Review Article

Community-Based Research is an Equity-informed Community Engagement Approach to Ensure Inclusion in Research with and on the South Asian Diaspora

ABSTRACT

Objectives: This study aims to explore the levels of engagement of South Asian participants in health research and to assess the effectiveness of the Community-Based Research (CBR) framework in promoting health equity among this diaspora in Canada. This review also seeks to identify the effectiveness of the democratic and inclusive model of CBR in integrating marginalized communities into health research.

Methods: This review was conducted following Alamgir, et al.'s [19] supplementation of Arksey and O'Malley's [18] scoping review methodological framework. EBSCO CINAHL, Ovid MEDLINE, and Ovid APA PsycINFO databases were searched with assistance from a University of Toronto librarian. Open-access papers, grey literature, and articles were searched through a snowball approach following the bibliographies of collected articles. The included articles fulfilled strict inclusion criteria and were published in English between January 2004 and July 2024. The data was screened, charted, and assessed for quality, rigour, and level of community engagement. The PI supervised, reviewed, supported, and edited each step in an insider-outsider role.

Results: Out of 63 articles, 20 were selected, revealing unique methodologies and interaction models to engage with South Asian communities in research. Key findings indicate that the most successful methods adhered to culturally pertinent practices, and applied a collaborative, inclusive and meaningful method of community engagement. Identified weaknesses of the research include participants not being involved throughout the entirety of the project, not many studies incorporating CBR; and a smaller number of insightful studies minimizing diversity and ensuring equity in this area.

Conclusion: This study emphasizes the importance of adopting the Community-Based Research framework for conducting health research studies with South Asian participants. Notably, research-inclusive methods, in which community members participate as research subjects and co-researchers were most effective.

Keywords

Equity and Inclusion in Research, CBR, Patient and Public Involvement (PPI), Community Engagement in Health Research, South Asian Community, and South Asian Research.

Introduction

Colonial ideologies barred the minority populations in North America from being at the advantageous forefront of research [1]. Indigenous peoples in Canada were over-exploited by settlers in many ways, including in academic research [1]. Similarly, Black communities were subjected to unethical research practices for many years, a notable example being the "Tuskegee Study of Untreated Syphilis," where researchers deceived participants who desperately needed treatment, leading to severe complications [2]. Despite often being overlooked, South Asian communities have also been subjects of unethical research practices [3]; however, the drive to rebuild trust within this over-exploited group is insufficient. Consequently, present-day South Asian communities face significant disadvantages regarding equitable health research opportunities. Past unethical experiences have translated into a lack of participation, recruitment, and retention, which has inevitably led to the abundance of health issues faced by present-day South Asian populations. In addition, their lack of presence in research has contributed to the South Asian community being pathologized and viewed as a homogenized community as opposed to a diverse population consisting of important subpopulations with varying needs. The unique healthcare needs and historical neglect of South Asian communities highlight the critical importance of dedicated health research. Addressing the barrier of trust is the essential first step toward improving health research outcomes for South Asians.

South Asians experience unique health challenges both in comparison to non-South Asians and among distinct South Asian ethnicities. South Asian people originate from India, Bangladesh, Pakistan, Sri Lanka, Nepal, Fiji, Bhutan, and Indo-Caribbean countries [4]. Their historical migration patterns have led to enormous diasporas all around the world. Due to genetic predispositions and lifestyle factors [5], they face inordinate health issues compared to the rest of the population, including cardiovascular disease, and certain types of cancers [6]. South Asians are also diagnosed with diabetes at a higher frequency than any other ethnic group [4]. Within this broad group, people from Sri Lanka, Bangladesh, Pakistan, and Fiji had the highest occurrences [7], demonstrating significant heterogeneity within South Asian subpopulations. Challenges in mental health are also emerging in the South Asian community with South Asian women having an increased risk of developing postpartum depression [8]. Moreover, South Asian students were shown to have poorer health than their Caucasian counterparts [9]. Several studies have suggested that stress from migration, discrimination, academics, finances, and conflicts within their culture and families contribute to this health disparity [9]. Addressing these challenges requires a nuanced understanding of both the differences and similarities within the diverse South Asian diaspora.

The limitations of published literature regarding South Asian health research impede the progress toward achieving equity. Throughout the scoping review process, a discrepancy in regional research became apparent. Most of the published research focused on the South Asian population residing in the United Kingdom, with limited publications on this topic in Canada. In addition, a noticeable divergence arose when most of the solutions in the literature suggested ways to increase recruitment without solutions for mitigating stigmatization and mistrust in research by the South Asian community. Furthermore, research is usually conducted with a Westernised framework and seldom considers diverse methodologies [10]. As a result, researchers are usually not trained to incorporate culturally significant research frameworks [10]. Therefore, it is critical to search for more ethical research practices, incorporate different methodologies, and prevent the exclusion of any subpopulations and diasporas to achieve equity.

It becomes evident from the literature that many South Asians are skeptical about participation in research because of mistrust in research processes and researchers' commitments. This hesitancy can come from many other reasons. One of which is the perceived stigma regarding the specific topic of research [11]. For example, many South Asian women stigmatize breast cancer and often fear changes in physical appearance and community perception [12]. Other concerns among ethnic minorities include immigration status, potential side effects, and religious beliefs [11]. Due to cultural dynamics, South Asian women are often hesitant to interact with unknown people, including researchers, without a male counterpart present with them [13]. Conducting follow-ups and giving knowledge back to the community is a practice that can be used to restore trust, as it ensures that research is not unilateral [14]. The most effective way to overcome skepticism is to take a multifaceted approach, incorporating inclusivity and diversity, and improving communication between academia and the larger community.

