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Engaging under- and/or never-engaged populations in health services: A systematic review

Lesley Moody

University Health Network, lesley.moody@cancercare.on.ca

Erica Bridge

Cancer Care Ontario, erica.bridge@cancercare.on.ca

Vidhi Thakkar

McMaster University, vidhi.thakkar@mail.utoronto.ca

Naomi Peek


Cancer Care Ontario, naomi.peek@cancercare.on.ca

Tanvi Patel

Cancer Care Ontario, Tanvi.patel@cancercare.on.ca

See next page for additional authors

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Authors

Lesley Moody, Erica Bridge, Vidhi Thakkar, Naomi Peek, Tanvi Patel, Suman Dhanju, and Simron Singh

Engaging under- and/or never-engaged populations in health services: A systematic review

Lesley Moody, *Clinical Director, Princess Margaret Cancer Centre, UHN, Lesley.moody2@uhn.ca*

Erica Bridge, *Cancer Care Ontario, erica.bridge@cancercare.on.ca*

Vidhi Thakkar, *McMaster University, vidhi.thakkar@mail.utoronto.ca*

Naomi Peek, *Cancer Care Ontario, naomi.peek@cancercare.on.ca*

Tanvi Patel, *Cancer Care Ontario, Tanvi.patel@cancercare.on.ca*

Suman Dhanju, *Cancer Care Ontario, suman.dhanju@cancercare.on.ca*

Simron Singh, *Sunnybrook Health Sciences Centre, Simron.singh@sunnybrook.ca*

Abstract

Patient engagement is a mechanism used to facilitate person-centred care, however, has not been realized in all patient populations. Often, many marginalized populations still remain under- and/or never-engaged. The purpose of this systematic review was to: 1) identify methods or interventions that have been used to engage under- and/or never-engaged populations in health services and 2) identify outcomes that are associated with engaging under- and/or never-engaged populations in health services. A comprehensive search using the Ovid MEDLINE, EMBASE and CINAHL databases was conducted to examine literature between January 2002 and January 2015. Twenty-nine studies met the inclusion criteria. Data was extracted from these studies and findings are synthesized based on discrete themes that map to the research objectives. The majority of studies were quantitative, repeated-measures designs and concentrated in the United States. Hispanic and Latino/a populations were most frequently included in these studies. The main methods of recruitment included: 1) referral from a healthcare provider, 2) patient self-referral after seeing advertisements on mass media or targeted media, 3) directly approached by researcher in-person or telephone, and 4) administrative databases. Interventions occurred primarily at the individual-level, however some system-level interventions were identified. Five main outcomes resulted from the interventions, including: 1) behavioural change, 2) physiological, 3) psychosocial, 4) system and 5) process. Finally, culture-specific components were embedded in the interventions, both as surface and deep structures. This study provides future direction for patient engagement related projects, as it relates to under-and never-engaged population in healthcare.

Keywords

Patient-centred care, patient and family engagement, health equity, patient participation, health services research, systematic review

Background

In recent years, providing person-centred care (PCC) has been at the forefront of the healthcare system,¹⁻⁷ particularly in the provision of cancer services.⁸ This person-centred approach enables the person (including the patient, family member(s), and/or caregiver(s)) receiving care to actively participate in their care.⁹ Patient engagement is a mechanism used to facilitate PCC, which incorporates behavioural concepts such as patient activation, where a patient's willingness and ability is defined through the acquisition of knowledge, skills and beliefs, to take independent actions to manage their healthcare.¹⁰ Patient engagement can transpire at various levels, specifically at the individual patient-level (i.e., where a patient participates in decision-making as it relates to their own care),¹¹ or at the system-level (i.e., where patients

and families act as advisors and participate in quality improvement or health system redesign initiatives).¹²

Evidence has indicated that patient engagement results in better health outcomes,¹³⁻¹⁷ better patient experience,¹³ and lower overall health care costs.^{13, 18-20} Despite this compelling evidence, patient engagement efforts often fail to include all patient populations. Often, engagement efforts in organizations have included individuals who can be classified based on the social determinants of health as: having a higher income and social status, higher level of education, employed, female, and white. As a result, some marginalized populations (e.g., individuals with low socioeconomic status, low health literacy, new immigrants, English as a second language, visible minorities, individuals with a disability and Lesbian, Gay, Bisexual, Transgender, Two-Spirited (i.e., individual identifying as

having both a masculine and feminine spirit), Queer (i.e., an individual who does not subscribe to conventional gender distinctions but identifies with neither, both, or a combination of male and female genders) (LGBT2SQ+) still remain under- and/or never-engaged groups.²¹⁻²⁵ Ensuring that all patients have an equal opportunity to be a part of the engagement process in healthcare has largely been driven by public demands for the greater responsiveness of health professionals and policy makers to address the health needs of marginalized populations,²⁶ and the growing inequities in population health.²⁷

Health inequities are often described using the social determinants of health, and these include: income and social status; social support networks; education; employment/working conditions; social environments; physical environments; personal health practices and coping skills; healthy child development; gender; and culture.²⁸ Health inequities in chronic conditions are often manifested throughout each stage of the continuum of care, from prevention and screening to treatment, and survival or end-of-life care.²⁹ For instance, members of racialized or visible minority backgrounds often have delays in timely access to care,²⁹ limited enrollment in clinical trials,³⁰ lower participation in recommended diagnostic tests or follow-up examinations,³¹ and have underutilized healthcare services due to limited access or due to cultural and/or family barriers.³² Additionally, the health system has been described as difficult to navigate, especially among those with generally low levels of health literacy, lower socioeconomic status, or limited English proficiency.³³ As a result, the patient experience of care is often poor among these patient populations.³³ It is reasonable then to assume that patient engagement in these marginalized populations is crucial to improving healthcare delivery and the patient experience.²⁹⁻³³ However, current engagement models may not be capturing the voice of these marginalized populations in the healthcare system. Thus, new models of engagement may be required to ensure equitable engagement in the healthcare system.

Given the aforementioned health equity concerns in health services, it is important to have a comprehensive understanding of the relevant literature in order to examine interventions or best practices to engage the under- and/or never-engaged populations. This will in turn assist with incorporating a health equity lens into policy planning and develop strategies to support community partners in engaging these populations. Consequently, the purpose of this systematic review is to examine existing interventions both at the individual- and system-level developed for engaging under- and/or never-engaged populations in the delivery of person-centred care. This systematic review will answer two main research questions:

1. What methods or interventions have been used to engage under- and/or never-engaged populations in health services, both at the individual- and system-levels?
2. What outcomes are associated with engaging under- and/or never-engaged populations in health services, both at the individual- and system-levels?

