Engaging Members of Underserved Communities in Health Research: Best Practices and Approaches

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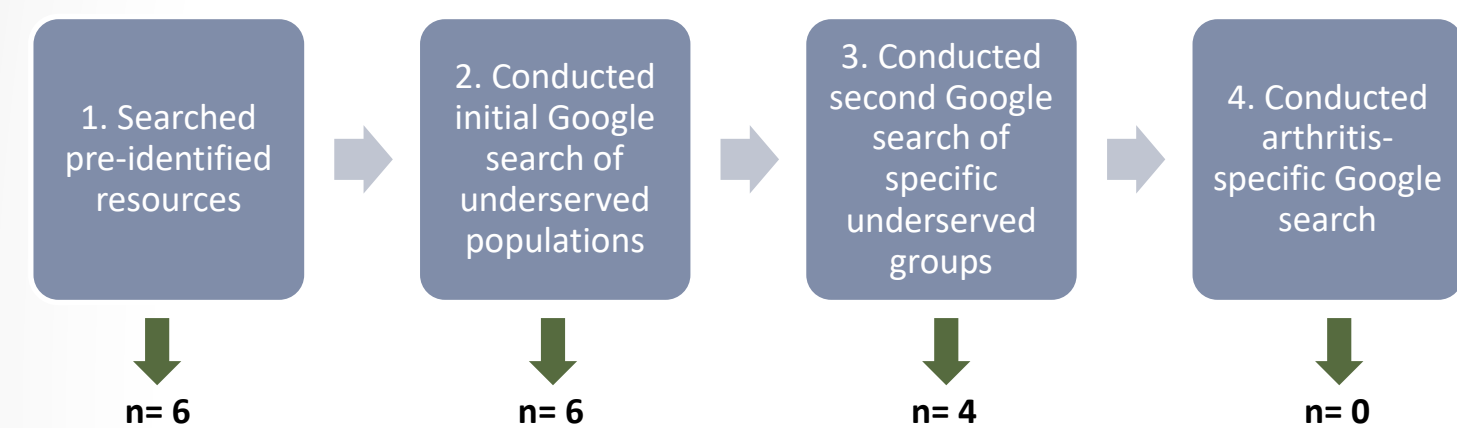
INTRODUCTION

Understanding how to involve underserved communities in research processes is an essential, but largely missing part of the patient-engagement and patient voices strategies shaping BC health research and care. These groups face barriers to accessing and receiving high quality care, and involving them in research processes is essential for better serving their needs and improving health outcomes.
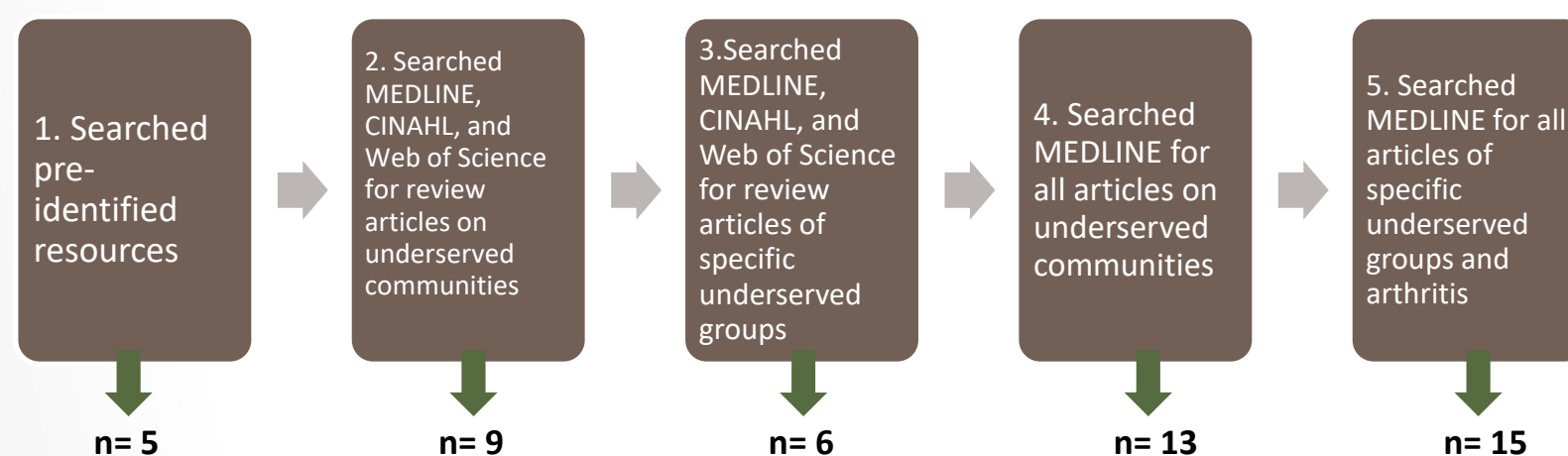
We conducted a literature review to determine current knowledge on best practices for engaging underserved communities (racial/ethnic minorities, refugees, immigrants, Indigenous Peoples, seniors, and low-income and homeless individuals) as partners in our study on the barriers to self-management support for underserved populations living with arthritis.