The objective of this study is to identify the effective practices and gaps in research among the South Asian diaspora in Canada conducive to addressing health equity disparities. It seeks to understand past experiences of South Asian communities in research collaborations, identify barriers, and identify ethical and most successful research practices. It aims to use community assets, social capital, and strengths of Community-Based Research (CBR) organizations to form guideline principles to collaborate with academic researchers in achieving equity and inclusion. Gaining diverse perspectives and capitalizing on the principles of appreciative inquiry could assist the research team in developing and implementing equity principles, which have the potential to optimize and revolutionize South Asian health research. The ultimate goal of such endeavours is to alleviate the disproportionate health burden on South Asian communities [15]. Conceptualized using the PCC framework centred on Population, Concept, and Context [16], the research questions for this review were: *What are the types and levels of engagement of South Asian and ethnic minority participants in health research? How has the community benefited from CBR-academic partnership research?*

Methods

Setting

This review was housed at Access Alliance Multicultural Health and Community Services (Access Alliance) from May to August of 2024. Access Alliance is a CBR-focused non-profit community health organization serving mainly immigrants, refugees, the uninsured, and any resident of Toronto (Canada) with precarious migration status who are made vulnerable by the system and poverty.

Protocol

This study was registered (DOI: 10.17605/OSF.IO/W5FDQ) with the OSF [17]. Conducting a scoping review was selected because this topic has not been extensively studied. It enabled the researchers to identify the extent or gap in the current literature and to propose future directions for bridging the gap. Arksey and O'Malley's [18] methodological framework was consulted that encompasses five critical steps including identifying the research questions, identifying relevant studies, selecting eligible studies, charting the data, and collating, summarising, and reporting the results. This framework was strengthened with a practice-based methodology by Alamgir et al. [19] by adding four components to it. The first one is adding the PRISMA-ScR [20] practice to screen, sort, and select relevant articles searched from databases. The second component is adding Flicker and Nixon's [21] collaborative data analysis practice for minimizing the subjective bias of the independent researcher and reducing the differential between inter-researcher variability in opinions. The third practice added to this original model is shifting the paradigm of the conventional principal investigator's role to an 'Insider-outsider' perspective that also reduced the principal investigator's influence on data analysis. Finally, incorporating the CASP checklist [22] as a monitoring tool for ensuring the quality and rigour of the review process and products.

Search Strategy

The search was a collaborative effort supported by a librarian of the University of Toronto with the Field Researcher (PR) and reviewed by the PI (AA). The first step was to identify exhaustive and mutually exclusive specific research questions (mentioned in the previous section) using the Population, Concept, and Context (PCC) guideline [16]. Ovid MEDLINE, Ovid APA PsycINFO, EBSCO CINAHL databases, peer-reviewed open-access journals, and articles mentioned in the bibliographies of the identified articles were searched following a snowball approach. An environmental scan based on Nagi et al.'s [23] methodology was also conducted to retrieve credible grey literature from credible websites. The searches were divided into four sections based on the topic: 1) Health Research Inequities, 2) Community Engagement in Health Research, 3) Inclusion in the Research Process, and 4) South Asian Participants. An additional topic was added to yield studies in Canada; however, limited publications were found. MeSH terms and subject headings were used in addition to search strings. Search strings (Table 1) were developed through the guidance of the U of T librarian. Keyword combinations (e.g. "health research", "community participation", "stakeholder engagement", "research design", "data interpretation", "citizen science", "South Asian participant", etc.), truncation, Boolean operators, wildcards, proximity operators, and field codes were chosen and used meticulously. The multipurpose (.mp.) search criterion was used to search all texts.

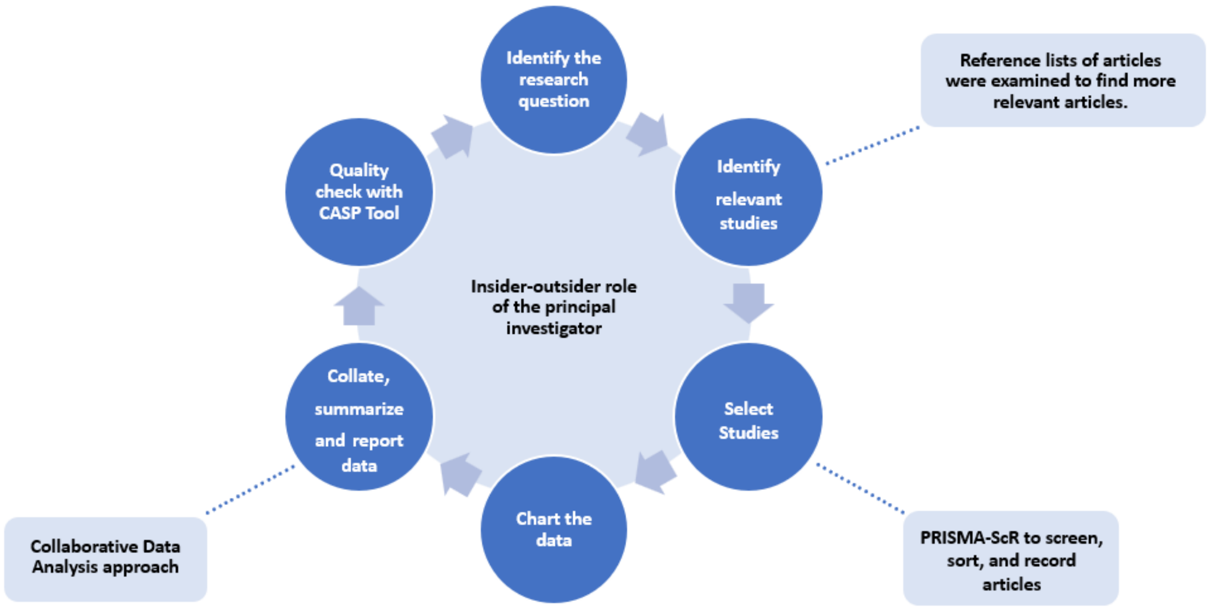

Figure 1. Supplemented model for Scoping Review.