Methods

Searches

This systematic review is registered with PROSPERO (CRD42015017171). The search was conducted using the Ovid MEDLINE, EMBASE and CINAHL databases. Articles that were published between January 2002 and January 2015 were included in this search. The literature in this area originated after 2002, when the Commonwealth Fund Report, defined cultural competence.³⁴ The search strategy was formulated using the following search terms: patient-centred care, patient participation, patient activation, self-efficacy, cultural competency, cultural diversity, healthcare disparities and evaluation concepts. A manual search was also conducted in tandem with the database search using Google Scholar. This search helped to provide content from grey (unpublished) literature and from fields other than medicine. Any overlapping published literature identified through this search that was already included in the systematic review was excluded.

Study Inclusion and Exclusion Criteria

The inclusion criteria was limited to articles that: 1) focused on patient engagement in under- and/or never-engaged populations, 2) described and/or evaluated an engagement intervention, 3) were published in the English language, and 4) availability of the full-text article.

Study Quality Assessment

A quality assessment of included articles was not conducted, as the purpose of the article was to identify interventions used previously to engage under and/or never engaged populations in healthcare. This is a limitation of the current study.

Data Extraction Strategy

Using a standardized form developed by the research team, data were extracted from included studies. Data extracted from each study included: study design, characteristics of the study population, methods used to recruit participants, description of the engagement intervention, and outcomes of engagement (Appendix 1).

Data Synthesis and Presentation

The analysis of this systematic review was guided by the research questions outlined in this study.³⁶ Findings are synthesized based on discrete themes and trends that map to the research questions.³⁶ Differences in study settings

and characteristics can be used to explain differences in results.³⁶

Results

Review Characteristics

All references were collated in citation files (n=1,343) (using Endnote Software), duplicates were removed (n=204) and titles and abstracts were screened against the eligibility criteria by two independent researchers (n=1,139). Initially, 10% of studies (n=114) were reviewed by both researchers until an acceptable level of agreement was reached (Kappa >0.80).³⁵

Disagreements in this initial screening were reviewed by the research team and discussed. Necessary adjustments were then made to the eligibility criteria. Both researchers proceeded to independently screen the remaining studies. During the title and abstract screening, 960 articles were removed as they did not meet the inclusion criteria. Potentially eligible studies (n=179) were then retrieved and reviewed in full-text by a single researcher. Upon full-text review, an additional 150 articles were removed as they did not meet the inclusion criteria. Twenty-nine studies met the inclusion criteria for this study. Figure 1 provides an overview of study selection process. The results from this study can be categorized by study characteristics, recruitment strategies, and intervention types, components, and outcomes.

Study Characteristics

The majority of studies were concentrated in United States (75.9%),³⁷⁻⁵⁸ followed by Canada (6.9%),^{59, 60} Thailand (3.4%),⁶¹ Puerto Rico (3.4%),⁶² United Kingdom (3.4%),⁶³ Australia (3.4%),⁶⁴ and Norway (3.4%).⁶⁵

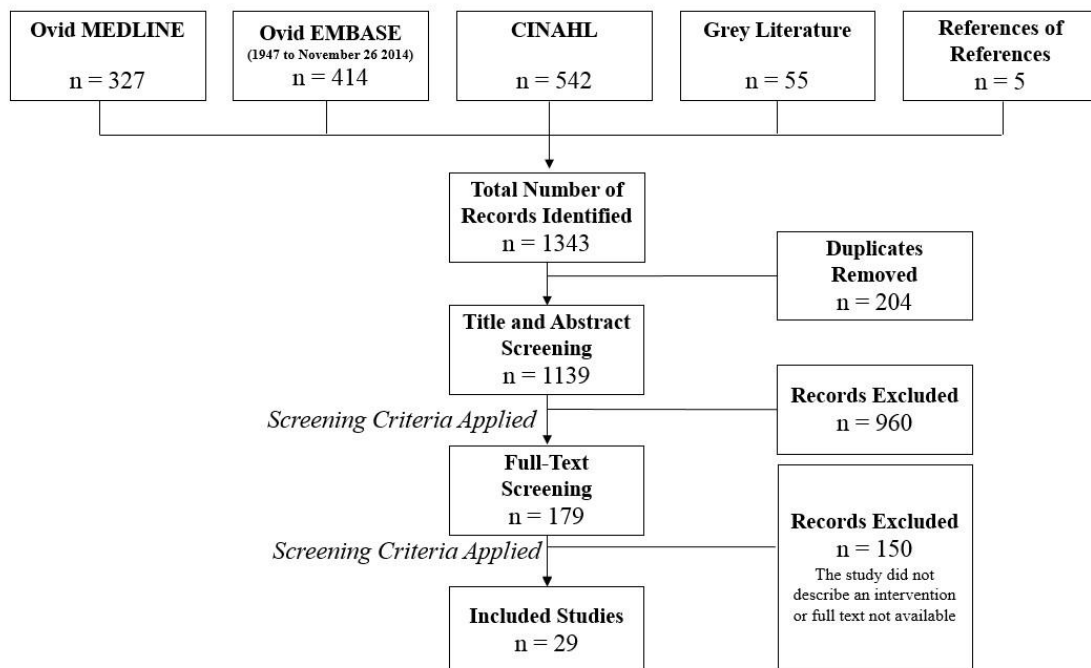
Most studies were quantitative (79.3%),^{37, 38, 40-55, 57, 58, 62, 64, 65} followed by qualitative (13.8%),^{39, 56, 59, 61} and mixed methods designs (6.9%).^{60, 63} The quantitative studies were comprised of repeated-measures research studies,^{37, 38, 40, 46, 49, 50, 58, 62} randomized controlled trials,^{41, 42, 45, 47, 55, 64, 65} quasi-experimental designs,^{43, 44, 48, 51-54} and a retrospective cohort study design.⁵⁷

The interventions targeted specific pre-identified populations, such as Hispanics/Latinos,^{39, 41, 48, 53-55, 62} East Asian (including Korean, Chinese or Vietnamese),^{40, 46, 49, 51, 52, 64} African Americans,^{37, 44, 50, 56} South Asian,^{59, 65} Hawaiian,^{42, 45} Europeans,^{64, 65} Aboriginal Canadians,⁶⁰ and Rural Thais.⁶¹ Other pre-identified populations included: individuals with chronic conditions,^{37-39, 41-43, 46-49, 52-57, 60, 61, 63, 64} and LGBT2SQ+ communities.^{43, 62, 63}