METHODS

Grey Literature Search Methodology

1. Searched pre-identified resources → n = 6
2. Conducted initial Google search of underserved populations → n = 6
3. Conducted second Google search of specific underserved groups → n = 4
4. Conducted arthritis-specific Google search → n = 0

Academic Literature Search Methodology

1. Searched pre-identified resources → n = 5
2. Searched MEDLINE, CINAHL, and Web of Science for review articles on underserved communities → n = 9
3. Searched MEDLINE, CINAHL, and Web of Science for review articles of specific underserved groups → n = 6
4. Searched MEDLINE for all articles on underserved communities → n = 13
5. Searched MEDLINE for all articles of specific underserved groups and arthritis → n = 15

RESULTS: SAMPLE

Variable		Academic (48 sources)	Grey (16 sources)
Year of Publication	2011	5	2
	2012	7	2
	2013	6	4
	2014	5	2
	2015	10	2
	2016	14	4
	2017	1	0
Country of Publication	Canada	14*	12
	Europe	5*	1
	US	25	3
	Australia	5	0
Source Type	Review	13	N/A
	Original study	13	N/A
	Commentary based on original study	18	N/A
	Commentary	4	N/A
	Guideline	N/A	6
	Report	N/A	5
	Presentation	N/A	2
	Other (e.g. poster, toolkit)	N/A	3

*One study was published in an online international journal and was a joint study between researchers from the UK and Canada

RESULTS: THEMES

UNDERSERVED COMMUNITIES AS RESEARCH PARTNERS

- Diversity
- Defining Partnership
- Community Representation
- Trust & Community Building
- Power Dynamics
- Benefits
- Research Literacy & Training
- Barriers
- Collaborative Engagement Methods

DISCUSSION

Nine key themes on best practices for engaging underserved communities in research were identified in the literature review. In addition to the essential topic areas, the literature provided concrete suggestions on how to implement these important considerations in the design and implementation of collaborative research on vulnerable populations. Collectively, the literature review findings form essential considerations for developing and implementing studies using partners from vulnerable groups, and provide a foundation for developing a draft model to guide researchers conducting collaborative research in these populations. We are currently using these best practices to guide our approach to engaging partners in our study to better understand the barriers to self-management support for individuals in underserved communities in Vancouver.

The best practices identified in our literature review reflect most of the key principles outlined in the AWESOME Model that was developed by Fraser Health in 2013 to help healthcare decision makers engage underserved patients in health care planning. These key principles are: being gender-sensitive, focusing on power, recognizing and working with diversity, recognizing the needs of decision makers in the process, valuing lived experiences, committing to using the patients' input, and reporting back to patients. While some of our findings (e.g. research literacy) are only applicable to research, and some of the recommendations made in the AWESOME Model are only applicable to healthcare planning (e.g. engagement methods), the commonalities suggest that key principles and practices for working with partners and individuals from these communities may transcend the purpose of engagement (research or healthcare planning).