Inclusion Criteria

The review included full-text, peer-reviewed publications that focused on South Asians or other similar ethnic minorities. Studies were eligible if they involved co-researchers over the age of 18, included participants at various stages of health research, and discussed frameworks and strategies for inclusion.

Exclusion Criteria

Articles were excluded if they did not focus on minority populations, did not include minority participants at any stage of research, were non-empirical (including theoretical literature and opinion pieces), were non-English language publications, were published before January 2004, were conducted in regions with a very small South Asian diaspora, were non-research-centred studies, were not accessible, or were duplicate publications.

Study Selection

Combinations of topics were searched using the AND operator, and the results were uploaded to the reference manager Zotero. This software kept a record of all articles compiled from multiple databases and search strategies and it was used to remove duplicates based on the first excluding principle in the PRISMA-ScR guidelines [20]. The first level screening was conducted on Zotero which involved screening article titles and abstracts. The second level of screening was conducted using the software Covidence, where an in-depth level of analysis and screening of full texts was performed and reasons for excluding articles were recorded. Articles were selected if they fulfilled the strict eligibility criteria. The screening process was recorded in a PRISMA-ScR flowchart (Figure 2).

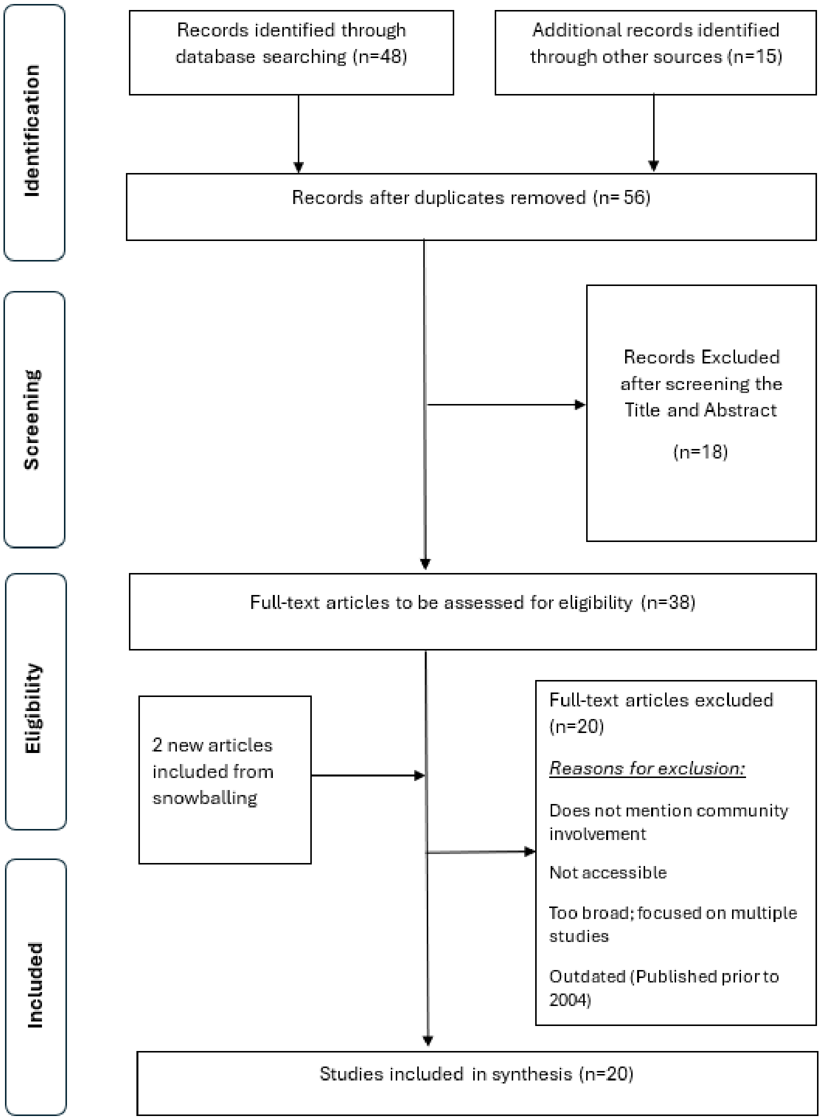

Figure 2. PRISMA-ScR flowchart depicting the study selection process for the scoping review. A total of 63 articles were initially identified, with 56 remaining after removing duplicates. 18 articles were excluded after the first level of screening, leaving 38 articles to be assessed during the second level of screening. Two additional articles were included during this time. After a thorough review of full-text articles, 20 articles were excluded leaving 20 for analysis.

Collating, summarising, charting, and synthesizing the results was completed after checking the quality and rigour of the process (Table 2) for writing the report. The level of community engagement as a sensitive indicator for conducting community-based research is also checked for quality assurance purposes of the literature review process (Table 3).