Recruitment Strategies

The recruitment strategies in the studies describe the settings and methods for participant recruitment. There were four recruitment methods used to enroll participants in the studies included: 1) referral from a healthcare provider (including Community Based Organizations (CBOs) or social networks),^{37-39, 42, 46-48, 50, 52-55, 61, 62, 64} 2)

Figure 1. Study Selection Process



patient self-referral after seeing advertisements on mass media (i.e., television, radio, mainstream newspaper, or billboard) or targeted media (i.e., direct mail, flyer/brochure, local/ethnically targeted newspaper, distribution posters, or video showings),^{37, 40, 42, 43, 45, 49, 50, 52, 54, 63, 64} 3) directly approached by researcher in-person or telephone,^{38-40, 44, 45, 50-55, 57-60, 62, 65} and 4) administrative databases.⁴⁸ Several included studies (48.3%) used multiple modes of recruitment in tandem.^{37-40, 42, 46, 48, 50, 52-55, 62, 64} Two studies did not outline a clear recruitment strategy.^{41, 56}

Description of Interventions

Intervention Types

The majority of interventions (75.9%) were categorized as individual-level.^{37-47, 49-52, 54, 55, 61-65} Individual-level interventions are activities occurring with the individual to increase the individual's knowledge. These interventions also influence attitudes and beliefs regarding the health condition of interest in order to facilitate individual behaviour change.⁶⁴ Most popular individual-level interventions included group therapies (68.2%),^{37, 38, 40, 41, 43, 45, 49-52, 55, 62-65} followed by individual counselling (22.8%),^{39, 42, 46, 47, 54} a health promotion campaign (4.5%),⁴⁴ and a self-help intervention (4.5%).⁶¹

Seven interventions (24.1%) were classified as system-level.^{48, 53, 56-60} System-level interventions are activities aimed at providing equitable health services through organizational systems and policies and by leveraging resources and participation of hospitals, health clinics and CBOs.⁶⁶ System-level interventions could not be further categorized as a type as all were unique in their delivery. These included: public assistance program,⁵⁷ social marketing,⁵⁹ targeted screening programs to specific populations,⁶⁰ patient system navigation programs,^{48, 53} quality improvement,⁵⁶ provider training,⁵⁶ community outreach,⁵⁶ and a communication skills programs related to cultural understanding.⁵⁸

Intervention Outcomes

Ninety-four outcomes were described as significant (i.e., results were deemed quantitatively or qualitatively significant by the authors) within the included studies (Table 1). The outcomes were grouped into five categories: 1) behavioural change outcomes (31.9%) (i.e., outcomes as they relate to the health behaviour of the participant), 2) psychosocial outcomes (34%) (i.e., quality of life or psychological well-being), 3) physiological (21.3%) (i.e., disease-specific clinical indicators), 4) system outcomes (3.2%) (i.e., impact the intervention had on an organization's delivery of services/ care), and 5) process outcomes (9.6%) (i.e., satisfaction with the program, trust with the healthcare system). Main significant outcomes reported within the included studies were: self-efficacy

(10.6%), knowledge (7.4%), self-management/patient activation (7.4%), and beliefs (5.3%).

As the majority of studies included interventions at the individual-level (75.9%), it is not surprising that most of the significant outcomes also appear at this level (87.2%).^{37-47, 49-52, 54, 55, 61-65} Similarly, individual-level group therapy interventions produced the largest number of outcomes (76.8%), compared to individual-counselling (11%), self-help (7.3%), and health promotion campaigns (4.9%). Of note, no system outcomes were found to be significant within individual-level interventions.

A limited number of significant outcomes were identified within system-level interventions (12.8%). Significant system outcomes (3.2%) were reported (e.g., time to treatment and access to care). A few significant behavioural (e.g. knowledge, awareness, screening), psychosocial (e.g., self-efficacy and beliefs) and process (e.g., trust in healthcare system and cultural, rituals and ceremonies) outcomes were found. However, no significant physiological outcomes appeared as a result of system-level interventions.

Intervention Components

Education and/or skills training at the individual-level was the most common component in included interventions (68.2%),^{37-42, 44, 45, 49, 50, 52, 55, 63-65} followed by individual counselling sessions/coaching (9.1%),^{46, 54} and support groups (9.1%),^{43, 61} Some interventions (13.6%) included multiple components.^{47, 51, 44} At the system-level intervention components included patient navigation programs,^{48, 53} quality improvement,⁵⁶ education skills and training,^{56, 58, 60} community outreach,⁵⁶ social marketing,⁵⁹ and a public assistance program for prostate cancer.⁵⁷ Integration of culture-specific and culturally-appropriate components in interventions was evident across all included studies, except for three (89.7%). These culture-specific components can be categorized as surface structures or deep structures and were found to be required when designing engagement strategies for the under/never engaged populations.

Surface Structures. Surface structures are superficial characteristics of participants and can be reflected in the intervention through materials and messages, by using language, people and places that the participants are familiar with and prefer.^{42, 67} Surface structures were reported in all but three studies (89.7%).^{47, 57, 58} Studies that reported surface structures incorporated the provision of print-materials that embraces cultural elements and artifacts.^{37, 38, 40-43, 45, 46, 48, 49, 51, 53-55, 59, 60, 63-65} These were written in the participant's native or first language and presentations were delivered by bilingual facilitators/

