Background

The Frontier Rural Innovations Network (Innovations Network) is a national Practice-Based Research Network (PBRN) focusing on the improvement of the rural healthcare delivery process to meet the Triple Aim: Better Outcomes, Better Healthcare, Better Healthcare Value. A PBRN is a group of primary care practices and clinicians who conduct research collaboratively by informing each other’s questions with data and critique. Clinicians can participate one of two ways or both: 1) by contributing data relative to their practice or community as evidence for a study; 2) by developing a research question and proposal for dissemination across the network. Read more about PBRNs here: http://www.ncbi.nlm.nih.gov/pubmed/17341759. The Innovations Network encompasses rural regions in Kentucky, Indiana, Louisiana, Mississippi, Virginia, West Virginia, Colorado, Washington, Montana, and Alaska (Appendix A).

Residents of frontier and rural areas of the United States are not as healthy as their urban and suburban counterparts. While there are many variables, a dearth of practical scholarly understanding and more limited access to primary care are significant contributing factors. Clinical research on rural-relevant issues is not proportionately reflected in medical literature. Primary care physicians are unevenly distributed geographically, tending to cluster around urban and suburban areas in the vicinity of the residency programs from which they graduate.

The overwhelming majority of clinical research is conducted in the Academic Medical Center model. While this paradigm has produced very useful results, it has limitations. First, only about one person out of a thousand (1/1000) receive their medical care in an Academic Medical Center (Green, LA et.al., NEJM 344:2021-2025). This limits the data set to a limited cross-section of the population. Furthermore, research questions tend to reflect the needs of the populations and viewpoints of researchers who reside within the vicinity of the Academic Medical Center. Frontier and rural health issues, which have great potential to inform the overall discussion, are proportionately missing from lines of inquiry.

Purpose

The Innovations Network is “innovative” for several reasons. First, it focuses research on rural healthcare issues, specifically improving the healthcare process to achieve the Triple Aim: Better Outcomes, Better Healthcare, Better Healthcare Value. Appendix B is a schematic of the rural healthcare system. The patient is at the center, the next concentric working outwardly from the patient
is “concerns”, the outermost being the settings where patients may receive “care”, broadly defined to include interventions performed outside the healthcare facility.

Rural healthcare issues are significantly underrepresented in medical literature, most research reflecting the suburban and urban contexts where Academic Medical Centers exist. This knowledge gap is to the detriment of the nation at large, as the Institute of Medicine (IOM) in *Quality through Collaboration* has identified rural areas as likely sources for innovative healthcare solutions. A lack of research on rural healthcare issues not only affects rural populations, but is also a gap in the understanding of the greater healthcare system as a whole.

Additionally, the Innovations Network engages trainees and faculty in authentic research into real healthcare issues that affect the institutions and communities in which they train and reside. Under value-based healthcare payment models and integrated delivery models, clinicians will need to continually evaluate and improve their practice. The Innovations Network will train future physicians in the new paradigm, while at the same time allowing seasoned clinicians to participate in lines of inquiry and continuing medical education related to practice transformation. Residents will work as members of an interdisciplinary team to improve the processes of the institutions and communities in which they train. Physician education programs bring value to the institutions and communities through research. The knowledge generated is meaningful to communities and institutions, thereby mitigating issues with late-stage translation, which has been identified by NIH and others, as a significant shortcoming of the traditional research paradigm. In the Innovations Network, trainees and faculty are agents of practice transformation, actively shaping the future of healthcare more than passively reacting; they are active members of the healthcare team.

Physicians tend to practice within proximity to the residency program from which they graduated. Since most residency training is conducted in an Academic Medical Center or other larger tertiary care facility located in an urban or suburban area, physicians are clustered around these communities. The training of physicians reflects their experience in these larger, relatively resource rich tertiary care settings. To alleviate the physician shortage in frontier and rural areas and train physicians to practice in their demographic and geographic context, smaller healthcare providers collaborate to operate community-based residency and clerkship programs. Community-based physician training programs are rich in hands-on training opportunities. However, a persistent challenge of community-based training programs, especially in frontier and rural areas, is supporting a high-quality academic training component. Didactic curriculum, faculty development, and research do not exist in abundance, as these are generally located in a university setting, not a rural community.

The Innovations Network is a PBRN, a research paradigm that allows clinicians and trainees in community-based programs to participate in research that has value to their communities, as well as the scientific and clinical community at-large. The Innovations Network enhances the academic capacity of community-based programs, mitigates professional isolation, which is a significant factor in rural physician attrition, and allows rural institutions and communities to “grow their own” physicians that have the broad-base of competency necessary to provide high-quality service to rural and frontier populations.
**Structure**
The Innovations Network is a national Practice-Based Research Network that consists of four (4) regional networks with administrative centers located in Colorado, Montana, Kentucky, and Mississippi (Appendix A). These networks extend across the aforementioned states, as well as Alaska, Washington, Louisiana, West Virginia, Arkansas, Indiana, Alabama, Tennessee, and Virginia. The regional networks have similar personnel structures, are on the same web-based collaborative platform and research processes, and are focused on a common theme: Improving the Rural Healthcare Process to meet the Triple Aim. Community Advisory Boards (CAB) guide the research processes locally and Innovations Network-wide.

Each regional network has research infrastructure, including research administration and technical support (Appendix C). An overall network Principal Investigator is the scientific leader for the network. The Overall PI assists other researchers with the development of proposals and analysis and translation of research findings, ensuring that projects have scientific rigor and align with the theme, vision, and goals of the network. Regional Networks have local scientific leadership to assist with validation and implementation issues, as well as participate in proposal development and analysis and translation of findings.

Research administration personnel include an overall Innovations Director, Regional Innovations Manager(s), and Innovations Coordinator(s). The Director is located centrally and coordinates research and education across all of the networks. Regional Innovations Managers and Coordinators are located at each network. The Manager oversees the research process and research education of the Regional Network and communicates with the National Network. The Coordinators are the direct liaison to the participating clinicians and clinics. They conduct validation training, collect data, conduct needs assessments, among other duties.

The Innovations Network has a similar structure to ensure consumer involvement in research and minimize threats to social validity. “Threats to the social validity of applied research” have been described by Tom Seekins, PhD and Glen W. White, PhD of the University of Montana and University of Kansas, respectively, in 2012. Seekins and White define social validity as “the extent to which potential adopters of research products judge them useful and actually use them.” These threats include:

- Selecting irrelevant topics for research
- Lack of clarity about important consumer goals
- Misunderstanding of the acceptability of research methods
- Misunderstanding the range of intervention acceptability
- Ignoring criteria that potential adopters would use to judge the significance of outcomes and impacts
- Misinterpreting results
- Lacking generality of findings in real life application

In 2001, the Institute of Medicine cited “patient-centered” approaches, including the patient perspective, as being a vital part of healthcare improvement. Inclusion of patient and community perspectives to reduce threats to social validity is at the core of Innovations Network research.
Researchers will utilize patient panels, focus groups, individual interviews, and community advisory boards as mechanisms to include the patient perspective in the healthcare improvement process.

Each regional network has a mechanism for patient involvement as determined by the circumstances of the research, population, subject, etc., thereby providing for comparison of processes and techniques across regions. The information and insights garnered through this array of processes inform the regional network Community Advisory Board (CAB), and consequently the national Innovations Network (Appendix D). The CAB of each regional network guides the research agenda and process, ensuring that it meets community needs, follows community principles and processes, and that data is interpreted in the proper context. Regional CABs will convene to form a national CAB that will ensure consumer involvement Innovations Network-wide. Read more about CABs here: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3103575/.

Frontier Rural Innovations Network Areas of Research Interest

- Patient Activation
- Obesity
- Diabetes
- Smoking Cessation
- Pain Management
- Transitional Care
- Swing Bed Utilization
- End of Life Care
- Integrated Behavioral Health
- Access to Primary Care
- Healthcare Payment and Delivery Models
- Inter-professional Healthcare Teams
- Provider Education
- Osteopathic Principles and Practice (OPP)

Description of Innovations Network Partners

**A-OPTIC –Pikeville, KY**

The Appalachian Osteopathic Postgraduate Training Institute Consortium (A-OPTIC) operates the Frontier Rural Innovations Network. A-OPTIC is accredited by the American Osteopathic Association (AOA) as an Osteopathic Postgraduate Training Institute (OPTI). A-OPTIC is a physician graduate medical education consortium. A-OPTIC provides academic resources –Research, Faculty Development, Curriculum – to community-based residency programs in rural and frontier areas of the United States, as well as administrative oversight to ensure continued program accreditation and quality improvement. A-OPTIC is also a Health Resources and Service Administration (HRSA) Teaching Health Center (THC).