Quality Assessment

To ensure the quality and scientific rigour of the review process, an additional step of quality assessment was conducted using the CASP Checklist for Systematic Reviews [22] (Table 4). CASP offers various assessment tools for different quality assurance purposes for categories of reviews such as systematic reviews with meta-analysis of observational studies, and checklists for randomized control trials, qualitative studies, cohort studies, diagnostic studies, etc.

Analysis

Data analysis was conducted using Braun and Clarke's [24] reflexive thematic analysis model for qualitative research. The process began with familiarisation with the data through careful and thorough readings of each article followed by generating initial codes and grouping similar codes into themes. Subsequent steps included meticulous reviewing, defining, and naming of these themes by the field researcher and the PI. Finally, the themes were discussed to answer the research questions in the results section of this manuscript.

An 'Insider-outsider' perspective was employed by the PI (AA) by participating in analysis with the field researcher (PR), and by editing with guidance as a supervisor. This step was taken to avoid the influence and bias of the PI in the review process. Flicker and Nixon's [21] DEPICT model of collaborative analysis was the essence of the review process between the field researcher and the PI. The PI and researcher worked together following a co-design model to resolve differences of opinion.

Results

After conducting searches through databases, snowballing, and grey literature, 63 relevant articles were identified. Following the removal of duplicates, 56 studies remained for assessment. The first level of screening, based on title and abstract relevance, excluded 18 studies. The remaining 38 articles underwent a second level of screening using the Covidence software, where full texts were reviewed against the eligibility criteria. During this stage, two additional articles were identified and included. Ultimately, 20 articles were included in the synthesis of this scoping review, while 20 were excluded due to reasons such as lack of community engagement, inaccessibility, not being published within the specified time frame, or discussing a broad range of studies rather than focusing on one or a few.

The studies included in this review were published in various regions: The United Kingdom (n=8), Canada (n=7), The United States (n=2), multiple countries excluding Canada (n=2), and multiple countries including Canada (n=1). The studies utilised a range of community engagement styles as shown in Figure 3. Eleven articles featured South Asian authorship.

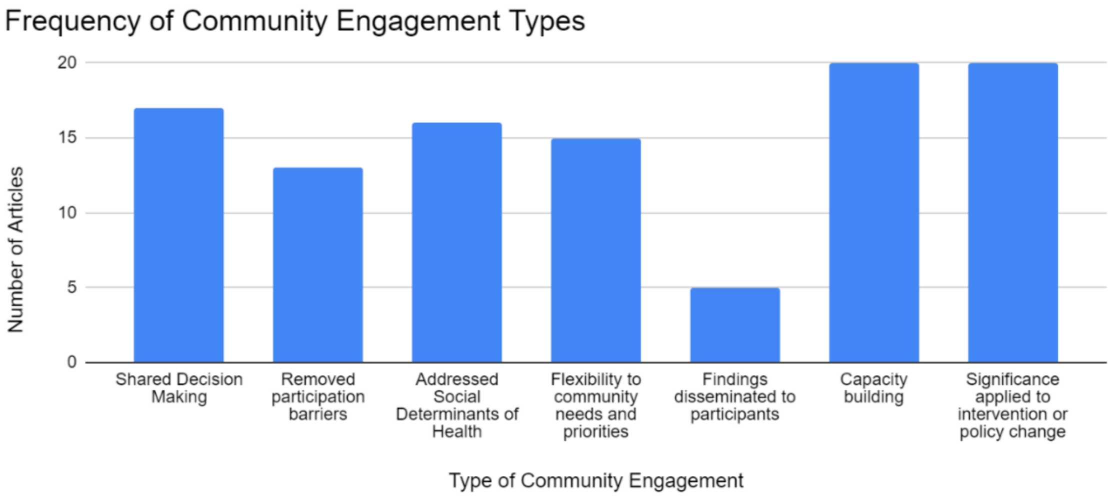

Figure 3. Bar graph representing the frequency of each type of community engagement. Shared Decision-Making (n=17), Removing Participation Barriers (n=13), Addressing the Social Determinants of Health (n=16), Prioritising Community Needs (n=15), Disseminating Findings to Participants (n=5), Capacity Building (n=20), and Applying the Findings to Health-Related Interventions or Policy Changes (n=20).

Various methods were employed in these studies, such as literature reviews, participant interviews, surveys, focus groups, and one collective auto-ethnography [25]. The findings are summarised into six key themes; the first three highlight the levels of community engagement in minority health research, and the subsequent three explore their effectiveness in mitigating barriers.

Establishing the Research Foundation through Community Involvement

Many health research studies demonstrate inconsistent community-based research (CBR) engagement. A recurring theme is that participants are primarily or exclusively involved in the early stages of research [26]. Researchers often prioritize community engagement during the development of relevant topics, research questions, and study protocols, as these foundational steps determine the direction of the research. Involving the public at these stages enables researchers to identify the topics that are most important to the community and urgently require investigation, ensuring that the results are meaningful and have a positive impact.

In contrast, the later stages of a research project, such as data screening, analysis, and summarising the work comprehensively, are typically handled by researchers alone. These steps require scientific expertise, and many researchers may exclude community members from these stages due to a perceived lack of benefit or financial constraints.

Participants as Collaborative Co-Researchers Involved in all Phases of Research

Despite the novelty of engaging minority populations throughout the entirety of a research project, few studies have extensively incorporated participants as co-researchers. An example includes a study conducted by Bryan et al., which aimed to gain insight into South Asian patients' experiences with knee replacement surgery [27]. This study incorporated three patients as co-researchers who were included in the design, data collection, data analysis, and interpretation of results. This 'insider-outsider' role played by patients enabled the research team to gain a broader perspective on recruitment strategies and the co-researchers' suggestions helped in identifying and overcoming technical barriers.