Table 1. Significant Intervention Outcomes at the Individual- and System-Levels

Outcome	Individual-Level Intervention Outcome N	System-Level Intervention Outcome N
Behavioural Change Outcomes (31.9%)		
<i>Self-Management/Patient Activation</i>	7	-
<i>Knowledge</i>	6	1
<i>Physical Activity</i>	3	-
<i>Smoking Cessation</i>	3	-
<i>Communication with care provider</i>	2	-
<i>Awareness</i>	1	1
<i>Screening</i>	1	1
<i>Treatment Attendance</i>	2	-
<i>Treatment Retention</i>	1	-
<i>Empowerment</i>	1	-
<i>Sexual Practices</i>	1	-
Psychological Outcomes (34%)		
<i>Self-Efficacy</i>	8	2
<i>Beliefs</i>	1	4
<i>Distress</i>	3	-
<i>Family Relationships</i>	3	-
<i>Social Support</i>	2	-
<i>Attitudes</i>	2	-
<i>Motivation</i>	2	-
<i>Coping</i>	1	-
<i>Mood Disturbance</i>	1	-
<i>Tension</i>	1	-
<i>Anxiety</i>	1	-
<i>Bicultural Efficacy</i>	1	-
Physiological Outcomes (21.3%)		
<i>Pain</i>	3	-
<i>BMI</i>	2	-
<i>Quality of Life</i>	2	-
<i>Weight</i>	1	-
<i>Sleep</i>	1	-
<i>Waist Circumference</i>	1	-
<i>Hemoglobin A1C</i>	1	-
<i>High-Density Lipoprotein</i>	1	-
<i>Energy</i>	1	-
<i>Fatigue</i>	1	-
<i>Self-Rated Health</i>	1	-
<i>Blood Sugar</i>	1	-
<i>Fasting Blood Glucose</i>	1	-
<i>Fasting Insulin</i>	1	-
<i>Serum Tag</i>	1	-
<i>MetS</i>	1	-
System Outcomes (3.2%)		
<i>Time to Treatment</i>	-	2
<i>Access to Care</i>	-	1
Process Outcomes (9.6%)		
<i>Satisfaction</i>	6	-
<i>Trust in Healthcare System</i>	-	1
<i>Confidence in Care Providers</i>	1	-
<i>Cultural, Rituals and Ceremonies</i>	-	1

educators/peers from similar cultural or ethnic background, with whom participants were able to relate to. Finally, sessions were conducted at a comfortable and familiar location.

Deep Structures. Deep structures are social, historical, environmental and psychological factors that influence behaviour in the participants and can be reflected in the intervention by incorporating cultural processes (e.g. prayers).^{42, 67} Deep structures were reported in two studies, which included traditional practices such as praying before beginning an intervention session,⁴² sharing food,⁴² and involving family members.^{42, 52} Cultural values and myths were also incorporated in interventions to ensure that these values were incorporated in the design and delivery of the intervention, in a format that the target population was comfortable with.^{39, 42, 52} Additionally, bilingual facilitators/ educators/ peers from similar cultural or ethnic background were also used, as a way to address any cultural barriers.

Discussion

The purpose of this systematic review was to examine existing interventions developed for engaging under- and/or never-engaged populations in healthcare. The review examined: 1) methods or interventions that have been used to engage under- and/or never-engaged populations in healthcare, and 2) outcomes associated with engaging under- and/or never-engaged populations in healthcare. Two main points can be discussed as a result of this review.

The first can be described as an understanding of equity within the context of engagement of under- and/or never-engaged population. Although health inequities span a number of social determinants of health (i.e. income and social status; social support networks; education; employment/working conditions; social environments; physical environments; personal health practices and coping skills; healthy child development; gender; and culture),²⁸ the majority of studies included in this review focus solely on culture (86.2%),^{37, 39-42, 44-46, 48-56, 58-65} and sexual orientation (3.5%).⁴³ Further, three interventions were also tailored to populations that had an experience with a particular chronic condition (10.3%).^{38, 47, 57} Consequently, the results of this study appear to only include two (i.e., culture and gender) of the ten social determinants of health in terms of engaging under- and/or never-engaged populations in healthcare. As such, we are left to question whether studies have explored engagement interventions using other determinants of health to characterize under- and/or never-engaged populations. Therefore, this study has elucidated that a gap in the literature may exist in terms of fully understanding interventions to engage under- and/or never-engaged populations, since various populations may be missing,

diminishing generalizability and transferability of results to different under- and/or never-engaged populations.

Not surprisingly, there did not appear to be a one-size-fits-all approach for designing interventions to engage under-, and/or never-engaged populations. However, our results suggest that authors who are designing and implementing interventions for under- and/or never-engaged populations (based on culture, gender and disease) are favouring certain intervention types and components to achieve significant outcomes. More specifically, individual-level interventions delivered through a group therapy method to provide education and skills training was primarily chosen (51.7%) and resulted in the greatest number of significant outcomes.^{37, 38, 40, 41, 45, 49-52, 55, 62-65} Further, it should be noted that the education and skills training were designed to ensure that they were culturally and/or ethnically appropriate and that relevant components were tailored to each population to encourage favourable outcomes. This is an important finding as under- and/or never-engaged populations have frequently reported experiencing disparate healthcare and outcomes or having received biased or stigmatized treatment,²⁹⁻³³ often leading to the mistrust of healthcare providers and/or the health system. Delivering culturally-tailored education and skills training within a group environment provides a setting in which healthcare professionals and under- and/or never-engaged populations can: 1) pay attention to histories of marginalization and mistrust, 2) have transparent discussion of power, 3) build on community strengths and local knowledge, 4) encourage cooperation, 5) identify opportunities for co-learning, 6) make important efforts towards sustainability, system development, and capacity building, and 7) make important efforts to protect the well-being, interests and rights of those populations.^[68] This provides an opportunity to build and foster trust. Further, the group environment provides a safe place whereby participants with similar backgrounds can interact within a social context, providing the opportunity for peer interaction and role modeling.⁶⁹

Limitations

This review includes a number of limitations, associated with the search strategy. Firstly, the search strategy for under- and/or never-engaged populations was quite broad to ensure that we captured all papers that referred to engagement with these populations. As a result, the under- and/or never-engaged populations are very different and seemingly have nothing in common, which may limit the generalizability of results. That being said, their commonalities are the engagement methods used, which was the purpose of this paper. Secondly, only English-language articles were retrieved for this review. As a result, studies published in other languages were not included. Thirdly, a data quality assessment was not conducted, therefore limiting our understanding of the quality of studies included in this review. Finally, a meta-analysis of

results was not conducted given the heterogeneity in study designs and outcome measurements, making it difficult to draw conclusions of association.

Conclusions

The findings of this study contribute to the scholarly literature on interventions in engaging under- and/or never-engaged populations in healthcare. The results of this study highlight interventions to engage under- and/or never-engaged populations in health, while also outlining gaps for future research (e.g., examining specific engagement interventions, outcomes of specific intervention types, and similarity and differences between different under- and/or never-engaged populations). This will help to provide future direction for patient engagement related projects, as it relates to under- and never-engaged population in healthcare. Based on the findings of this study, healthcare organizations should consider the following recommendations when planning interventions:

1. Ensure inclusion of proper intervention types and components when designing interventions for under- and/or never-engaged populations in healthcare;
2. When recruiting, look to culturally specific locations or venues where under- and/or never engaged populations are likely to be found; and
3. Ensure that there is an in-depth understanding of the target population, as interventions are often not transferrable between different populations.