A-OPTIC has three categories of Membership: Residency, Medical School, and Research. Members are currently located in nine (9) states. A-OPTIC has fourteen (14) Residency Members and two (2) Academic Members –William Carey University College of Osteopathic Medicine in Hattiesburg, MS and
the University of Pikeville - Kentucky College of Osteopathic Medicine in Pikeville, KY. A-OPTIC’s Research Members include Community Care Central Colorado, an ACO in Colorado Springs, CO; the Frontier Medicine Better Health Partnership, in St. Regis, MT; International Heart Institute and University of Montana in Missoula, MT; Pacific Northwest University, Yakima, WA; and others. This network of diverse organizations has a common interest to improve access and quality of care in rural and frontier areas of the United States.

**Community Care Central Colorado – Colorado Springs, CO**
Community Care Central Colorado is an Accountable Care Organization (ACO) and a Regional Care Collaborative Organization (RCCO) serving Colorado in Teller, El Paso, Park and Elbert counties. An RCCO provides coordinated care for Medicaid clients by connecting them with Medicaid providers and other community and social services. Community Care helps clients get the right care when they are returning home from the hospital or nursing facility and help with other care transitions, too, like moving from children’s to adult health services, or moving from a hospital to nursing care.

As part of this commitment to improving the quality and effectiveness of the care delivery process for patients, there are various Community Care research projects that are planned, ongoing, or completed. Community engagement and collaboration are key components of these initiatives.

**International Heart Institute of Montana – Missoula, MT**
The International Heart Institute of Montana Foundation is a unique and comprehensive research and educational facility that was created through a joint venture between St. Patrick Hospital and The University of Montana. It is located in Missoula, Montana, and is comprised of a group of professionals who are dedicated to improving patient care. The International Heart Institute Foundation cultivates high-quality cardiac care by conducting basic, translational, and clinical cardiac research while developing new technology for commercial applications and offering training and educational opportunities. The Foundation’s research and education programs work closely with The International Heart Institute of Montana’s cardiology team to advance medical care for heart patients everywhere.

**University of Montana – Rural Institute, College of Health Professions, Family Medicine Residency of Western Montana – Missoula, MT**
Since 1979, the Rural Institute, Montana’s Center of Excellence in Disabilities, has sought to enhance the quality of life for people with disabilities, especially those individuals living in Montana and other rural areas across the country. Our objective is to increase the independence, productivity, community integration, and inclusion of those with disabilities through education, research, and demonstration services.

As part of the national network of University Centers for Excellence in Developmental Disabilities (UCEDDs), we share a vision that foresees a nation in which all Americans, including Americans with disabilities, participate fully in their communities. The Rural Institute employs nine faculty and over 50 staff members who are currently working on 30+ projects that cover a broad range of disability related topics which include:

- Assistive Technology
Situated on the beautiful University of Montana campus, the College of Health Professions and Biomedical Sciences is home to cutting-edge research and top-notch educators. Degree offerings include Bachelor of Arts and Master's in Social Work, Master's and Certificate of Public Health, Doctor of Pharmacy, Doctor of Physical Therapy, Master of Science and Doctor of Philosophy in Neuroscience, Biomedical & Pharmaceutical Sciences, Toxicology, and Medicinal Chemistry. The College prepares persons to serve in the professions of pharmacy, physical therapy, public health, and social work. Students also have opportunities to participate in research projects with faculty who are committed to academic excellence. Many members of the faculty have not only a national reputation but also an international reputation. As an example, the Skaggs School of Pharmacy ranks among the top 25% of pharmacy schools in total National Institutes of Health funds received. Our students are placed in many diverse learning environments in numerous rural training sites across the entire state of Montana.

The Family Medicine Residency of Western Montana is a three-year family medicine program sponsored by The University of Montana and affiliated with the University of Washington Family Medicine Residency Network and A-OPTIC. FMRWM was founded on the belief that a residency program should develop excellent physicians and should serve the community, whether in a bustling university town or a hamlet of 200 people. And, since we are fortunate enough to call Western Montana home, the program aims to inspire a work/life balance that nurtures both personal and professional passions.

**Methodist Hospital Family Medicine Residency Program – Henderson, KY**

The Methodist Hospital Family Medicine Residency is located in Henderson, Kentucky, and has been in existence since 2003. Through the Osteopathic Family Medicine Program, the Medical Staff of Methodist Hospital is dedicated to providing an atmosphere of learning, collaboration, and excellence to all students and residents. The residents, who choose Methodist Hospital as the healthcare facility that will enhance their education and provide practical hands on experience, enjoy a diverse environment designed to provide the highest standards of professional ethics and integrity. In partnership with the University of Pikeville - Kentucky College of Osteopathic Medicine (KYCOM) and as a member of the Appalachian Osteopathic Postgraduate Training Institute Consortium (A-OPTIC), becoming a teaching
hospital elevated Methodist to a new level of providing comprehensive, consistent, and quality healthcare to patients.

William Carey University College of Osteopathic Medicine – Hattiesburg, MS
The William Carey University College of Osteopathic Medicine (WCUCOM) educates medical students at training sites that span a five-state region of the Gulf Coast and will graduate its first class of medical students as Doctors of Osteopathic Medicine (DO) in 2014. The school pursues a mission to advance knowledge and provide leadership in addressing the shortage of primary care physicians in the Gulf South Region, particularly within rural and underserved communities. It is committed to providing the highest quality educational experience possible for its students.

University of Pikeville – Kentucky College of Osteopathic Medicine – Pikeville, KY
The mission of the University of Pikeville – Kentucky College of Osteopathic Medicine (KYCOM) is to provide men and women with an osteopathic medical education that emphasizes primary care, encourages research, promotes lifelong scholarly activity, and produces graduates who are committed to serving the health care needs of communities in rural Kentucky and other Appalachian regions.

Since its inception in 1997, more than 700 physicians have graduated from KYCOM, with 60 percent serving primarily in rural healthcare facilities in Eastern Kentucky and other regions of Appalachia. KYCOM has earned high marks in rural medicine ranking fifth among all medical schools in the nation, both D.O. and M.D., in U.S. News & World Report’s 2014 edition of Best Graduate Schools. KYCOM is ranked second in the percentage of graduates who enter primary care residencies.

Pacific Northwest University of Health Sciences – College of Osteopathic Medicine – Yakima, WA
Based in Yakima, Washington, the College of Osteopathic Medicine (COM) is in the heart of medically underserved and rural populations. When its doors opened in 2008, it was the Pacific Northwest’s first medical school in 60 years.

The four-year accredited osteopathic medical education program begins in Yakima at Butler-Haney Hall and the Cadwell Student Center. Combined, these two buildings provide 56,000 square feet of learning space including a spacious anatomy laboratory with camera projection capability, a large osteopathic manual medicine classroom, a simulation laboratory, research and study space, a student government office, student lounge, and numerous break-out rooms for small group interaction. During years three and four, students tackle the rigors of clinical rotations at hospitals and clinics throughout the Northwest where regional deans and regional coordinators support and guide their steps toward residency.

At PNWU-COM, highly capable and committed staff, administrators, and faculty, including practicing physicians, focus on high-tech, high-touch medical education, as well as osteopathic principles and practice to train the next generation of physicians. In addition, more than 650 adjunct clinical faculty share in PNWU’s commitment to serve the rural and medically underserved of the Northwest.

East Central Health Network – Regional Rural Primary Care Training Campus – Decatur, MS
East Central Health Network (EC-HealthNet) is a network of community-based organizations, clinics and tertiary care, critical access, and specialty care hospitals across east central Mississippi and northern
Alabama. The network was created to coordinate health services across the region. EC HealthNet has developed a Rural Regional Primary Care Training Campus (RRPCTC) that will offer AOA and ACGME accredited residency training in Family Practice and Internal Medicine. The RRPCTC overlays the existing network of EC-HealthNet healthcare providers which includes tertiary care centers, primary care centers, and critical access hospitals. EC-HealthNet RRPCTC facilities are part of the Frontier Rural Innovations Network. Residents receive wraparound research support and have longitudinal rotations in research with a timeline for completing specific tasks culminating in a publishable product. Faculty members also have access to research support and are encouraged to participate. These components contribute to meeting the overall purpose of the EC-HealthNet RRPCTC: to train physicians in rural areas to increase the likelihood that they will choose to practice in a rural area and have the clinical philosophy and skills to care for rural residents of these communities.

**Frontier Medicine Better Health Partnership** – St. Regis, MT

The Frontier Medicine Better Health Partnership (FMBHP) is a collaboration among frontier/rural healthcare communities; Interdisciplinary Medical Education Center; iVantage, an industry leader providing comprehensive hospital evaluation tools; Vree Health; and the Appalachian Osteopathic Postgraduate Training Institute Consortium (A-OPTIC).

The FMBHP was formed to address the unique healthcare challenges in frontier/rural communities and develop solutions that are scalable nationwide. By working closely with a state-wide network of Critical Access Hospitals in Montana, the FMBHP plans to develop, implement, test, refine, and operate a model of healthcare delivery and payment for frontier/rural America based on community-validated best practices. The FMBHP system is supported by a “just in time” inter-professional workforce development center.