Similarly, a study conducted by Lakhanpaul et al., aimed at developing an intervention for the management of asthma among South Asian people [28] using CBR. This study included community members as research partners, involving them in research question development, recruitment, intervention development, interpreting research findings, and disseminating results. Community facilitators were involved to assist participants with language barriers and accommodate participant preferences. The study emphasized family engagement to understand how asthma is perceived and managed by family members.

Cultural Sensitivity and Appropriateness in Research

Cultural sensitivity can be incorporated in many ways. Hayward et al.'s [29] study on assessing frameworks for ethical research with Indigenous peoples in Canada highlights the importance of adhering to culturally pertinent practices. This can include using minority frameworks in conjunction with the standard Westernised research framework [10]. For example, Indigenous people value respect towards other living beings and natural resources [29]. This value can be integrated into the research design to ensure cultural sensitivity and respect towards this minority, which could ultimately lead to gaining their trust.

The literature review leading up to this scoping review highlighted that South Asian women are often difficult to recruit due to hesitancy or cultural norms [13]. A unique and innovative solution for their recruitment may encompass the use of cultural activities to create a comfortable atmosphere. This was accomplished by a study by Redwood et al. where the research team hired local South Asian artists to establish the activity of 'Rangoli' art, where South Asian women participants could participate in cultural art while simultaneously being interviewed by the research team [30]. The researchers aimed to create a casual conversational environment to ensure that the women felt comfortable sharing their experiences. This approach was intended to collect authentic data, free from the potential biases and constraints of traditional interview methods.

In a study where minority women shared their experiences and recommendations for participating in CBR, developing close ties with the community was a major theme [31]. It is crucial to develop a familiarity with the community where research takes place and extensively study the characteristics, cultural values, and beliefs held by people in that community before the commencement of research. This enables researchers to identify potential conflicts between the research protocol and community culture or incorporate newfound culturally sensitive methods.

Fostering a Positive Perception of Research

Community engagement has significantly transformed participants' perspectives on research, fostering positive outcomes. Hayward et al.'s [29] study has found that Indigenous participants involved in research collaborations viewed research as sacred. In addition, this study states that this operationalization has the potential to heal historically overexploited communities. The inclusion of Indigenous communities has helped researchers address racism, power imbalances, and oppression. Overall, stronger relationships between researchers and communities were formed and the results produced by the studies had far greater impacts.

Additionally, in a study with minority groups with a high risk of HIV [32], participants changed their perception of research, recognizing it as a collective endeavour aimed at benefiting society as a whole. Engaging in the research process enabled participants to gain a deeper understanding of the intricacies involved in scientific progress, leading them to appreciate the challenges faced by researchers. By actively participating, they developed a sense of responsibility and collaboration, contributing to a broader appreciation for the role of research in promoting the common good.

Lee et al.'s [25] study involving diverse populations with psychosis claimed that CBR has enabled participants to develop a research interest and that it offered them a distinctive and enriching educational experience. One participant articulated the experience as a privilege, expressing appreciation for the opportunity to contribute valuable insights from their community to academic research.

One of the most extensive employments of CBR was accomplished by Lakhanpaul et al.'s [28] study on asthma management in South Asian children. This study revealed that community engagement has increased participation, recruitment, and retention due to enthusiasm expressed by the community members involved. The incorporation of ethnoreligious community facilitators increased the level of trust between participants and researchers.

Addressing Inequities and Power Dynamics

Research is often regarded as unilateral; where researchers take information from participants and retain control over the results, perpetuating power inequalities. The aforementioned theme of cultural sensitivity and the use of culturally pertinent frameworks can lead to the dismantling of the hierarchy between participants and researchers. Not only can participants address any perceived power imbalances, but specific frameworks such as Indigenous methodologies involve balancing power as a key component [29]. These frameworks emphasize the collective ownership of knowledge as one of the most important aspects of research because it mitigates power dynamics by employing collective rights.

Community-based research is unique because it aims to put forward the perspective that community members are equal to academic researchers. Power inequities are dismantled through the use of democracy in decision-making. In Lakhanpaul et al.'s [28] study, for example, South Asian families, healthcare providers, and other community members actively participated in various stages, including problem identification, intervention development, data interpretation, and dissemination of findings. This extensive incorporation of diverse perspectives helps to mitigate the influence of power. Furthermore, equity was promoted through the use of facilitators who assisted participants in overcoming language, knowledge, and other barriers. This ensured that all voices were heard and valued, enhancing the overall effectiveness and inclusivity of the research.

Increasing the Impact and Validity of Research

Not only does CBR improve community perceptions and minimize power inequalities, it also has the potential to transform research to be more impactful, generalizable, and beneficial to the community. A study by Manikam et al. [33] highlighted that South Asian community members and healthcare providers had very distinct topics of research prioritization, validating the importance of stakeholder engagement. By incorporating the perspectives and experiences of patients and the public, researchers can ensure that the study design and implementation are aligned with the needs of the community, which can ultimately increase the impact of the research.

An article by Pii et al. [26] mentions that Patient and Public Involvement (PPI) in cancer research can enhance the relevance, ethics, and validity of the study. Content validity and reliability of assessment tools are increased due to the perspectives of cancer patients and survivors as they could evaluate the tools' appropriateness based on their lived experiences [34].

This collaborative approach not only enhances the quality of the research but also fosters a sense of empowerment and inclusion among participants. Actively involving cancer patients and survivors, challenges the traditional view of them as frail and unable to contribute to society, instead recognizing them as valuable partners in the research process. Roura et al. [35] also emphasize that Participatory Health Research can drive broader societal changes by challenging stereotypes of migrants as powerless individuals. Instead, it highlights their role as active contributors to society.