References

1. Baker A. Crossing the quality chasm: a new health system for the 21st century. *BMJ*. 2001;323(7322):1192.
2. Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. *Health Aff*. 2008;27(3):759-69.
3. CIHR Institute of Health Services and Policy Research in collaboration with Terrence Sullivan & Associates. Pan-Canadian Vision and Strategy for Health Services and Policy Research: 2014-2019. Montreal, QC: CIHR Institute of Health Services and Policy Research, 2014.
4. Naylor D, Fraser N, Girard F, Jenkins T, Mintz J, Power C. Unleashing innovation: excellent healthcare for Canada. Report of the Advisory Panel on Healthcare Innovation. 2015.
5. Ministry of Health and Long-Term Care. Patients First: Action Plan for Healthcare. Toronto, ON: Ministry of Health and Long-Term Care, 2015.
6. CIHR. Canada's Strategy for Patient Oriented Research. Ottawa, ON: CIHR, 2011.
7. Matthews D. Bill 46: An Act respecting the care provided by health care organizations. Toronto, ON, 2010.
8. Cancer Care Ontario. Ontario Cancer Plan IV (2015-2019). <https://cancercare.on.ca/common/pages/UserFile.aspx?fileId=333871>. Accessed 1 April 2019.
9. Bidy R, Griffin C, Johnson N, et al. Person-Centred Care Guideline. Cancer Care Ontario. Program in Evidence-Based Care (PEBC). <https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=340815>. Accessed 1 April 2019.
10. Centre for Advancing Health. A New Definition of Patient Engagement: What is Engagement and Why is it Important? http://www.cfah.org/file/CFAH_Engagement_Behavior_Framework_current.pdf. Accessed 1 April 2019.
11. Prey JE, Woollen J, Wilcox L et al. Patient engagement in the inpatient setting: a systematic review. *J Am Med Inform Assoc*. 2014;21:742-50.
12. Baker GR, Fancott C, Judd M, O'Connor P. Expanding patient engagement in quality improvement and health system redesign: three Canadian case studies. *Health Manage Forum*. 2016;29:176-82.
13. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff*. 2013;32(2):207-14.
14. Collins K, Nicolson P, Bowns I. Patient satisfaction in telemedicine. *Health Informatics J*. 2000;6(2):81-5.
15. Hekkert KD, Cihangir S, Kleefstra SM, van den Berg B, Kool RB. Patient satisfaction revisited: a multilevel approach. *Soc Sci Med*. 2009;69(1):68-75.
16. Rickert J. Health Affairs Blog. <http://healthaffairs.org/blog/2014/05/09/measuring-patient-satisfaction-a-bridge-between-patient-and-physician-perceptions-of-care/>. Accessed 1 April 2019.
17. Auras S, Geraedts M. Patient experience data in practice accreditation—an international comparison. *Int J Qual Health Care*. 2010;22(2):132-9.
18. Levit LA, Balogh E, Nass SJ, Ganz P, editors. Delivering high-quality cancer care: charting a new course for a system in crisis. Washington, DC: National Academies Press; 2013 Dec.
19. Welch SJ. Twenty years of patient satisfaction research applied to the emergency department: a qualitative review. *Am J Med Qual*. 2010;25(1):64-72.
20. Riskind P, Fossey L, Brill K. Why measure patient satisfaction?. *J Med Prac Manag*. 2011;26(4):217.
21. Minkler M, editor. Community organizing and community building for health and welfare. *Rutgers University Press*. 2012.
22. Cooke B, Kothari U, editors. Participation: The new tyranny?. Zed books; 2001.