**References**


Rural Health Continuum

Care Settings/Services

Patient Concerns

- Public/Population Health
- Specialty Care
- Outpatient/inpatient Hospital Care
- Support Groups
- Home (Home Health/Hospice)
- Workplace
- Primary Care
- Community
- Faith Based Organizations
- Schools
- Post Acute Care
- Pain
- Pregnancy
- Diabetes
- Obesity
- Other Chronic Diseases
- Behavioral/Mental Health
- Emergency/Trauma Care
- Acute Care Need
- Nutrition
- Health Screenings
- Vaccinations
- End of Life Care
- Addiction
- Diabetes
- Birth
- Adolescence
- Adult
- Senior
- Prenatal
- Early Childhood
- Young Adult
Community Advisory Board Structure

- Montana Community Advisory Board
- KYCOM Community Advisory Board
- A-OPTIC National Community Advisory Board
- William Carey/Gulf South Community Advisory Board
- Colorado Community Advisory Board
Research conducted in a practice-based research network (PBRN) differs from other multisite research and presents particular planning challenges. The American Academy of Family Physicians National Research Network (AAFP NRN) has developed a number of procedures used for planning and implementing studies, which address the challenges of national PBRN studies. In this study, we highlight challenges common to PBRN research and describe the methods used by the AAFP NRN to address those challenges. The following tasks were identified as important to implementing PBRN research studies: (1) selecting fundable, feasible studies that interest members and have the potential to improve quality of care; (2) creating a practical budget that covers the costs of the study; (3) composing study teams and securing written agreements between team members; (4) recruiting and selecting study sites; and (5) training practice staff and physicians. Striking the balance of scientific rigor with practical application of PBRN studies must be addressed throughout these tasks. Proper planning for PBRN studies significantly affects the success of study implementation. Although developed by a national PBRN, the planning procedures described in this study may be adapted for state or regional PBRNs. (J Am Board Fam Med 2007;20:220–228.)

A PBRN is a group of ambulatory practices devoted principally to providing quality patient care. These practices affiliate with one another to investigate questions related to both improving the care they provide and improving their discipline.1 PBRN research studies take place primarily in the office and the research questions are generally those of interest to the participating practices.

The history of primary care PBRNs in the United States began in the 1970s, with the appearance of the earliest regional networks.2-3 In 1978, the creation of a national family medicine PBRN was set in motion, leading to development of the Ambulatory Sentinel Practice Network (ASPN). The AAFP NRN was established in 2000 to replace ASPN as the national family medicine PBRN.4,5 Since the AAFP NRN’s inception, primary care PBRNs have grown significantly in size and number. The growth of PBRNs over the past 2 decades has been supported by a number of funding opportunities from the Agency for Healthcare Research Quality (AHRQ) specifically directed toward primary care PBRNs.6 In 2004, AHRQ identified 111 primary care PBRNs operating in the United States.3,6,7

PBRNs emphasize a close collaboration between practicing clinicians and researchers.1 Engaging network members in reflective inquiries can lead to practice improvement as well as new researchable questions for the network.8 However, the engagement of busy practices in practice-based research along with its growth in popularity and complexity of studies have led to increasing challenges in planning and implementing research studies in busy practices. Key challenges in this process include selecting studies that meet the goals and objectives of the network and its members; creating a practical, accurate, and sufficient study budget; developing study teams and agreements between team members; recruiting and selecting study sites; and training the practice staff for participation in network studies.9-12
AAFP NRN membership includes approximately 350 clinicians and study coordinators from 180 practices in 50 states and Canadian provinces. To date, the AAFP NRN has completed data collection in 17 studies and is currently working on 8 active projects. AAFP NRN studies range from simple physician surveys to complex randomized control trials and have included studies on topics such as bioterrorism preparedness of family physicians,\(^{13}\) patient safety in family physician offices,\(^{14-20}\) diabetes,\(^{21}\) alcohol screening,\(^{22}\) patient communication, practice change, and depression screening and care.

In this study, we discuss the 5 strategies that have been developed in the AAFP NRN through an iterative process of adjusting and improving procedures to plan and launch new studies. We expect that these processes and procedures, as well as the lessons that we have learned, will be useful for both new and experienced networks interested in successfully implementing PBRN studies.

**Selecting Fundable, Feasible Studies**

Because of the large number of projects that may be under consideration at any one time in the AAFP NRN, a multistep process for “vetting” studies has been developed. In the true spirit of PBRNs, this process incorporates input from both AAFP NRN staff and network members. A variety of issues influence study selection. A proposed study must be a topic of interest to members, of importance to the discipline, and feasible for the NRN. Figure 1 outlines the general process for evaluating study ideas and launching new studies, although this process may vary for a particular study.

Study ideas in the AAFP NRN come from a variety of sources, including directly from clinician members (the traditional bottom-up concept), principal investigators external to the AAFP NRN, potential funders, AAFP NRN staff, other PBRNs, and indirectly from requests for applications/proposals. Each study concept, regardless of the source of the idea, is first evaluated by the AAFP NRN’s senior leaders (network director, research director, associate research director, and senior scientists). They review available documents including protocols, outlines, and abstracts, and address 4 main questions: (1) Is this a researchable study question? (2) Is the AAFP NRN the best place to answer the question? (3) Does this study fit with the goals and objectives of the NRN? and (4) Is this study fundable?/Do we have the available resources?

If the senior leadership agrees that the idea meets these 4 criteria, a 1-page concept overview is presented to 1 of the 2 AAFP NRN Scientific Review Committees (SRC). Each SRC consists of 6 AAFP NRN physicians and 1 study coordinator (usually a nurse or medical assistant). Proposals are distributed to the 2 SRCs on a rotating basis. The SRC’s objective is to determine whether the study proposal is suitable and feasible in a primary care practice. SRC members may also make suggestions on a study’s methodology to enhance its implementation in a busy family medicine practice. The physician serving as committee chair is responsible for collecting committee member input and transmitting the final decision back to the AAFP NRN leadership.

Next, we assess the interest of the AAFP NRN membership. This process occurs before practice recruitment to validate that there is sufficient member interest in a particular study topic to meet recruitment goals. An AAFP NRN staff member communicates with network members who are appropriate for a given study, provides them with a 1-page overview of the study concept and a description of the responsibilities of the clinician or practice, and requests that they let us know if they are potentially interested in participating.

After a study idea progresses to this point in the process, the senior management begins developing a complete study protocol and pursuing funding options. Ultimately, it is the final decision of the AAFP NRN leadership and staff as to whether a project will proceed. However, because the success of network studies is contingent on participation of members, we strive to assure that they have ample input into the design of a research project early in the process.

The AAFP NRN developed its Principles for Industry-Funded Research (available at www.aafp.org/natnet) to guide negotiations with potential external commercial funders who invite the AAFP NRN to collaborate or take the lead on protocol development. This document outlines the principles by which the NRN collaborates with such industry sponsors, and clarifies the roles of both the AAFP NRN and the intended funders in the development, data collection, analysis, and dissemination of the research project.

\(^{13}\) doi: 10.3122/jabfm.2007.02.060103
Creating a Practical Budget
We begin to create a detailed budget once a preliminary protocol has been developed and potential funding source(s) have been identified. The Network Director and Research Administrator begin the budget process by reviewing the preliminary protocol and assigning costs by category, starting with personnel. Historically, we have tended to underestimate the amount of time required by staff to implement network studies. Therefore, we now pay particular attention to adequate salary coverage for the project manager and research assistants when possible. Once personnel costs have been determined, all other project-related costs are added into the budget. Our experience indicates that 2 other cost categories for PBRN studies require particular attention: study site training costs and payments to participating practices.

Depending on the funding source, a draft budget is either submitted for approval in the case of

Figure 1. The planning and study selection process for studies conducted in the AAFP NRN.
commercial and most private philanthropic funding or, in the case of government-sponsored funding, reviewed to determine whether the proposed budget fits into the funder’s allotment for the project. If the budget exceeds the available funds, the AAFP NRN director will make adjustments that ensure the project can be conducted without compromising the integrity of the study.

Composing the Study Team
The dynamics of the research team are essential to the success of any study. The composition of the team offers distinctive challenges to PBRN research. Members of the team generally include the principal investigator (PI), coinvestigators, project manager, consultants, statistician, research assistants, senior scientist(s), practicing physicians, and practice study coordinators. In addition, PBRNs carrying out prospective cohort studies, clinical trials, or practice change interventions must also consider sophisticated information management resources and formal linkages with the statistical and methodologic expertise existing in academic centers.7 An overall description of the study team’s roles appears in Table 1.

Practice-based research is distinctive because physicians and study coordinators from the selected practices are essential members of the study team. Their roles are critical in the planning stage of a research study. They provide invaluable feedback on the feasibility of implementing the protocol in practice. These practice representatives provide feedback on whether the proposed study protocol is feasible given their specific local requirements. Early engagement of these team members always improves implementation of the study protocol.