Discussion

The findings from this study suggest that CBR is a valuable operationalization in inclusive and equity-informed health research despite its rare usage and inconsistent employment. Based on the studies examined in this scoping review, CBR is often used for establishing research foundations, seldom used in all phases of research, and often employs cultural sensitivity. It benefited the community by fostering positive perceptions, building trust, and addressing power dynamics. Furthermore, it had the potential to increase the impact and both the internal and external validity of the research. These findings are consistent with other published literature. In this section, I discuss how the findings of this scoping review can advance health research equity for South Asian communities. I also discuss various unmet gaps in the published literature and how they can be overcome with the practice of Community-Based Research.

Establishing the foundation of a research study using community involvement is an important theme that was encountered. Although all stages of research are equally important and capable of incorporating CBR, the purpose and research questions to be addressed must reflect the needs of the population or the community. It would be prodigal to receive hundreds of thousands of dollars in funding and spend multiple years conducting a study with little to no relevance or benefit to targeted communities or populations. This is particularly relevant to South Asians as research regarding their health has often not been meaningful or helpful in addressing health disparities. Therefore, the direction and basis of the research need to perpetually incorporate community input.

Just as determining the essence of research is important, other steps such as data collection, analysis, interpretation, and dissemination are undoubtedly important. The theme of Participants as Collaborative Co-Researchers Involved in all Phases of Research is one with the most disparate number of publications. Only two articles selected for the scoping review extensively used CBR in all stages of research. One of which was Lakhanpaul et al.’s [28] study regarding Asthma management in South Asian children in the United Kingdom. The second was Bryan et al.’s [27] study regarding knee replacement surgery recovery among South Asian patients in British Columbia, Canada. This significant gap in both the literature and in practice needs to be addressed due to the added value of including South Asian patients and community members as co-researchers.

The method of data collection requires careful consideration due to maintaining construct and content validity. As previously discussed, participants can offer valuable insights based on their lived experiences and they can attest to the quality of a measurement tool.

The inclusion of South Asian community members in data interpretation and analysis is imperative to minimize colonial biases and inaccurate and harmful stereotypical judgements. Agarwal et al. 's [36] literature review uncovered a study which inaccurately and unethically attributed South Asian COVID-19 morbidity with deliberate ignorance of pandemic risk and bans on cultural gatherings.

An additional evident gap in research protocol includes the lack of results dissemination to communities. In this scoping review, only five studies mentioned they disseminated their results to the participants and relevant stakeholders. This supports the traditional and problematic perception of research as a one-sided process where researchers take from communities without the intention to give back. The community-based researchers claim that South Asian community members often wonder what happened to their data and what implications it had.

Cultural Sensitivity and Appropriateness in Research was a novel theme, especially in the context of South Asian health research, but it is nevertheless an important one to ensure that participants feel acknowledged and respected. Culturally relevant methods are also important for gaining their trust and mitigating other barriers. This practice was sparingly used in research studies with only two articles extensively employing this theme. This is another gap both in practice and in research which has the potential to transform perspectives regarding research participation.

The theme of fostering a positive perception of research played a crucial role in addressing the research question. This broad theme encompasses diverse expressions. The effectiveness of Community-Based Research (CBR) is directly evidenced by participants' shifts in perception. Several studies have noted a clear transition in participants' perspectives, moving from viewing research as merely taking or mercenary to recognizing it as a process aimed at improving the world. The main goal of this study was to assess the impact of Community-Based Research (CBR) on the community. The theme of addressing inequities and power dynamics emerged as a significant finding, directly linking CBR to participant equity. This important result underscores the necessity of CBR in South Asian health research. By ensuring equitable access for all demographic groups—including women, the elderly, and individuals with illnesses or disabilities—the ultimate goal of achieving health equity within the South Asian community becomes more attainable. These results supported the hypothesis as they provided solid evidence of CBR enhancing perceptions and building trust.

Increasing the Impact and Validity of Research was an unanticipated theme that arose after conducting this study because it explained the benefit of CBR to academic researchers in addition to the population being researched. This theme highlights the significance of incorporating CBR in South Asian health research exclusively due to the lack of impact that research has had on this demographic group. South Asian research is also impacted by lack of validity as previously mentioned due to unjust stereotypical views overshadowing data interpretation. Incorporating CBR addresses these challenges by fostering more accurate and impactful research outcomes.

Strengths and Limitations

This study has several notable strengths and limitations. The study's focus on South Asian health research addresses a significant gap in the literature and provides valuable insights into this underrepresented demographic. One key limitation is the potential for bias due to limited perspectives allowing for study selection bias and data interpretation bias. This minimizes the internal validity of the study. Geographic publication disparities and population changes over time threaten external validity.

Despite these limitations, the study provides important contributions to the field of South Asian health research, highlighting the need for more inclusive and community-driven approaches to addressing health inequities.

Conclusion

This study aimed to explore the levels of engagement of South Asian participants in health research and to evaluate the effectiveness of the Community-Based Research (CBR) framework in promoting health equity among the South Asian diaspora in Canada. This scoping review reveals that Community-Based Research (CBR), despite its effectiveness in mitigating trust barriers and enhancing research quality, is underutilised in South Asian health research. Particularly in Canada, few studies engage South Asian communities as co-researchers and those that do often limit their involvement as the research progresses. Additionally, findings are rarely disseminated to participants and other stakeholders, reducing the potential impact and relevance of the research.