23. Dressendorfer RH, Raine K, Dyck RJ, Plotnikoff RC, Collins-Nakai RL, McLaughlin WK, Ness K. A conceptual model of community capacity development for health promotion in the Alberta Heart Health Project. *Health Promot Pract.* 2005;6(1):31-6.
24. Raphael D. Social determinants of health: Canadian perspectives. Canadian Scholars' Press; 2009.
25. Laverack G, Labonte R. A planning framework for community empowerment goals within health promotion. *Health Policy Plan.* 2000;15(3):255-62.
26. Zakus JD, Lysack CL. Revisiting community participation. *Health Policy Plan.* 1998;13(1):1-2.
27. Ritchie D, Parry O, Gnich W, Platt S. Issues of participation, ownership and empowerment in a community development programme: tackling smoking in a low-income area in Scotland. *Health Promotion Int.* 2004;19(1):51-9.
28. Public Health Agency of Canada. Social determinants of health. <http://cbpp-pcpe.phac-aspc.gc.ca/public-health-topics/social-determinants-of-health/>. Accessed 1 April 2019.
29. Shavers VL, Harlan LC, Stevens JL. Racial/ethnic variation in clinical presentation, treatment, and survival among breast cancer patients under age 35. *Cancer.* 2003;97(1):134-47.
30. Simon C, Zyzanski SJ, Eder M, Raiz P, Kodish ED, Siminoff LA. Groups potentially at risk for making poorly informed decisions about entry into clinical trials for childhood cancer. *JCO.* 2003;21(11):2173-8.
31. Kerner JF, Yedidia M, Padgett D, Muth B, Washington KS, Tefft M, Yabroff KR, Makariou E, Freeman H, Mandelblatt JS. Realizing the promise of breast cancer screening: clinical follow-up after abnormal screening among Black women. *Prev Med.* 2003;37(2):92-101.
32. Payne R, Medina E, Hampton JW. Quality of life concerns in patients with breast cancer. *Cancer.* 2003;97(S1):311-7.
33. Levy J, Ansara D, Stover A. Racialization and Health Inequities in Toronto. Toronto Public Health. <http://www.toronto.ca/legdocs/mmis/2013/hl/bgrd/backgroundfile-62904.pdf>. Accessed 1 April 2019.
34. Beach MC, Saha S, Cooper LA. The role and relationship of cultural competence and patient-centeredness in health care quality. New York, NY: Commonwealth Fund; 2006 Oct 17.
35. Viera AJ, Garrett JM. Understanding interobserver agreement: the kappa statistic. *Fam Med.* 2005;37(5):360-3.
36. Greenhalgh T, Roberts G, Macfarlane F, Bate P, Kyriakidou O, Peacock R. Storylines of research in diffusion of innovation: a meta-narrative approach to systematic review. *Soc Sci Med.* 2001;61:417-30.
37. Sheppard VB, Wallington SF, Willey SC, et al. A peer-led decision support intervention improves decision outcomes in black women with breast cancer. *J Cancer Educ* 2013;28(2):262-9.
38. Bartels SJ, Aschbrenner KA, Rolin SA, Hendrick DC, Naslund JA, Faber MJ. Activating older adults with serious mental illness for collaborative primary care visits. *Psychiat Rehabil J.* 2013;36(4):278-288.
39. Sheppard VB, Figueiredo M, Cañar J, et al. Latina a LatinaSM: developing a breast cancer decision support intervention. *Psycho-Oncology.* 2008;17(4):383-391.
40. Kim JH, Menon U. Pre-and postintervention differences in acculturation, knowledge, beliefs, and stages of readiness for mammograms among Korean American women. *Oncol Nur Forum.* 2009;36(2):E80-E92.
41. Vincent D. Culturally tailored education to promote lifestyle change in Mexican Americans with type 2 diabetes. *J Am Acad Nurse Pract.* 2009;21(9):520-527.
42. Mokuau N, Braun KL, Daniggelis E. Building family capacity for Native Hawaiian women with breast cancer. *Health Soc Work.* 2012;37(4):216-224
43. Fobair P, Koopman C, Dimiceli S, et al. Psychosocial intervention for lesbians with primary breast cancer. *Psycho-Oncology.* 2002;11(5):427-438.
44. Blumenthal DS, Fort JG, Ahmed NU, Semanya KA, Schreiber GB, Perry S, Guillory J. Impact of a two-city community cancer prevention intervention on African Americans. *J Natl Med Assoc.* 2005;97(11):1479-1488.
45. Braun KL, Fong M, Kaanoi ME, Kamaka ML, Gotay CC. Testing a culturally appropriate, theory-based intervention to improve colorectal cancer screening among Native Hawaiians. *Prev Med.* 2005;40(6):619-627.
46. Ma GX, Fang C, Shive SE, et al. A Culturally Enhanced Smoking Cessation Study among Chinese and Korean Smokers. *Int J Health Educ.* 2005;8:1-10.
47. Kalauokalani D, Franks P, Oliver JW, Meyers FJ, Kravitz RL. Can patient coaching reduce racial/ethnic disparities in cancer pain control? Secondary analysis of a randomized controlled trial. *Pain Med.* 2007;8(1):17-24.
48. Dudley DJ, Drake J, Quinlan J, et al. Beneficial effects of a combined navigator/promotora approach for Hispanic women diagnosed with breast abnormalities. *Cancer Epidemiol Biomarkers Prev.* 2012; 21(10):1639-1644.
49. Choi SE, Rush EB. Effect of a short-duration, culturally tailored, community-based diabetes self-management intervention for Korean immigrants: a pilot study. *Diabetes Educ.* 2012;38(3):377-85.
50. Kannan S, Sparks AV, Webster JD, Krishnakumar A, Lumeng J. Healthy Eating and Harambee: curriculum development for a culturally-centered bio-medically oriented nutrition education program to reach African American women of childbearing age. *Matern Child Health J.* 2010;14(4):535-547.

51. Sim SC, Zhou XD, Hom LD, Chen C, Sze R. Effectiveness of pre-counseling genetic education workshops at a large urban community health center serving low-income Chinese American women. *J Gen Couns.* 2011;20(6):593-608
52. Chesla CA, Chun KM, Kwan CM, et al. Testing the efficacy of culturally adapted coping skills training for Chinese American immigrants with type 2 diabetes using community-based participatory research. *Res Nurs Health.* 2013;36(4):359-72.
53. Ramirez A, Perez-Stable E, Penedo F, Talavera G, Carrillo JE, Fernández M, Holden A, Munoz E, San Miguel S, Gallion K. Reducing time-to-treatment in underserved Latinas with breast cancer: The Six Cities Study. *Cancer.* 2014;120(5):752-760.
54. Alegría M, Polo A, Gao S, et al. Evaluation of a Patient Activation and Empowerment Intervention in Mental Health Care. *Med Care.* 2008;46(3):247-256.
55. Alegría M, Carson N, Flores M, et al. Activation, Self-management, Engagement, and Retention in Behavioral Health Care: A Randomized Clinical Trial of the DECIDE Intervention. *JAMA Psyc.* 2014;71(5):557-565.
56. Peek ME, Wilkes AE, Roberson TS, et al. Early lessons from an initiative on Chicago's South Side to reduce disparities in diabetes care and outcomes. *Health Aff.* 2012;31(1):177-186.
57. Miller DC, Gelberg L, Kwan L, et al. Racial disparities in access to care for men in a public assistance program for prostate cancer. *J Community Health.* 2008;33(5):318.
58. Martin MY, Keys W, Person SD, et al. Enhancing patient-physician communication: a community and culturally based approach. *J Cancer Educ.* 2005;20(3):150-154.
59. Ahmad F, Cameron JI, Stewart DE. A tailored intervention to promote breast cancer screening among South Asian immigrant women. *Soc Sci Med.* 2005;60(3):575-586.
60. Arora S, Kurji AK, Tennant MT. Dismantling sociocultural barriers to eye care with tele-ophthalmology: lessons from an Alberta Cree community. *Clin Invest Med.* 2013;36(2):57-63.
61. Sukwatjane A, Pongthavornkamol K, Low G, Suwonnaroop N, Pinyopasakul W, Chokkhanchitchai S. Benefits of a self-help group for rural Thai elders with type-2 diabetes. *Pac Rim Int J Nurs Res Thai.* 2011;15(3):220-232.
62. Toro-Alfonso J, Varas-Díaz N, Andújar-Bello I. Evaluation of an HIV/AIDS prevention intervention targeting Latino gay men and men who have sex with men in Puerto Rico. *AIDS Educ Prev.* 2002;14(6):445-456.
63. Harding R, Bensley J, Corrigan N. Targeting smoking cessation to high prevalence communities: outcomes from a pilot intervention for gay men. *BMC Public Health.* 2004;4(1):43.
64. Swerissen H, Belfrage J, Weeks A, et al. A randomised control trial of a self-management program for people with a chronic illness from Vietnamese, Chinese, Italian and Greek backgrounds. *Patient Educ Couns.* 2006;64(1):360-368.
65. Telle-Hjellset V, Kjøllestad MK, Bjørge B, et al. The InnvaDiab-DE-PLAN study: a randomised controlled trial with a culturally adapted education programme improved the risk profile for type 2 diabetes in Pakistani immigrant women. *Br J Nutr.* 2013;109(03):529-538.
66. Centers for Disease Control and Prevention. Social Ecological Model. <https://www.cdc.gov/cancer/crccp/sem.htm>. Accessed 1 April 2019.
67. Resnicow K, Baranowski T, Ahluwalia JS, Braithwaite RL. Cultural sensitivity in public health: defined and demystified. *Ethn Dis.* 1999;9(1):10-21.
68. UC Davis Center for Reducing Health Disparities. Building partnerships: Key considerations when engaging underserved communities under the MHSA. http://www.dhcs.ca.gov/services/MH/Documents/BP_Key_Considerations.pdf. Accessed 1 April 2019.
69. Glanz K, Rimer BK, Viswanath K, editors. Health behavior and health education: theory, research, and practice. John Wiley & Sons; 2008.