Table 1. Research Project Team Member Roles

<table>
<thead>
<tr>
<th>Members of the research team</th>
<th>Role/Responsibilities</th>
<th>Housed</th>
<th>Knowledge and Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principal Investigator (PI)</td>
<td>Leads the study team. Oversees the development of the protocol and all aspects of the study related science. Ultimately responsible for carrying out the research study.</td>
<td>Internal or external</td>
<td>Preferably experienced in practice-based research. Knowledgeable in the field of study.</td>
</tr>
<tr>
<td>Coinvestigator</td>
<td>Works with the PI to implement the study</td>
<td>Internal or external</td>
<td>Has skills and knowledge in a content or research-skills field</td>
</tr>
<tr>
<td>Project manager</td>
<td>Is responsible for ensuring that all details of the study are carried out successfully, in partnership with the PI. Develops and keeps track of the timeline. Oversees the submission of application to the primary IRB. Works with the Research Coordinator to ensure a realistic budget is instituted. Manages all other aspects of the study and AAFP NRN staff.</td>
<td>Internal and/or external. For studies in which the PI is external, there may be both an external and internal project manager.</td>
<td>Master’s degree preferred. Experience in practice-based research.</td>
</tr>
<tr>
<td>Consultants</td>
<td>Budgeted for a certain period of time to work on specific tasks.</td>
<td>External</td>
<td>Has a specific skill or knowledge in a subject area that is pertinent to the study.</td>
</tr>
<tr>
<td>Research assistant</td>
<td>Assists the project manager in taking the study to the field. Manages the project data.</td>
<td>Internal</td>
<td>Bachelor’s or master’s degree. Previous research experience.</td>
</tr>
<tr>
<td>Senior scientist</td>
<td>Represents the interest of the AAFP NRN members and staff and is sensitive to the work burden expected.</td>
<td>Internal</td>
<td>PhD level. Has knowledge of internal AAFP NRN procedures.</td>
</tr>
<tr>
<td>Practice lead physician/clinician</td>
<td>Oversees implementation of the study in the practice.</td>
<td>External</td>
<td>MD, DO, occasionally PhD, PharmD, NP, or PA</td>
</tr>
<tr>
<td>Practice study coordinator</td>
<td>Coordinates the research locally in each participating practice. Generally responsible for data collection.</td>
<td>External</td>
<td>Office manager, nurse, technician, or practice research coordinator</td>
</tr>
</tbody>
</table>
The AAFP NRN first involves these practice leaders during the face-to-face study training session, as described in the following sections.

The AAFP NRN has developed policies and procedures to standardize network operations. These policies strengthen the understanding of the research team, expedite our work, and eliminate future misunderstandings. In addition, we have developed model agreements designed to ensure a common understanding between the AAFP NRN and outside research team members. All the policies and agreements listed below are available at www.aafp.org/natnet.

“Writing Process for Manuscripts” includes the roles, expectations, timelines, and procedures for writing papers related to studies conducted in the AAFP NRN. This writing process was developed to facilitate the timely dissemination of research findings to practices and to the academic press. This agreement states that the AAFP NRN expects to publish the results of every study conducted in our network.

The Publication Policy outlines how investigators working with the AAFP NRN are to prepare manuscripts for primary and secondary publication. It covers topics such as authorship, manuscript preparation and titles, conflict resolution, and acknowledging the AAFP NRN and study sites in published papers.

The External PI Agreement provides a detailed description of the relationship between the AAFP NRN and PIs who are not staff of the AAFP. It clarifies that any projects brought to the network by external PIs must be consistent with the AAFP NRN’s mission, objectives, and current research agenda. The document also outlines the development of project budgets, AAFP NRN policies for day-to-day project operations, financial responsibilities and authority of the AAFP NRN director, and expectations for the dissemination of findings.

The Data Sharing Agreement sets forth the terms, conditions, and obligations concerning data sharing between the AAFP NRN and any another network or person. It clarifies that if the AAFP NRN conducts a study resulting in a project dataset, then it owns such data.

The General Affiliation Agreement asserts that the AAFP NRN is interested in promoting collaborative arrangements with state and regional networks. It also delineates the conditions under which the AAFP NRN and regional networks can collaborate, including study selection, decision making, data collection, and IRB approval for collaborative studies.

**Recruiting and Selecting Sites**

Practice recruitment and selection is another challenge for PBRNs. The practice recruitment and selection strategy is developed by the central research team for each study based on the number of practices, physicians, staff, and/or patients needed, determined by the power analysis and augmented by expected attrition.23–26 Once the target sample size has been set, AAFP NRN staff assess whether a sufficient number of practices can be recruited exclusively from the AAFP NRN membership based on the study’s requirements for particular patient and/or practice characteristics.

In situations where AAFP NRN members will not provide adequate numbers, a decision is made whether affiliated state or regional networks will be invited to participate. The AAFP NRN staff generally works with affiliate network directors or administrators to identify members of those networks who may be appropriate for the study.

Once the recruitment strategy is developed, the project staff initiates the recruitment process. The chronology of practice recruitment and selection from AAFP NRN practices is generally the following:

1. A broadcast recruitment E-mail is sent to all eligible AAFP NRN members announcing the study and briefly describing the eligibility criteria.
2. One week later, a personalized letter that includes responsibilities and timeline, a 1-page study overview, a Study Interest Form, and a postage-paid return envelope are sent to all eligible AAFP NRN members.
3. Two days later, another broadcast E-mail is sent to all eligible members announcing that recruitment letters and invitations for the study have been mailed.
4. Affiliated networks recruit their own practices to participate in a study.

One to 2 weeks later, if adequate numbers of AAFP NRN and affiliated network practices have not volunteered to participate in the study, we send individual E-mails and make personal telephone calls to selected AAFP NRN members inviting them to...
participate. In addition, we may contact staff of the AAFP regular electronic newsletter, *AAFP News Now*, about publishing a recruitment article in an upcoming edition. If necessary, we may contact additional affiliated networks about their participation in the study.

We select practices from the pool of eligible and interested practices that meet inclusion criteria and maximize diversity based on geographic location, practice type, size, and any other pertinent characteristics. We also consider other factors such as whether a practice is already participating in another study, and a practice and study coordinator’s previous experience in network studies (in particular, if we are selecting practices for a more complex study). We have created a database to assist us in practice selection in which we store these data on all AAFP NRN member practices, physicians, and study coordinators.

For each participating practice, the lead physician, study coordinator, Practice Signatory Official (as designated by the practice), and the study PI sign a Practice Agreement. This document states that the practice agrees to carry out all designated responsibilities of the study and the AAFP NRN agrees to provide materials, provide and pay for training, and provide the designated stipend. Institutional Review Board (IRB) issues are spelled out in the Unaffiliated Investigator Agreement.

At times during the recruitment phase we must make tough decisions about balancing scientific rigor with the realities of “real-world” medical practice. For example, occasionally we are forced to modify the initial sampling plan to achieve the required sample size. In a recent study, we initially planned to include few residency practices. However, an eligibility requirement that a practice either had to deliver at least 50 babies or perform 50 well-baby visits in the previous year forced us to change our original recruitment strategy and include residency practices to get sufficient numbers for our study. In addition, although in an ideal world we would have the luxury of randomly selecting practices to increase the representativeness of our sample, this is not always possible in PBRN studies. Sometimes we need to include all interested practices to reach sample size requirements. Finally, although a study design may require equal numbers of practices with or without a particular characteristic (eg, those with and without electronic medical records), we sometimes learn after a study begins that a practice, in fact, did not really have that characteristic. Thus, when the budget permits, we oversample practices just as we oversample patients. For instance, if a study is randomized at the practice level and the power analysis indicates that 10 practices per arm are sufficient, we plan for attrition by budgeting for 12 practices per arm.

**Training Practice Staff and Physicians**

The AAFP NRN has adopted a strategy of providing face-to-face training for practices selected to participate in a research study. When funding permits, we require each participating practice to send a team, usually comprising the site’s lead physician and study coordinator, for a weekend of training. Sessions generally run all day Saturday and, occasionally, through Sunday morning. In this way, staff and physicians are not out of the office during a busy work week. Bringing these people together ensures that the lead physicians and study coordinators understand the protocol and all participating practice staff receive the same instructions for implementing the study in the practice. This increases the likelihood that the study will be implemented with fidelity in all participating practices.

The entire research team, including all investigators, consultants, project manager, and research assistants, conducts the weekend sessions. The sessions have evolved into both a successful strategy for implementing studies in practices and a place where the practices make significant contributions that improve the design and feasibility of study protocols. Discussions encourage brainstorming on best strategies for implementing the protocol in a practice. As mentioned previously, practice leadership provides a new perspective, which frequently leads to improved protocol design and implementation, and ultimately to high quality study data.27

Training sessions also provide the opportunity for site leaders and the research team to get to know one another. In contrast to many regional networks, our national staff has few opportunities to meet face-to-face with members. Training sessions may be the only time during the study period that the research team and practice staff meet. These personal connections between the practice members and the research team lead to better communication throughout the study period and eventually lead to a more successful research study.

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When key personnel from study sites are unable to attend the face-to-face training, we provide telephone training or ask someone who did attend the training to orient those who did not. However, these techniques cannot replicate the experience of a face-to-face training weekend with all the practices.

