJ, *et al.* Translating a heart disease lifestyle intervention into the community: the South Asian Heart Lifestyle Intervention (SAHELI) study; a randomized control trial. *BMC Public Health* 2015;**15**:1064. doi:10.1186/s12889-015-2401-2
- 69 Vlaar EMA, van Valkengoed IGM, Nierkens V, *et al.* Feasibility and effectiveness of a targeted diabetes prevention program for 18 to 60-year-old South Asian migrants: design and methods of the DH!AAN study. *BMC Public Health* 2012;**12**:371. doi:10.1186/1471-2458-12-371

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1 **FIGURE LEGENDS**

2 Figure 1: Flowchart of Included and Excluded Studies

3

For peer review only

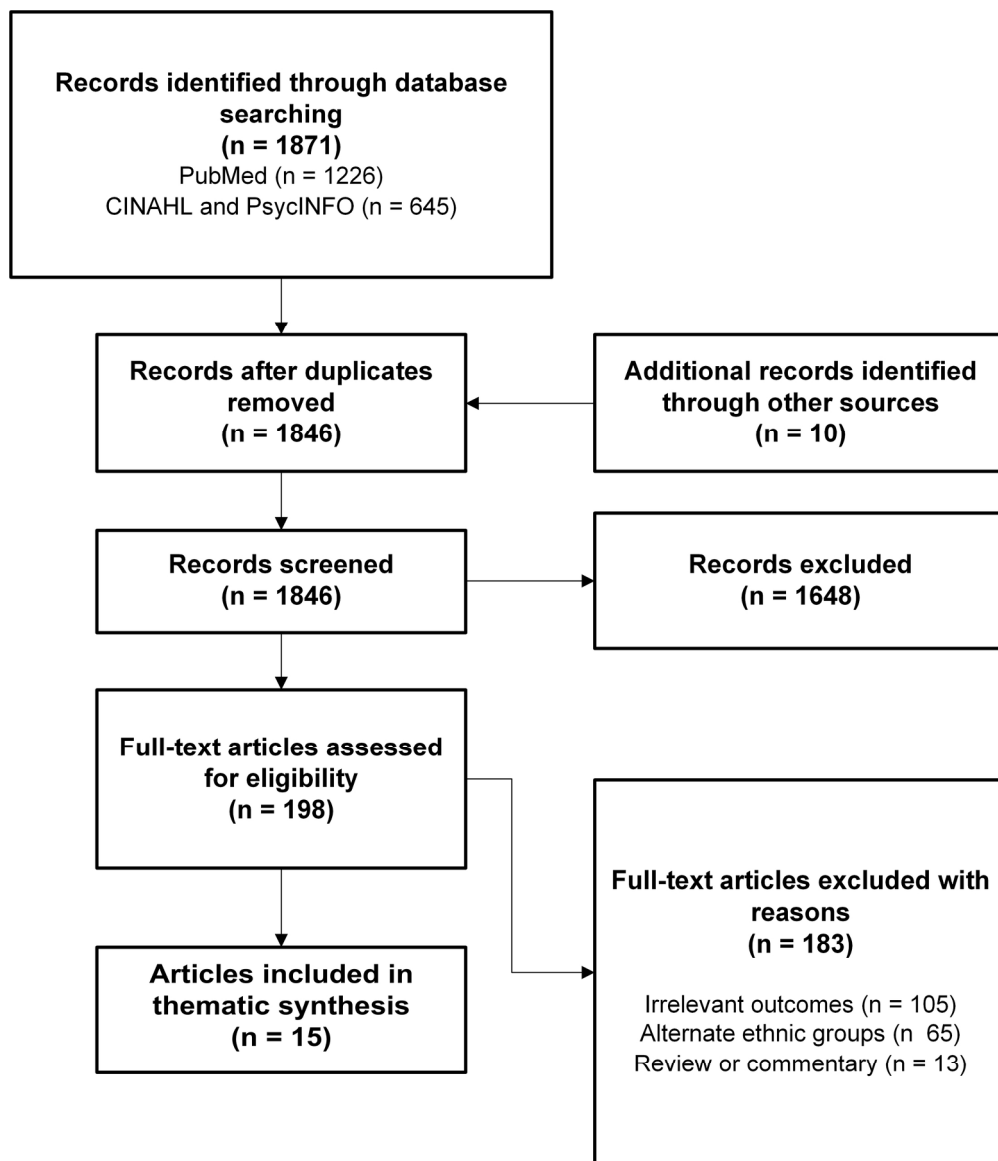


Figure 1: Flowchart of Included and Excluded Studies

Figure 1

188x217mm (300 x 300 DPI)

1 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

2

3 Search String:

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

10

11



PRISMA 2009 Checklist

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49

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

Page 1 of 2

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

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: www.prisma-statement.org.

Page 2 of 2

For peer review only - <http://bmjopen.bmj.com/site/about/guidelines.xhtml>