Appendix 1. Data Extraction Table of Included Studies

First Author, Year	Study Design	Country	Identified Populations	Recruitment Method	Intervention Type	Intervention Components	Intervention Outcomes *qualitative results †statistically significant
Sheppard, 2013[37]	Repeated-Measures	USA	African American women with breast cancer (n=76)	1. Referral by healthcare provider 2. Patient self-referral	Individual-Level <i>Group Therapies</i>	Education and Skills Training	Behavioural Change Outcomes Communication with care provider* Psychosocial Outcomes Self-efficacy Process Outcomes Satisfaction†
Bartels, 2013[38]	Repeated-Measures	USA	Adults with serious mental illness and cardiovascular health risk conditions (n=17)	1. Referral by healthcare provider 2. Directly approached by researcher(s)	Individual-Level <i>Group Therapies</i>	Education and Skills Training	Behavioural Change Outcomes Patient Activation† Psychosocial Outcomes Self-efficacy Process Outcomes Satisfaction†
Sheppard, 2008[39]	Case Study	USA	Latinas with breast cancer (n=37)	1. Referral by healthcare provider 2. Directly approached by researcher(s)	Individual-Level <i>Individual Counselling</i>	Education and Skills Training	Behavioural Change Outcomes Communication with care provider* Knowledge* Psychosocial Outcomes Self-efficacy
Kim, 2009[40]	Repeated-Measures	USA	East Asian (Korean American) women (n=300)	1. Directly approached by researcher(s) 2. Patient self-referral	Individual-Level <i>Group Therapies</i>	Education Training	Behavioural Change Outcomes Knowledge† Acculturation Psychosocial Outcomes Beliefs – susceptibility Beliefs – pros Beliefs – cons† Self-efficacy† Beliefs – fears Beliefs – modesty Beliefs – fatalism

Appendix 1. Data Extraction Table of Included Studies (cont'd)

First Author, Year	Study Design	Country	Identified Populations	Recruitment Method	Intervention Type	Intervention Components	Intervention Outcomes *qualitative results †statistically significant
Vincent, 2009[41]	Randomized controlled trial	USA	Hispanic (Mexican Americans) with type 2 diabetes (n=20)	N/A	Individual-Level <i>Group Therapies</i>	Education and Skills Training	Behavioural Change Outcomes Knowledge Self-management Psychosocial Outcomes Self-efficacy Physiological Outcomes Weight† BMI† Process outcomes Satisfaction*
Mokuau, 2012[42]	Randomized Controlled Trial	USA	Native Hawaiian women with breast cancer (n=29)	1. Referral by healthcare provider 2. Patient self-referral	Individual-Level <i>Individual Counselling</i>	Educational and Skills Training	Behavioural Change Outcomes Knowledge Self-management Psychosocial Outcomes Self-efficacy† Coping†
Fobair, 2002[43]	Quasi-Experiment (multiple measures, no control)	USA	Lesbian women with breast cancer (n=20)	1. Patient self-referral	Individual-Level <i>Group Therapies</i>	Support Group	Physiological Outcomes Pain† Sleep† Psychosocial Outcomes Distress† Mood disturbance† Tension† Anxiety† Depression Self-efficacy† Coping Body image Sexuality Family relationships† Decrease in social support† Process Outcomes Satisfaction†

Appendix 1. Data Extraction Table of Included Studies (cont'd)

First Author, Year	Study Design	Country	Identified Populations	Recruitment Method	Intervention Type	Intervention Components	Intervention Outcomes *qualitative results †statistically significant
Blumenthal, 2005[44]	Quasi-Experimental	USA	African American (n=3,914-4,053)	1. Directly approached by researcher(s)	Individual-Level <i>Health Promotion Campaign</i>	Education Training Social Marketing	Behavioural Change Outcomes Knowledge Screening† Fruit and vegetable intake Physical activity† Smoking cessation† Awareness† Psychosocial Outcomes Beliefs
Braun, 2005[45]	Randomized Controlled Trial	USA	Native Hawaiians (n=121)	1. Directly approached by researcher(s)	Individual-Level <i>Group Therapies</i>	Educational Training	Behavioural Change Outcomes Screening Knowledge† Psychosocial Outcomes Self-efficacy† Attitudes† Intentions†
Ma, 2005[46]	Repeated-Measures	USA	East Asian (Chinese and Korean) smokers (n=43)	1. Referral by healthcare provider 2. Patient self-referral	Individual-Level <i>Individual Counselling</i>	Individual Counselling Sessions	Behavioural Change Outcomes Smoking cessation†
Kalauokalan, 2007[47]	Randomized Controlled Trial	USA	Adult cancer patients (n=67)	1. Referral by healthcare provider	Individual-Level <i>Individual Counselling</i>	Education Training Coaching	Physiological Outcomes Pain management†
Dudley, 2012[48]	Quasi-Experimental	USA	Hispanic women in cancer screening (n=460)	1. Referral by healthcare provider 2. Administrative databases	System-Level	Patient Navigation Program	System Outcomes Time to treatment†

Appendix 1. Data Extraction Table of Included Studies (cont'd)

