

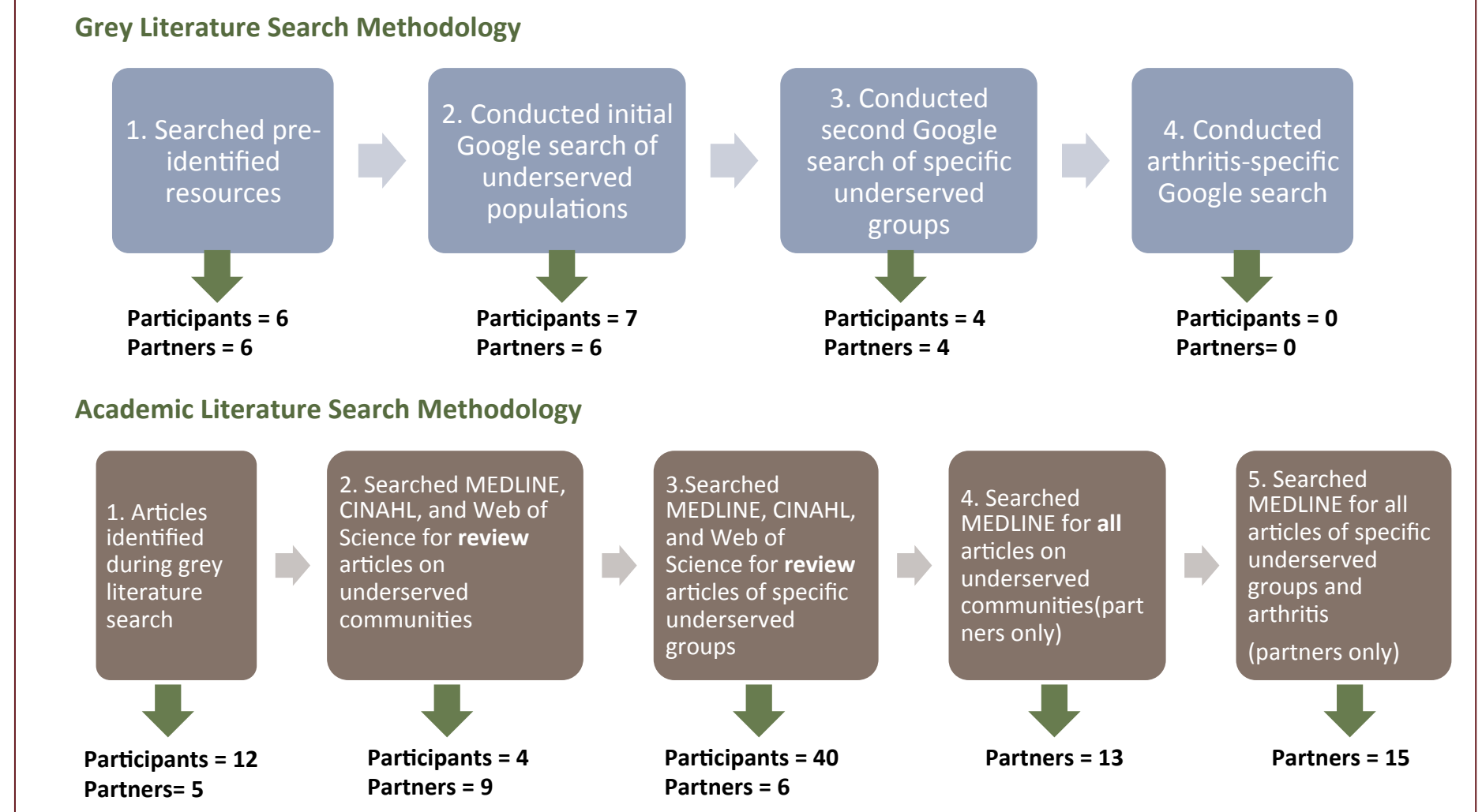
INTRODUCTION

In preparation for our study on the barriers underserved populations (UP) experience in self-managing arthritis and co-morbidities, we conducted a literature review on how to best members of these groups as: 1) research partners through community-based organizations (CBOs); and 2) research participants. Underserved populations face more challenges in accessing care and in the quality of services they receive, but are far less represented in research than the general population. Thus, it is important for studies with clinical or healthcare policy implications to consider including or focusing on these populations.

For purposes of our study, underserved populations included: 1) ethnic minorities; 2) Indigenous; 3) older adult; 4) homeless; 5) low income; 6) refugees; and 7) immigrants.

Indexed databases (Medline/PubMed, CINAHL, Web of Science) and webpage searches (Google) were used to conduct the review. Relevant data were extracted and synthesized. We identified important themes from the literature that researchers should consider when engaging members of these communities as partners and participants, and identified best practices that should be considered for optimal and high quality engagement. We are currently using incorporating this knowledge in our study on barriers to self-management in persons with arthritis and co-morbidities. We are also using the findings as a foundation to develop a conceptual model for engaging underserved populations in research that may help future researchers conducting studies with these communities.