In addition, we develop an in-depth training manual that includes copies of and instructions for completion of all forms; the AAFP IRB application; all consent forms; instructions for completion of human subjects training; contact information for the central research team, practice physicians, practice study coordinators, and other key people; the study protocol, as appropriate; suggestions for study implementation, including recruitment and consent process for subjects; and other pertinent information. The manual is the basis of the training curriculum and agenda. A template for the manual and schedule appears in Table 2.

The cost and logistic issues involved in planning training sessions has led to the development of some useful guidelines. In an effort to control expenses and simplify the process of making travel arrangements for the training sessions, we use a travel agency. All participants are asked to make their own travel arrangements through the agency within the provided parameters for arrival and departure times and maximum ticket price. In this way, we can also limit the number of participants who arrive late or leave early. In addition, all flight expenses are billed directly to the AAFP NRN, eliminating the inconvenience of reimbursing participants. This system has worked well for both participants and the research team.

After training, practice participants and the research staff are generally excited and motivated to implement the study. To preserve the momentum generated from the training, we try to minimize the time between training and implementation in practices. However, this is not always possible for reasons such as if numerous changes to the protocol are made as a result of feedback from training participants; if practices need to train their staff and physicians before study initiation; or if practice-specific implementation strategies need to be developed. In cases where there is an extended period of time between the training session and study implementation.

### Table 2. Elements for Research Study Training Manual

<table>
<thead>
<tr>
<th>Topic</th>
<th>Description</th>
<th>Time Alotted in 12-Hour Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research protocol</td>
<td>Brief overview to explain research design and protocol to the practice staff and physicians</td>
<td>1 to 2 hours</td>
</tr>
<tr>
<td>Pertinent skills</td>
<td>Study-specific skills discussed as necessary</td>
<td>Varies</td>
</tr>
<tr>
<td>IRB and HIPAA issues</td>
<td>Overview of IRB process, copy and status of AAFP IRB application, HIPAA requirements, and instructions for Human Subjects Training</td>
<td>30 minutes</td>
</tr>
<tr>
<td>Patient recruitment</td>
<td>Inclusion/exclusion criteria and suggested methods of patient recruitment</td>
<td>30 minutes</td>
</tr>
<tr>
<td>Obtaining consent/authorization</td>
<td>Policies regarding proper methods for obtaining patient consent for research and authorization for disclosure of PHI, consent and authorization forms</td>
<td>45 minutes to 1 hour</td>
</tr>
<tr>
<td>Study implementation</td>
<td>Overview of implementation in study, may or may discuss details of implementation (study specific)</td>
<td>3 hours</td>
</tr>
<tr>
<td>Data collection and case report forms</td>
<td>Explanation of and purpose of patient data collection instruments, serious adverse event forms, and data tracking forms as well as instruction on how and when to complete these forms</td>
<td>2 hours</td>
</tr>
<tr>
<td>Train-the-trainer skills</td>
<td>Strategies for training onsite practice staff</td>
<td>30 minutes</td>
</tr>
<tr>
<td>Sustaining enthusiasm</td>
<td>Strategies to sustain momentum and suggestions to prevent problems</td>
<td>30 minutes</td>
</tr>
<tr>
<td>Questions and feedback</td>
<td>Time allotted after each topic for questions or feedback by practice staff and physicians</td>
<td>2 hours</td>
</tr>
<tr>
<td>Contact information</td>
<td>Contact information for members of research team, lead physicians, practice study coordinators, and other pertinent resources</td>
<td></td>
</tr>
</tbody>
</table>
implementation in the practice, we conduct one-on-one refresher telephone calls with the study coordinator or the lead physician before the start of data collection.

Conclusion

Although the nature of PBRNs presents numerous challenges to conducting quality studies, the AAFP NRN has identified a number of processes that facilitate the implementation of studies on a national level. These strategies include how to select fundable, feasible studies; compose the study team; recruit and select sites; and train practice staff and physicians. The planning procedures described in this paper can be modified to work for state or regional PBRNs, and can create a strong foundation on which to build rigorous PBRN studies. Proper planning for PBRN studies significantly improves the success of study implementation and the dissemination of scientifically sound results.

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Community Advisory Boards in Community-Based Participatory Research: A Synthesis of Best Processes

Susan D. Newman, PhD, RN, CRRN; Jeannette O. Andrews, PhD, APRN-BC, FNP; Gayenell S. Magwood, PhD, RN; Carolyn Jenkins, DrPH, APRN, BC-ADM, RD, LD, FAAN; Melissa J. Cox, MPH; Deborah C. Williamson, DHA, MSN, CNM

Abstract

Community-based participatory research (CBPR) is a paradigm to study and reduce disparities in health outcomes related to chronic disease. Community advisory boards (CABs) commonly formalize the academic–community partnerships that guide CBPR by providing a mechanism for community members to have representation in research activities. Researchers and funding agencies increasingly recognize the value of the community’s contribution to research and acknowledge that community advisory boards are a key component of successful CBPR projects. In this article, we describe the best processes for forming, operating, and maintaining CABs for CBPR. We synthesize the literature and offer our professional experiences to guide formation, operation, and maintenance of CABs.

Introduction

Community advisory boards (CABs) often serve as a source of leadership in the partnerships of community-based participatory research (CBPR) and provide structure to guide the partnership’s activities. CAB composition typically reflects the community of interest; its members may share a common interest, identity, illness experience, history, language, or culture (1). CABs provide an infrastructure for community members to voice concerns and priorities that otherwise might not enter into the researchers’ agenda, and advise about suitable research processes that are respectful of and acceptable to the community (2). Research assessing the roles, responsibilities, and processes of CABs supports their effectiveness in building mutually beneficial partnerships between academic researchers and communities (3-7). However, not all community-based researchers have incorporated CABs, nor have CABs been successful in every setting or situation (8,9).

The Center for Community Health Partnerships at the Medical University of South Carolina (MUSC) is a group of community partners, researchers, clinicians, and educators whose purpose is to engage and mobilize academic–community partnerships that promote health and lessen the impact of chronic illness (10). The Center provides a systems-level infrastructure for MUSC academic–community partnerships and promotes institutionalization and sustainability of these partnerships and their products. The Center’s founding members formed a CAB to guide its vision and mission. This process prompted a review of the literature and discussions about the purpose of the board, membership, operating procedures and principles, leadership roles, training needs, sustainability, and evaluation. Our immediate goal was to identify the best processes for forming, operating, and maintaining a CAB. To accomplish this goal, we adopted the integrative practice framework from Cargo and Mercer, which identifies a continuum of CBPR processes from initial engagement to maintenance (11). We based the concept of best processes on Green’s recommendations that academic–community partnerships tailor established processes to meet their
unique needs (12). A central issue in the adoption of these processes is the transfer of knowledge to the practitioners in the field, whether academic or community, and to recognize the multiple factors that influence adoption and implementation of these processes in all settings and stages (13). In this article we present best processes for forming, operating, and maintaining CABs that guide CBPR, by synthesizing processes reported in the literature and demonstrating their adoption and implementation in the field using exemplars from our Center members’ experiences.

Two of the Center’s academic researchers (S.D.N., J.O.A.) conducted a review of the literature to identify processes of CAB functioning. We searched Ovid/Medline, CINAHL, and PsycINFO databases for manuscripts published in English from 2000 to 2009 by using the following search terms: “community advisory boards,” “advisory boards,” or “community-based participatory research” or “participatory research.” Inclusion criteria were descriptions of CABs, which included in-depth discussion of roles, purpose, and structure in guiding community research. Our search revealed few published, peer-reviewed articles that focused solely on the development and functioning of a CAB (2,4,5-7,9,14-16). Rather, we found discussions of CABs embedded in articles discussing CBPR, often making this valuable information difficult to find through traditional search strategies. Additionally, bibliographies provided a rich resource for other publications and sources that described CABs. Additional searches were conducted in CBPR textbooks (17-19) and other CBPR-related documents, such as websites and listserves (20).

During our analysis and synthesis of the literature, we identified key processes of CAB functioning and coded our findings in an organizational matrix with 3 domains (formation, operations, maintenance) on the basis of an adaptation of Cargo and Mercer’s framework (11). We then solicited input from Center members (G.S.M., C.J., M.J.C., D.C.W.) who had experience with CABs and requested that they review the matrix and reflect on best processes on the basis of their experiences. We held team meetings to cross-check the literature synthesis and personal experiences, reconcile analyses to identify processes for each domain of the matrix, then refine description of the processes on the basis of discussion and consensus. We quickly determined that the processes of CAB functioning are not linear but are iterative and cyclical, and may overlap or be revisited. We presented the initial findings at a national conference of academic CBPR researchers and to the Center’s academic and community representatives to further validate the findings. We held subsequent team discussions to refine the findings on the basis of feedback we received.