This scoping review aims to persuade South Asian health researchers to consider integrating community engagement throughout the entirety of their research. It underscores the importance of cultural sensitivity and appropriateness, tailored to specific ethnic or religious groups, and advocates for CBR to generate valid, relevant, and generalizable results.

Despite its many strengths, CBR is often limited by time and funding for participant engagement since participants do not possess the same level of scientific expertise as researchers and thus require additional resources. In addition, many participants have language barriers and preferences regarding information sharing. Nonetheless, its potential to effectively engage and empower overexploited communities and minority groups makes it indispensable.

Recommendations for future research collaborations include developing familiarity with the community before research, using community engagement consistently throughout the research process, employing ethical and culturally relevant methods, disseminating research results to those whom they affect, and continuing to keep close ties with communities for future collaborations.

Disclosure

The authors declare no conflicts of interest concerning this study. This study was conducted as part of a research student placement agreement between the University of Toronto and Access Alliance Multicultural Health and Community Services (Course: HMB496Y1: Research Project in Human Biology, University of Toronto).

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Appendix

Table 1. Medline Search Strings

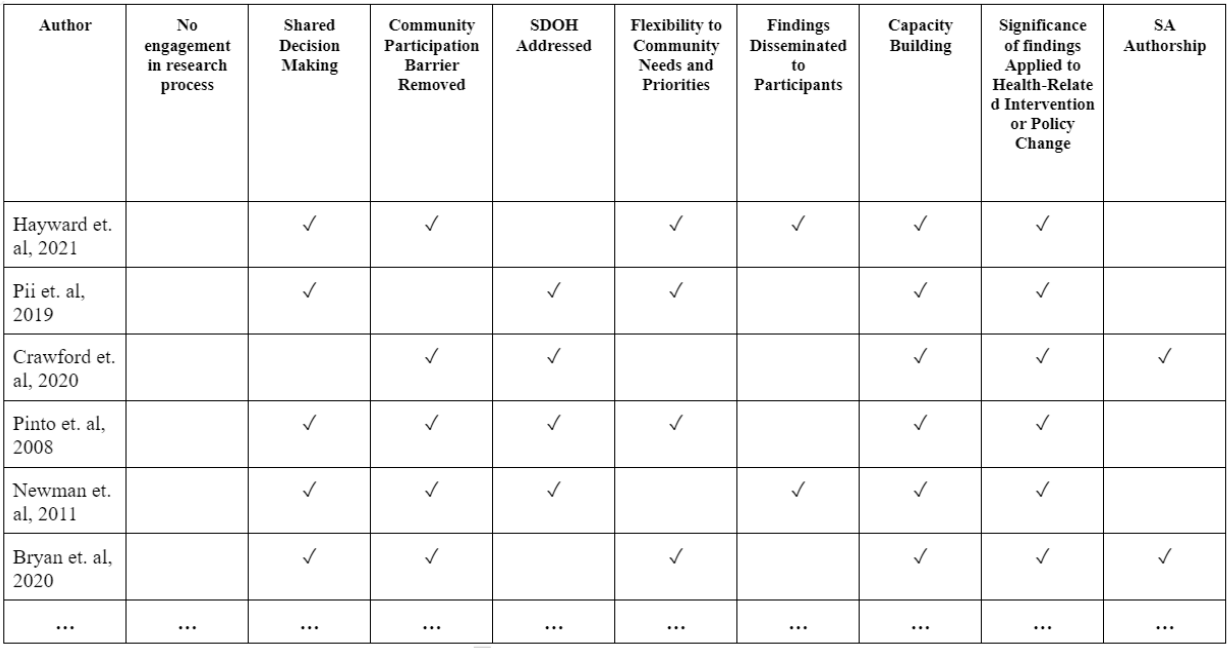
#	Searches	Results
1	Health Equity/ or Health Inequity/ or Health Status Disparities/	25180
2	(("Health* research" adj2 (inequit* or inequalit* or equit* or equalit*)) or "health disparit*").mp.	24526
3	1 or 2	45452
4	exp Community-Based Participatory Research/ or Community Participation/ or Citizen Science/	24708
5	("community participation" or "stakeholder engagement" or ((consumer or stakeholder* or community) adj2 (activation or activated or oriented or driven or engage* or empower* or framework* or approach* or guidance or guide or implement* or involve* or participat* or partner* or research* or	86765

	tool or toolkit* or technique*))).mp.	
6	4 or 5	87201
7	Research design/ or Data analysis/ or Data collection/ or Information dissemination/	240486
8	("Research design" or (data adj2 (interpret* or analy* or collecti*OR disseminati* or accessibility)) or "citizen science").mp.	668280
9	7 or 8	769046
10	(*Asian people/ or Southeast Asian people/ or exp Asia, Southern/) and exp Research Subjects/	394
11	(("South Asia*" or India or Indian or Indians or Bangladesh* or Nepal* or "Sri Lanka*" or Pakistan* or Bhutan* or Fiji or Fijian or Maldiv* or Desi) adj4 (participant or attendee or attendan* or study or examinee or researchee)).mp.	23000
12	10 or 11	23374
13	exp Canada/ or Canad*.mp.	262974
14	3 and 12 and 13	1
15	6 and 12 and 13	2
16	9 and 12 and 13	10