METHODS



RESULTS: SAMPLE

Variable		Academic		Grey	
		Partner (n=48)	Participants (n=56)	Partner (n=16)	Participants (n=20)
Year of Publication	2011	5	11	2	0
	2012	7	5	2	6
	2013	6	11	4	0
	2014	5	9	2	1
	2015	10	12	2	4
	2016	14	5	4	0
	2017	1	3	0	0
	Unknown	0	0	0	9
Country of Publication	Canada	14*	6	12	8
	Europe	5*	13	1	6
	US	25	30	3	5
	Australia	5	7	0	1
Source Type	Review	13	9	0	0
	Original study	13	38	0	0
	Commentary	22	9	0	0
	Article	0	0	0	6
	Guideline	0	0	6	3
	Report	0	0	5	5
	Presentation	0	0	2	4
	Other	0	0	3	2

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

RESULTS: THEMES



Common Themes for Partners and Participants

- DIVERSITY**
Engaging the Underrepresented & Ensuring Non-biased Research Processes
- Dominant social groups determine who is "competent" to engage in research
 - Social detriments of health determine likelihood of research engagement
 - Multiple unique subgroups exist within the same underserved groups
- BARRIERS**
Sociocultural and Environmental Challenges to Partnering in Research
- Partners may experience barriers including, but not limited to: culture, gender, financial status, language, inflexible employment, unstable housing etc.
- BENEFITS & MEANINGFUL RETURN**
Valuable Remuneration
- People and organizations may be motivated to become partners for non-financial reasons (e.g., gaining skills, sharing knowledge, helping others, connecting with others with similar lived experiences)
 - Not all participants may find the same type of remuneration of value

Partners-specific Themes

- 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
- POWER DYNAMICS**
Power Differences Between Team Members
- May arise due to socioeconomic, educational, cultural/ethnic backgrounds, and citizenship
 - Key barrier to collaborative research
- COMMUNITY REPRESENTATION**
Recruitment of Community Partners
- Partners need to represent the communities of focus
 - Partners can be individuals or CBOs themselves
- 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
- DEFINING PARTNERSHIP**
Roles & Degrees of Involvement
- Involving partners can be instrumental in research design and recruitment, and in building trust with participants
 - Roles may include participation with any, or all phases of research design and implementation
- 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

SUMMARY

This literature review on engaging members of underserved communities in research, either as partners or participants, has illuminated a number of important themes to consider, and best practices to implement.

Some of these are so essential to work in this field that they need to be considered in all research processes and in any partner or participant role. These include considerations of diversity, barriers to engagement, and benefits from engaging in research. Other themes are more specific to the type of role the underserved community member is playing in the study. For partners the key themes are: trust & community building, power dynamics, community representation, research literacy and training, defining partnership, and collaborative engagement methods. For participants the key themes are: engaging community, cultural safety, meeting participants' needs, accessible communication, fostering meaningful relationships, resource planning, and safety & confidentiality.

Overall, the future quality of research using partners and/or participants from underserved communities is dependent upon our ability to learn from those who have gone before us and by using the wealth of knowledge that already exists on best practices. It is imperative that we consciously and continuously reflect and refine our methodologies for research engagement in these communities, and document and share our new insights with our colleagues doing work in this important field.

Participant-specific Themes

- ENGAGING COMMUNITY**
Engaging Local Leaders and Community
- Engaging local leaders and community-based organizations may provide invaluable support and advice throughout the study and improve the quality of recruitment data collection and retention
- CULTURAL SAFETY**
Understanding and Respecting Cultural Differences
- There may be unique cultural values, norms, and expectations not known to outsiders
- MEETING PARTICIPANTS' NEEDS**
Adapting and Using Non-traditional Research Methods to Fit the Needs of Participants
- Individuals may not be reachable by traditional recruitment methods due to social or financial reasons or fear of institution and stigma
- ACCESSIBLE COMMUNICATION**
Effectively Communicating in all Research Processes
- Cultural, linguistic and health challenges may prevent effective communication with the participants
 - Participants may stay silent or alter their responses in fear of repercussions or because of shame
- FOSTERING MEANINGFUL RELATIONSHIPS**
Fostering Relationships with the Participants, Family and the Community
- Frequent staff turnover within the research team may hinder relationship building
 - Participants may be lost to follow-up and cannot be contacted due to their complex life circumstances or lack of perceived benefit
- RESOURCE PLANNING**
Planning and Providing Adequate Support
- Lack of sufficient time and resources could exclude some people needing more assistance and reduce quality of data
 - Non-traditional methods of recruitment and retention require greater financial and human resources
- SAFETY & CONFIDENTIALITY**
Creating a Safe Environment
- Mistrust of the institution may compromise recruitment, quality of the data collected and retention
 - Concern for stigma or harm to self or to the community prevents full participation
 - Serious negative consequences to the participants if confidentiality is breached
 - Literacy level, mental capacity or language barrier may prevent participants from fully engaging in informed consent process