Overview of Research at the Center for Community Health Partnerships

The Center houses 45 projects with approximately $6.5 million annual expenditures. The projects involve partnerships with various communities and are at various stages in partnership development and research implementation. Approximately half of the projects have study-related CABs. We will describe the Center’s overall CAB and 3 study-related CABs (Appendix A). All studies received approval from the MUSC institutional review board.

The Center’s 20-member CAB is composed of representatives from regional for-profit, nonprofit, school, faith-based, and government organizations, as well as community members. The purposes of the Center’s CAB are to 1) identify community priorities, needs, and interests; 2) set research priorities; 3) provide input or resources or both for the Center’s research activities; 4) identify community members to participate on project steering committees; and 5) promote community support for and involvement with research.

Partnership with people with spinal cord injury (Photovoice)

The Photovoice study (21,22) aimed to identify and address barriers and supports to community participation for people who use wheelchairs for mobility and was the catalyst for the formation of a CAB representing their interests.

Wallerstein and Duran contend that the best CBPR practices require an emancipatory perspective that promotes the participation of community members to transform their lives (23). People with disabilities have expressed a need for inclusive, action-based research methods in which they function as partners and consultants, not as research subjects (24-26). Our 6-member CAB is composed of people with spinal cord injury and the director of a nonprofit disability advocacy organization. People who participated in the Photovoice project and expressed an interest in continuing their role as a partner in research agreed to create a more formalized CAB. This CAB continues to serve as a
partner with the academic researcher (S.D.N.) and share decision-making power regarding conduct of research and use and ownership of the products.

**Partnership with public housing residents (Sister-to-Sister)**

In 2001, an inner-city school official invited the academic investigator (J.O.A.) to work with the community to help women and families to quit smoking (27,28). The academic and community partners agreed to form a 5-member working group of local laypersons (“insiders”) to provide guidance on community preferences, contexts, and a comprehensive community assessment. The following year, on the basis of community interest and initial compatibility of the project, an 8-member CAB was formed, consisting of housing authority officials, members of for-profit and nonprofit community organizations, and lay community members. The purpose of the CAB is to guide the development, implementation, and evaluation of a smoking cessation intervention tailored for women (ie, Sister-to-Sister) living in public housing neighborhoods. After several feasibility and pilot studies, this collaborative partnership is now engaged in a randomized controlled trial that is testing the effectiveness of a multilevel smoking cessation intervention in public housing neighborhoods in 2 states. Because of the complexity, scope, and expansion of the study, neighborhood advisory boards in each of the intervention neighborhoods ensure that the intervention activities are relevant to each site.

**Partnership with coalition on diabetes (Charleston-Georgetown Diabetes Coalition)**

In 1999, the Charleston-Georgetown Diabetes Coalition applied for a Centers for Disease Control and Prevention (CDC) Racial and Ethnic Approaches to Community Health (REACH) grant and asked the MUSC (C.J., G.S.M.) to lead the group’s efforts (29-31). Each of the organizations or communities that are part of the coalition selected 1 representative to become a lead member of the coalition. The group has 10 funded partner members and 4 other members who are engaged in community activities in the 2-county area. Members are added by invitation of a coalition partner and approval by 70% of current members. All members work together to direct research and support community efforts related to diabetes in the African American community. Anyone from the community or local organizations may bring issues, concerns, suggestions, or requests to the group for action.

**Defining Processes for Formation, Operation, and Maintenance**

CABs may engage in processes of formation, operation, and maintenance to accommodate the realities of working in a dynamic community setting (12). *Formation* processes address key activities related to defining the role and purpose of a CAB and subsequent identification and recruitment of key stakeholders from the community for participation in the CAB. *Operation* processes address the development of procedures to guide the logistical operation of the CAB, the development of guiding principles to assure the values of the community are represented and respected, and the establishment of leadership and decision-making protocols. *Maintenance* processes address evaluation of CAB actions and outcomes and plans for sustainability. Ongoing attention to evaluation and sustainability is essential to the maintenance of both newly formed and long-standing CABs. Results of evaluation assessments and strategic planning for sustainability may require CABs to address processes of formation and operations once again.

**Best Processes: Formation**

**Clarifying purpose, functions, and roles**

CBPR teams often form a CAB to gain representation of community perceptions, preferences, and priorities in the development of a research agenda and research processes (32). Examples of additional board functions include advising on study protocol design and implementation, facilitating community consent, evaluating and communicating the risks and benefits of research, helping provide resources, evaluating education materials, disseminating information, and using research findings to advocate for policy change (5,6,9,27,33).

Ideally, CAB members function as partners in CBPR; however, members are often placed in the role of advisors. “Partners” and “advisors” each operate at a different level in the partnership power gradient. Members in a *partnering role* bring issues and concerns from the community to the table, which the board discusses and resolves in a manner that is mutually beneficial to both the research team and the community (7). Members serving in an *advisory role* provide information, guidance, or suggestions from the community; however, the research team may choose to accept or reject the advisors’ input (7). Clarification of
both the intended purpose of the CAB and intended roles of CAB members facilitates the selection and recruitment of appropriate community representatives to serve on the board and maximizes their contribution as research partners. The members of our individual study CABs work in a partnering role with the academic partners, making collaborative decisions in their respective studies through each stage of the research process (Appendix A).

**Determining membership composition and recruitment strategies**

To select appropriate board members, specific inclusion criteria should be established that reflect the goals of the research and the intended functions and purpose of the CAB (19). Brainstorming to identify potential members and determine the best recruitment and selection strategies is an iterative process requiring input from all members of the research team (32). The process requires consideration of types of expertise and resources needed and who can bring that expertise to the partnership. The intended outcomes of the study facilitate determining what type of person (eg, service provider, consumer, community leader) or agency is represented on the CAB (34). Identification of people or agencies with specific expertise in the topic of interest is necessary to create a knowledgeable CAB and to help position the research project favorably in the community. New partnerships are often encouraged to start small and to involve a few community-based organizations that are highly regarded by community members (35). The composition of the CAB for people with spinal cord injury increases consumer direction of disability and rehabilitation research. As the research program progresses, the CAB can decide whether to expand CAB membership by inviting service providers, agency leaders, and other community stakeholders to participate in an advisory or partnering role.

Our Center assesses community and capacity to guide identification of potential partners (36,37). Center organizers created a “potential member matrix” that includes the types of organizations to be considered; their reputation, activities, and achievements in the community; their capability to contribute resources; their self-interests; and their potential conflicts. The matrix facilitated preliminary fieldwork to identify potential CAB members (19). Once people or agencies meeting the initial inclusion criteria were identified, a process of screening (telephone and personal interview) and recruitment (personal invitations followed by letters to the organization) was used to refine the selection process, to carefully evaluate those who expressed an interest in serving, and to assure a good fit with the intent and purpose of the CAB.

Before gaining final commitment to serve, the CAB and potential member should review the potential member’s intended role and clarify expectations, including and defining mechanisms of communication to help ensure a shared understanding of the requirements of the board member position. A signed letter of commitment provides documentation of the agreement and helps to minimize potential misunderstandings. The REACH Charleston-Georgetown Diabetes Coalition uses a document outlining the roles and scope of work for each partnering organization: the document is signed by both the partner representing the community organization and the academic partner and is renegotiated annually.

Generating a new CAB to work on a community issue may not always be the right approach or the best use of resources. Locating a CAB partnership in an existing community structure may be a more effective strategy; in such a situation, the academic partner asks for admission to the partnership and in turn forms a work group within the existing organization. Partnering with an existing group may also promote sustainability; however, this approach is not well described in the CAB literature and requires further examination to determine the benefits and pitfalls.

**Best Processes: Operation**

**Operating operating procedures**

Operating procedures provide logistical guidance regarding how the team works together to complete tasks, including setting the agenda and documenting minutes. When establishing procedures, consideration of group dynamics and accepted social norms must be considered to ensure open communication (38). Procedures that address group dynamics include having everyone listen to one another and demonstrate mutual respect, letting members agree to disagree, having all members participate in board meetings and activities, and having meetings start and end on time (35,39). Members periodically reassess and revise the procedures, on the basis of process evaluations, to maintain an equitable balance of power (36) (Appendix B).

**Establishing operating principles**

Defining the community values or principles that guide
research is another initial task of a CAB (15). The process of developing principles that reflect the local context provides the opportunity to develop trust and build relationships among board members. The CAB then uses these principles to evaluate research protocols to assure that they honor and protect the values of the community (15). Resources (40,41) provide a framework on which a CAB can build principles that are specific to the context of its community and the research project. The CAB of the REACH Charleston-Georgetown Diabetes Coalition used the Community-Campus Partnerships framework to develop partnership principles (Appendix C).

Establishing leadership, balancing power, and making decisions

A key element of effective group process is the fair and appropriate distribution of power and leadership; however, balancing power among diverse partners who represent multiple levels of social hierarchy is challenging (38). A potential strategy is to maintain community and academic cochairs; 2 community cochairs may lessen the possibility that academia dominates the community, especially in settings with a history of extreme power imbalance (32). The CAB for the Sister-to-Sister study uses a written protocol that clearly delineates the responsibilities of the partnership’s cochairs (Appendix D). Effective leadership and balancing of power supports members’ satisfaction, participation, and overall effectiveness by using democratic and consensus-based decision-making (19,42).