Themes	Best Practices
DIVERSITY *Engaging the Underrepresented* • Dominant social groups mainly determine who is "competent" to engage in research • Social detriments of health determine likelihood of research engagement	• Consider engaging groups that are underrepresented as research partners • Develop strategies that enable these groups to seek and engage with research processes
DEFINING PARTNERSHIP *Roles & Degrees of Involvement* • Involving partners can be instrumental in research design and recruitment, and in building trust with participants • Partnerships can range from co-production to having partners input controlled by researchers to varying degrees • Roles may include participation with any, or all phases of research design and implementation	• Meaningfully engage community partners in research projects to increase the quality of research • Consider all kinds and degrees of involvement, and mutually agree on a set of roles best suited for each partner in the project • Discuss and agree on the kinds of support that will be provided, logistics, potential risks, and any other issues specific to the partners or study • Create a signed living document detailing the discussion/decisions made on roles and involvement
COMMUNITY REPRESENTATION *Recruitment of Community Partners* • Partners need to represent the communities of focus • Partners can be recruited through job postings at CBOs through low-barrier hiring processes	• Select partners who are peers of the populations of interest in the study • Reach out to community-based organizations, peer-run organizations, and non-governmental agencies that support diverse populations, and are visible and respected in the community
TRUST & COMMUNITY BUILDING *Building Trust & Community with and amongst Partners* • Trust is vital to partnership success • There is mistrust of research and academic institutions in some populations due to historical patterns of exploitation and non-sustained efforts	• Build open, honest, and empathetic communication • Be cognizant of historical context of research engagement and mitigate these barriers • Air concerns and agree on decision making processes • Build community by sharing of food, conducting ice breaker activities, and engaging in shared learning
POWER DYNAMICS *Power Differences Between Team Members* • May arise due to socioeconomic, educational, cultural/ethnic backgrounds, and citizenship, and are deeply embedded socially and historically • Key barrier to collaborative research	• Put concrete strategies in place to mitigate effects of power differentials through: careful planning; thinking carefully about the concept of partnership; bidirectional learning between community partners and academic researchers; and by breaking down bidirectional stereotypes
BENEFITS *Value to Researchers and Community Partners* • People and organizations may be motivated to become partners by the opportunity to share their knowledge, help others, give back to their communities, connect with others who have similar lived experiences, and to learn new skills • Because of the time and work required to engage in research, and the value their contributions make to the quality of the study, partners should be compensated appropriately	• Discover what drives research partners to engage in research and find approaches to support motivations • Compensate partners equally and fairly in the rate and method of remuneration. Discuss the impact of remuneration may have on partners' financial situations and offer choices in remuneration form • Provide acknowledgements and other tangible forms of appreciation they can use for future employment, education, and research opportunities • Offer partners the opportunity to participate in dissemination planning and implementation
RESEARCH LITERACY AND TRAINING *Accessibility of Research Processes and Information, and Educational Programs to Assist with Engagement* • Training may include: ethics, communication skills, research methods, and technology skills. • Training and familiarity with research project allows partners to make informed decisions regarding their training plan, and inspire confidence in their own skills and project • Hands-on and bi-directional training is important	• Develop a training plan that involves ongoing training, evaluation, and debriefing with all partners based on their previous knowledge and skills • Present information in ways that appeal to multiple learning styles such as audio, visual, and verbal • Keep the language at meetings and in all documents jargon-free, and avoid making assumptions about partners' perspectives and opinions • Researchers should be trained in collaborative methods of research and engagement processes
BARRIERS *Sociocultural Challenges to Partnering in Research* • Partners may experience many barriers including, but not limited to: financial, language, mobility, household responsibilities, inflexible employment, unstable housing, unpredictable schedules, and food insecurity	• Provide flexibility in meetings dates/locations to accommodate their health and other life issues • Provide childcare, transportation support, links to counselling services, work space etc. as needed • Hold accessible research meetings in locations that are familiar to partners such as community spaces • Provide easy methods for partners to stay in touch
COLLABORATIVE ENGAGEMENT METHODS *Approaches to Collaborative Discussions & Decision-making* • Collaborative research is a cyclic and iterative process that involves revisiting decisions • Collaborative methods should appeal to different styles of learning and participation	• Check-in often about work and partnership process • Allow for alternative forms of participation (e.g., provide paper for anonymous questions and notes) • Use collaborative discussion methods such as periodic go-arounds, learning circles, and small group meetings before larger meetings

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