Table 2. Data Extraction and Charting

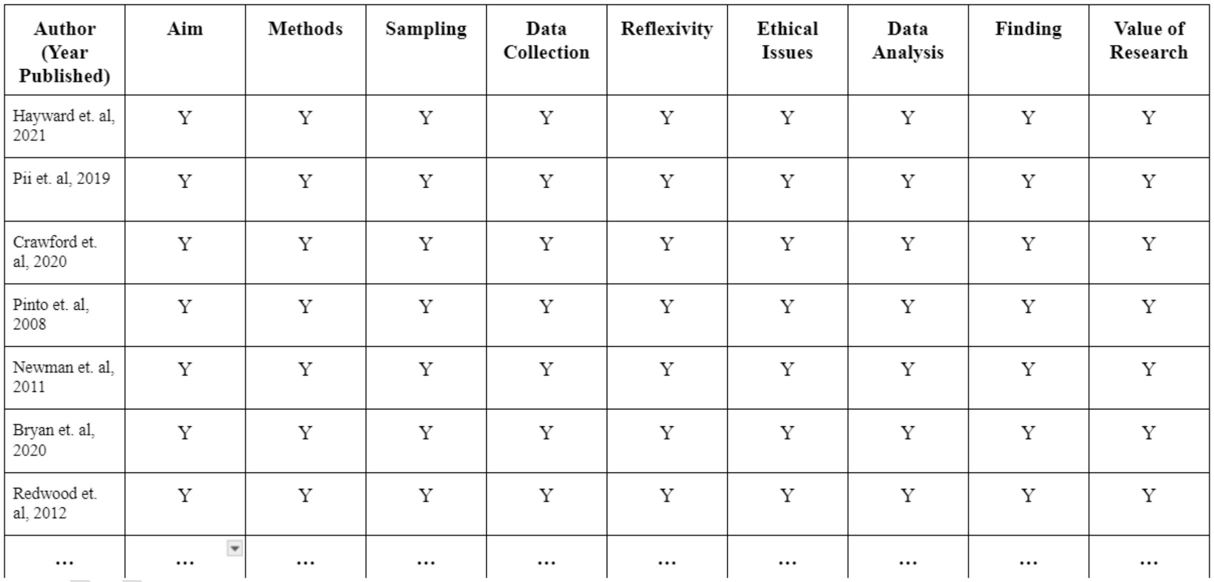
Author	Focus or Aim of Study	Methodology	Participants	Data Collection	Results
Hayward et al., 2021	The aim of the study was to assess frameworks, ethic boards, and protocols for research with Indigenous participants to develop key themes that are important for ethical engagement of Indigenous participants.	Scoping review based on Arksey and O'Malley (2005) and Levac et al.'s (2010) models for conducting scoping reviews.	Review of studies with Indigenous participants in Canada.	Data was collected from peer-reviewed literature reviews, studies, reports, and frameworks developed by Indigenous communities and organisations in Canada.	Three common themes were identified and compiled from an array of frameworks; adjusting rights for both individuals and groups, adhering to culturally pertinent ethical practices, and ensuring community-centred research.
Pii et al., 2019	The aim of the study was to assess the use of Patient and Public Involvement (PPI) in cancer research; with emphasis on methods, challenges, and future directions.	Systematic review based on PRISMA guidelines. Databases MEDLINE, CINAHL, and PsycINFO were consulted.	Variable participant populations from numerous countries with distinct types of cancer.	Data was collected from studies with PPI incorporated in any stage of the cancer research process.	Most studies incorporated PPI during the early stages of research which involved defining study characteristics, outlining recruitment strategies, and prioritising research topics.
Crawford et al., 2020	The aim of the study was to test a survey assessing cancer screening behaviours among South Asians in Canada.	Recruitment of participants in two Ontario cities to complete the interviewer-led survey, available in both English and Urdu.	328 South Asian people from ages 50 to 74 with average risk of colon cancer, who are permanent residents, and were able to speak English or Urdu.	Data was collected through a four-section survey containing 84 items on both paper and digital platforms.	The tool was found to be practical and reliable. There was a significant difference in perception of colon cancer screening between those who have been screened versus those who have not.
…	…	…	…	…	…

Table 3. Levels of Community Engagement



Author	No engagement in research process	Shared Decision Making	Community Participation Barrier Removed	SDOH Addressed	Flexibility to Community Needs and Priorities	Findings Disseminated to Participants	Capacity Building	Significance of findings Applied to Health-Related Intervention or Policy Change	SA Authorship
Hayward et. al, 2021		✓	✓		✓	✓	✓	✓	
Pii et. al, 2019		✓		✓	✓		✓	✓	
Crawford et. al, 2020			✓	✓			✓	✓	✓
Pinto et. al, 2008		✓	✓	✓	✓		✓	✓	
Newman et. al, 2011		✓	✓	✓		✓	✓	✓	
Bryan et. al, 2020		✓	✓		✓		✓	✓	✓
…	…	…	…	…	…	…	…	…	…

Table 4. CASP Quality Appraisal



Author (Year Published)	Aim	Methods	Sampling	Data Collection	Reflexivity	Ethical Issues	Data Analysis	Finding	Value of Research
Hayward et. al, 2021	Y	Y	Y	Y	Y	Y	Y	Y	Y
Pii et. al, 2019	Y	Y	Y	Y	Y	Y	Y	Y	Y
Crawford et. al, 2020	Y	Y	Y	Y	Y	Y	Y	Y	Y
Pinto et. al, 2008	Y	Y	Y	Y	Y	Y	Y	Y	Y
Newman et. al, 2011	Y	Y	Y	Y	Y	Y	Y	Y	Y
Bryan et. al, 2020	Y	Y	Y	Y	Y	Y	Y	Y	Y
Redwood et. al, 2012	Y	Y	Y	Y	Y	Y	Y	Y	Y
…	…	…	…	…	…	…	…	…	…