CABs generally find that the decision process runs more smoothly if they establish a protocol for decision-making. For example, a designated member may make low-stakes decisions independently, such as determining the typeface for a brochure (38). Having small subcommittees is an effective approach to making decisions on issues that do not require input from the entire CAB membership. Subcommittees decentralize decision making, help balance power, and provide the opportunity for partners, who may feel intimidated in large groups, to participate freely in small group discussions (38). Complex, high-stakes issues generally require a decision by consensus; however, gaining consensus does not mean that the decision must be unanimous (19). The 70% majority is a common strategy for meeting consensus that works well for the Sister-to-Sister CAB. Consensus decision making is often a more time-consuming process; however, incorporating everyone’s opinions results in collective support by the CAB membership and increased group solidarity on the decision (19).

Best Processes: Maintenance

Evaluating partnership processes

A multimethod approach to collecting evaluation data increases the likelihood of a well-rounded assessment of the CAB structure and processes. Key informant interviews, meeting observations, focus groups, documents such as activity logs, and member surveys provide different perspectives of the partnership and enhance the comprehensiveness and credibility of evaluation (43). Qualitative methods, such as key informant interviews, provide a platform for CAB partners to address frustrations and concerns (44) (Appendix E).

Quantitative methods, such as surveys, provide a standardized measure of partnership processes that allows a baseline measure to be established and reevaluated over time to gauge continued effectiveness (45). Measures of process evaluation incorporate items to assess group dynamics within a CAB partnership framework, including shared leadership, open communication, mechanisms for resolving conflicts, and trust and cohesion (44,46,47). Evaluation of CAB leadership considers whether leaders provide praise and recognition, seek out members’ opinions, and approach members for help with specific tasks (45). Process evaluation also includes assessment of more pragmatic issues such as turnover rate of board members, success in recruiting members with specific skills or connections to influential leaders, members’ perceptions of the benefits and costs of participation, and the degree to which members perceive the partnership to be effective and sustainable over time (45,47). Evaluations that address partnership priorities increase the likelihood that partnership collaboration continues, thus promoting sustainability (19,43).

Sustainability

A plan for sustainability is essential during the early stages of partnership. CAB functioning influences the survival of partnerships, because well-managed boards are often able to continue even amid funding difficulties (48). Formal sustainability planning ideally begins before initiation of research, but at a minimum of 1 year before the active project or current funding ends (49). The CAB
defines the meaning of sustainability for the partnership and the criteria for sustainability that members will use to evaluate components of the partnership or program.

Strategies that instill a sense of empowerment and capacity building are essential to promote the retention and satisfaction of CAB members. Training in the principles of CBPR and the language and skills of research helps build the capacity of the CAB and generate belief in the partnership’s ability to enact change in the community.

Recognition of CAB members’ contributions of time, resources, and expertise, through some type of compensation, promotes continued engagement in the partnership (49). Many partnerships do not have the means to provide monetary remuneration. Identifying other means to promote member retention and ensuring that the benefits of membership outweigh the costs is essential. Such strategies may include adequate orientation and training of new members, opportunities for social interaction and participation, adequate access to information and resources, influence in decision making, and recognition for contributions (19). Inexpensive strategies to recognize members’ contributions include potluck dinner parties, awards or honors given by the partnership, positive letters to a member’s colleagues or superiors, and public recognition in local media (49).

Continuing relationships informally during gaps in funding or activities helps to maintain communication between partners and provides the opportunity for brainstorming about the next steps for the partnership. Gaps in funding also provide an opportunity to think ahead and plan for ways to avoid, or at least minimize, these gaps in the future. When sustainability is not possible, clear communication between the researchers, the CAB, and community members will leave the door open for future collaborations. The partnership developed in the Photovoice study has experienced gaps in funding yet remains viable and is currently engaged in another funded project.

Conclusion

A CAB provides a focus for research efforts, an ongoing partnership to address community health concerns, and a mechanism for building capacity in the community and the academic institution. Establishing and sustaining a CAB is a time- and labor-intensive process — which many new partnerships underestimate. Careful initial consideration of the desired functions of a CAB will indicate whether the need is to create a new or expand an existing partnership to improve the health of the community. Continuing to share successes and challenges related to the processes of forming, operating, and maintaining effective CABs promotes ongoing learning and provides a frame of reference for continuing action and research on the best processes in CBPR.

Acknowledgments

We thank our community and academic partners for their collaboration and selfless contributions in building community partnerships. Without their wisdom and support, our work together would not be possible.

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Author Information

Corresponding Author: Susan D. Newman, PhD, RN, CRRN, Assistant Professor, 99 Jonathan Lucas St, MSC 160, Charleston, SC 29425. Telephone: 843-792-9255. E-mail: newmansu@musc.edu.

Author Affiliations: Jeannette O. Andrews, Gayenell S. Magwood, Carolyn Jenkins, Melissa J. Cox, Deborah C. Williamson, Medical University of South Carolina, College of Nursing, Charleston, South Carolina.

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Appendices

Appendix A. Activities and Decisions of Community Advisory Boards, by Study and Project Phase

**Photovoice (21,22)**

Identifying the problem
- Identifies environmental factors affecting community participation after spinal cord injury.

Study design and project startup
- Reviews and endorses application for funding.
- Allots study “work space” in agency facility.
- Obtains funding.

Participant recruitment and data collection methods
- Reviews and refines participant inclusion criteria and recruits participants.
- Discusses and approves participant incentives (eg, food at meetings, cameras).
- Identifies adaptive equipment (eg, cable release, tripods) and refines data collection protocol to minimize transportation issues.

Data collection, analysis, and interpretation
- Collects photographic data of community environmental factors.
- Provides interpretation of photos in 1-to-1 interviews with academic partner.
- Interprets results of collective group findings during celebratory meeting.
- Identifies key issues for action and strategizes next steps.

Dissemination
- Coauthors peer-reviewed manuscript reporting study process and outcomes.
- Designs and distributes pamphlet at Disability Advocacy Day.
- Organizes training in legislative advocacy.
- Engages local media (eg, newspaper).
- Engages state legislators for policy change.

**Sister-to-Sister (27,28)**

Identifying the problem
- Sponsors town hall meetings in community to determine interest.
- Codevelops quantitative survey for administration to a random sample of women in public housing neighborhoods.

Study design and project startup
- Guides intervention development based on survey of community women (ie, multilevel intervention).
- Negotiates study design (ie, delayed intervention in comparison neighborhoods).
- Reviews and approves all instruments.

Participant recruitment and data collection methods
- Determines incentives for participants (eg, gift cards, lotions, kitchen tools) and methods for recruitment.
- Community advisory board, community representatives, and hired community health workers participate in recruitment.
- Consensus on data collection methods and time frames.

Data collection, analysis, and interpretation
- Assists with evaluation of qualitative data.
- Assists with interpretation of quantitative and qualitative data.

Dissemination
- Creates community newsletter (quarterly dissemination).
- Holds neighborhood cookouts to disseminate major findings at end of pilots.
- Engages local media (eg, radio, newspaper).
- Coauthors scientific abstracts and publications.

**REACH Charleston-Georgetown Diabetes Coalition (29-31)**

Identifying the problem
- Community partners join to form REACH Charleston-Georgetown Diabetes Partners Coalition.
- Identifies the community assets and needs related to diabetes for African Americans living in the 2 counties.

Study design and project startup
- Designs a comprehensive assets and needs assessment.
- Develops 3-pronged intervention approach: 1) community education and diabetes self-management training, 2) health systems change led by community partners and staff, and 3) coalition building for collaboration and community action.
Participant recruitment and data collection methods

- Works collaboratively as partners to decrease disparities.
- Hires and trains community health workers, registered dietitians, and registered nurses to recruit community members and volunteers.
- Collects and examines epidemiologic data and audits medical records related to diabetes.
- Conducts focus groups with community leaders, health professionals, and people with diabetes and their support networks.
- Conducts survey of people with diabetes.

Data collection, analysis, and interpretation

- Continues data collection and tracking the number of participants and community events by partners and staff.

Dissemination

- Participates in providing feedback to health agencies where audits occurred.
- Shares data with community groups through newsletter, quarterly written reports, news releases, and presentations.

Evaluation and reflection

- Assists with evaluation and action plan for each year: 1) annual medical records audit by staff with report and planning by partners; 2) annual focus groups with community leaders, health professionals, and people with diabetes and their support persons; and 3) annual survey of community residents.

Appendix B. Example: Operating Procedures — Racial and Ethnic Approaches to Community Health (REACH) Charleston-Georgetown Diabetes Coalition

1. Approve meeting schedule that addresses the needs of its members, funding organizations, and community-based participatory approach groups, and review as needed.