First Author, Year	Study Design	Country	Identified Populations	Recruitment Method	Intervention Type	Intervention Components	Intervention Outcomes *qualitative results †statistically significant
Choi, 2012[49]	Repeated-Measures	USA	East Asian (Korean) adults with type 2 diabetes (n=41)	1. Patient self-referral	Individual-Level <i>Group Therapies</i>	Education and Skills Training	Behavioural Change Outcomes Self-management† Physical activity† Physiological Outcomes Waist circumference† Hemoglobin A1C level† High-density lipoprotein level† Psychosocial Outcomes Well-being Process Outcomes Satisfaction*
Kannan, 2010[50]	Repeated-Measures	USA	African American women (n=102)	1. Referral by healthcare provider 2. Patient self-referral 3. Directly approached by researcher(s)	Individual-Level <i>Group Therapies</i>	Education and Skills Training	Behavioural Change Outcomes Self-management* Process Outcomes Satisfaction*
Sim, 2011[51]	Quasi-Experimental	USA	East Asian (Chinese American) women (n=86)	1. Directly approached by researcher(s)	Individual-Level <i>Group Therapies</i> <i>Individual Counselling</i>	Education Training Counselling	Behavioural Change Outcomes Knowledge† Psychosocial Outcomes Self-efficacy† Attitudes† Motivation† Process Outcomes Satisfaction

Appendix 1. Data Extraction Table of Included Studies (cont'd)

First Author, Year	Study Design	Country	Identified Populations	Recruitment Method	Intervention Type	Intervention Components	Intervention Outcomes *qualitative results †statistically significant
Chesla, 2013[52]	Quasi-Experimental	USA	East Asian (Chinese or Chinese-American) with Type 2 diabetes (n=145)	1. Referral by healthcare provider 2. Patient self-referral 3. Directly approached by researcher(s)	Individual-Level <i>Group Therapies</i>	Education and Skills Training	Behavioural Change Outcomes Knowledge† Psychosocial Outcomes Self-efficacy† Bicultural efficacy† Family emotional support† Family conflict Family instrumental support† Distress† Physiological Outcomes Quality of Life† Hemoglobin A1C level
Ramirez, 2014[53]	Quasi-Experimental	USA	Latino women in cancer screening (n=109)	1. Referral by healthcare provider 2. Directly approached by researcher(s)	System-level	Patient Navigation Program	System Outcomes Time to treatment†
Alegría, 2008[54]	Quasi-Experimental	USA	Latinos with mental health diagnosis (n=231)	1. Referral by healthcare provider 2. Patient self-referral 3. Directly approached by researcher(s)	Individual-Level <i>Individual Counselling</i>	Counselling	Behavioural Change Outcomes Patient activation† Patient empowerment Treatment retention† Treatment attendance†
Alegría, 2014[55]	Randomized Controlled Trial	USA	Latinos with mental health diagnosis (n=647)	1. Referral by healthcare provider 2. Directly approached by researcher(s)	Individual-Level <i>Group Therapies</i>	Education and Skills Training	Behavioural Change Outcomes Patient activation† Self-management† Engagement Retention

Appendix 1. Data Extraction Table of Included Studies (cont'd)

First Author, Year	Study Design	Country	Identified Populations	Recruitment Method	Intervention Type	Intervention Components	Intervention Outcomes *qualitative results †statistically significant
Peek, 2012[56]	Process evaluation - community based participatory research	USA	African Americans, focused on diabetes (n=not reported)	N/A	System-level	Quality Improvement Collaborative Education and Skills Training Provider Training Community Outreach	N/A
Miller, 2008[57]	Retrospective cohort study	USA	Men with prostate cancer (n=357)	1. Directly approached by researcher(s)	System-level	Public assistance program for prostate cancer	Process Outcomes Satisfaction† Confidence in care providers† System Outcomes Use of emergency department care without hospitalization Frequency of prostate-specific antigen testing
Martin, 2005[58]	Repeated-Measures	USA	Resident physicians (n=15)	1. Directly approached by researcher(s)	System-level	Communication Skills Training	Psychosocial Outcomes Self-efficacy†
Ahmad, 2005[59]	Case Study	Canada	South Asian women (n=74)	1. Directly approached by researcher(s)	System-level	Social Marketing	Behavioural Change Outcomes Awareness† Knowledge† Screening† Psychosocial Outcomes Self-efficacy† Beliefs - barriers† Beliefs - risks† Beliefs - seriousness† Beliefs - benefits†
Arora, 2013[60]	Mixed Methods	Canada	Aboriginal Canadians with diabetes (n=10)	1. Directly approached by researcher(s)	System-level	Targeted Screening Program	System Outcomes Access to care* Process Outcomes Trust in healthcare system* Cultural rituals and ceremonies*

Appendix 1. Data Extraction Table of Included Studies (cont'd)

First Author, Year	Study Design	Country	Identified Populations	Recruitment Method	Intervention Type	Intervention Components	Intervention Outcomes *qualitative results †statistically significant
Sukwatjanee, 2011[61]	Case Study	Thailand	Rural Thais, with Type 2 diabetes (n=20)	1. Referral by healthcare provider	Individual-Level <i>Self-Help Intervention</i>	Support Group	Behavioural Change Outcomes Knowledge* Empowerment* Physiological Outcomes Quality of Life† Blood sugar† Psychosocial Outcomes Social support* Self-efficacy*†
Toro-Alfonso, 2002[62]	Repeated-Measures	Puerto Rico	Latino gay men (n=587)	1. Referral by healthcare provider 2. Directly approached by researcher(s)	Individual-Level <i>Group Therapies</i>	Education and Skills Training Peer Educators	Behavioural Change Outcomes Sexual practices†
Harding, 2004[63]	Mixed Methods	UK	Gay men (n=98)	1. Patient self-referral	Individual-Level <i>Group Therapies</i>	Education and Skills Training	Behavioural Change Outcomes Smoking cessation*
Swerissen, 2006[64]	Randomized Controlled Trial	Australia	Italian, Greek, Vietnamese or Chinese with a chronic illness (n=474)	1. Referral by healthcare provider 2. Patient self-referral	Individual-Level <i>Group Therapies</i>	Education and Skills Training Peer Educators	Behavioural Change Outcomes Physical activity† Self-management† Physiological Outcomes Energy† Self-rated health† Pain† Fatigue† Shortness of breath Disability Psychosocial Outcomes Self-efficacy† Distress† Depression Illness intrusiveness System Outcomes Health service utilization

Appendix 1. Data Extraction Table of Included Studies (cont'd)

First Author, Year	Study Design	Country	Identified Populations	Recruitment Method	Intervention Type	Intervention Components	Intervention Outcomes *qualitative results †statistically significant
Telle-Hjellset, 2013[65]	Randomized Controlled Trial	Norway	Pakistani female adults, aged 25 and over, born in Pakistan or in Norway by two Pakistani parents; N= 177	1. Directly approached by researcher(s)	Individual-Level <i>Group Therapies</i>	Education and Skills Training	Physiological Outcomes Fasting blood glucose† Fasting insulin† Serum TAG† BMI† MetS†