2. Review mission, roles, membership, and guidelines annually.

3. Define goals and develop or update strategic plan to address goals annually.

4. Circulate and review minutes at the following meeting.

5. The chair and chair-elect create agendas 1 week in advance of each meeting and then review the agenda at the beginning of the meeting for any additions.

6. Invite board members to meetings with Centers for Disease Control and Prevention contacts as scheduled.

7. Prioritize communication between meetings. Contact the chair and chair-elect first and, if needed, contact the entire committee. Distribute notices for upcoming meetings and communications that need to occur between meetings by e-mail.

8. The chair and chair-elect communicate with members who have not attended at least half of the meetings to determine what about the coalition is and is not working for them, including their level of interest and commitment. Share feedback with the coalition and refine guidelines as needed.

9. REACH Community Action Plan teams from each member agency report in-depth on a rotating basis, and each team provides a short report.

10. Invite the liaison from each member agency to attend coalition meetings to report periodically on their projects.

Appendix C. Example: Operating Principles — Racial and Ethnic Approaches to Community Health (REACH) Charleston-Georgetown Diabetes Coalition

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Appendix C. Example: Operating Principles — Racial and Ethnic Approaches to Community Health (REACH) Charleston-Georgetown Diabetes Coalition

To accomplish the REACH mission, principles guiding the conduct of projects and relationships are based on

- Building and sustaining effective partnerships for reducing or eliminating disparities.
- Establishing trust and building collaborative knowledge and understanding of the goals, objectives, and activities related to the problems (issues) we are addressing.
- Having an agreed-upon mission, values, goals, measurable outcomes, and accountability for the partnership.
- Building the relationships between partners including mutual trust, respect, genuineness, and commitment.
- Identifying strengths, assets, needs, and capacity of all partners.
- Balancing power among partners and enabling sharing of resources among partners.
- Having clear and open communication among partners while striving to understand each partner’s needs and self-interests and while developing a common language.
- Providing feedback among all stakeholders in the partnership, with the goal of continuously improving the partnership and its outcomes.
- Sharing the benefits of the partnership’s accomplishments.
- Recognizing that a partnership can dissolve for multiple reasons but a planned process for closure is essential for all.
- Acknowledging accountability to sponsors and working collaboratively to reach requirements.
- Sharing ownership of and accountability to the grant and our program among all partners.
• Working together to sustain the benefits of collaboration and partnership.

These principles were based on principles of good community-campus partnerships (41). The coalition annually renews its partnership principles.

Appendix D. Example: Community Advisory Board Leadership Structure — Sister-to-Sister Community and Academic Cochair Responsibilities

**Community cochair responsibilities**

1. Provide leadership to the Sister-to-Sister team in areas such as constituency engagement and communication, and creation of effective community and academic partnerships.

2. Lead board meetings every other month (alternate monthly meetings led by academic cochair).

3. Elicit agenda items from community residents and work with the academic cochair to establish the meeting agenda at least 2 weeks before the scheduled meeting date.

4. Ensure that meetings start and end at agreed-upon times.

5. Introduce each agenda item and facilitate round-robin discussion among all board members.

6. Elicit voting on key decisions, following the 70% rule of consensus.

7. Bring meetings to a conclusion with a summary of key issues decided on and any further follow-up that may be needed.

8. Coordinate the planned neighborhood activities guided by the study design.

9. Appoint ad hoc committees, as needed.

10. Represent the Sister-to-Sister team in discussions with community members and other networking forums as appropriate.

**Academic cochair responsibilities**

1. Provide leadership to the Sister-to-Sister team in areas such as research staff participation and communication, and creation of effective community and academic partnerships.

2. Lead board meetings (alternate meetings led by community cochair).

3. Elicit agenda items from the research team and work with the community cochair to establish meeting agenda at least 2 weeks before the scheduled meeting date.

4. Ensure the distribution of the agenda and previous meeting minutes (by mail) at least 1 week before the scheduled meeting date.

5. Ensure that meetings start and end at agreed-upon times.

6. Introduce each agenda item and facilitate round-robin discussion among all board members.

7. Elicit voting on key decisions, following the 70% rule of consensus.

8. Bring meetings to a conclusion with a summary of key issues decided on and any further follow-up that may be needed.

9. Work with the community cochair and assist with the coordination of the board’s community activities as guided by the study.

10. Coordinate all technical support needed by the board and community events.

11. Represent the Sister-to-Sister team in discussions with community and academic members and other networking forums as appropriate.

12. Monitor board members’ attendance, participation, and ethical conduct as guided by the advisory board manual and operating procedures.

13. Make logistical arrangements for food at meetings.

14. Monitor and process paperwork for CAB supplies and remuneration of community members.

15. Guide the evaluation process of study-related neighborhood activities and the CAB.


Appendix E. Example: Evaluation Questions for Key Informant Interviews with Sister-to-Sister Neighborhood Advisory Board Members

1. Tell me about your experiences with the board so far.

2. Do you feel like the membership of the board reflects the community’s interest? Is the community being represented in the way you think it should be?

3. Tell me about the meetings. Does everyone have the opportunity to present their opinions? How are the meetings conducted? How are conflicts resolved? Does anyone dominate the meetings? How are decisions made?

4. Do you have an understanding about the budget for the board’s activities? Do you agree with how the resources are being used?

5. Do you think the board is accomplishing what it set out to do? What impact are the board’s activities having on the community?
6. Are there any other challenges that you experienced on the board?

7. What are your recommendations for the board as we move forward with the project?
Occasional Notes

The Ecology of Medical Care Revisited

Since its publication in the Journal in 1961, “The Ecology of Medical Care,” by White et al.,¹ has provided a framework for thinking about the organization of health care, medical education, and research (Fig. 1). This conceptualization, inspired in part by careful reporting on the part of British general practitioners,² suggested that in a population of 1000 adults, in an average month, 750 reported an illness, 250 consulted a physician, 9 were hospitalized, 5 were referred to another physician, and 1 was referred to a university medical center. These data have been used repeatedly by investigators, authors of textbooks, task forces, and government agencies.³⁻⁹ The 1961 report was based on multiple sources of information, mostly from the United States and Britain, dating from 1928. Some of the estimates were subsequently characterized as “intelligent guesses,” with the truth unknown.¹⁰

In 1961, the number of general practitioners in the United States was in steep decline, and the overall number of physicians and the number of subspecialists were growing rapidly. Medicare and Medicaid had yet to be created. Much of the current medical armamentarium, such as computed tomography, organ transplantation, endoscopy, effective antidepressant drugs, and coronary-artery bypass surgery, had not been developed. Nurse practitioners, physician assistants, and the specialty of family practice did not exist.

Much has changed in medicine and in the organization and financing of health care since 1961. Some of these changes — such as new medications and forms of technology, increased expenditures, managed care, and changes in the medical work force — might be expected to have altered the ecology of medical care.¹¹⁻¹⁸ There have also been substantial improvements in the collection and reporting of data on health care in the United States.¹⁹⁻²¹ We have updated the 1961 report by White et al. and have also extended the original study to incorporate data on children and additional sites and types of health care services. Like White, who revised the model in 1973,²² and Thacker and colleagues, who used a longitudinal approach in applying it to a rural setting,²³ we found some variation but overall stability of the relationships proposed 40 years ago.

Methods

Data

We used the 1996 Medical Expenditure Panel Survey because it contains the most recent, nationally representative data on most of the components of utilization included in the 1961 analysis. Reported data on households cover demographic characteristics, health conditions, health status, use of medical services, charges and payments for services, access to care, satisfaction with care, health insurance coverage, income, and employment.²⁴ Of the respondents to the 1995 National Health Interview Survey who were selected for inclusion in the subsequent Medical Expenditure Panel Survey, 83.1 percent participated in the first round of data collection in 1996. Data in the survey can be adjusted with the use of weights to make inferences about national trends.²⁵ Although the survey is a remarkably comprehensive source of information on health care utilization, it did not meet all our needs. Consequently, we collected additional data using a short survey administered by the Gallup Organization.²⁶

The Gallup survey was based on telephone interviews with adults in 1001 households. This nationally representative sample was selected through random-digit dialing, with three attempts made to contact a potential respondent before another was chosen. Data were collected for 1001 adults and 480 children who resided in the surveyed households. Not more than two children per household, the youngest and oldest, were included. Interviews were conducted between April 23 and May 7, 2000. The Gallup survey was the primary source of data for estimating the number of people who had considered seeking health care in the previous month and who had received care from a complementary or alternative medical care provider, excluding use of alternative treatment without a visit to a provider.

The Gallup Organization provided weighting factors (to permit inferences to be made for the U.S. population) and estimates of sampling errors, making possible the calculation of national estimates and providing the range within which estimates might vary. The largest 95 percent confidence interval in this study was the ±3 percent range for the estimate of the number of persons who had considered seeking health care in a one-month period. For estimates based on the Medical Expenditure Panel Survey, the largest 95 percent confidence interval was 211.6 to 222.4 for the number of persons per 1000 who had visited a physician’s office in a one-month period.

We lacked a single reliable source of data for estimating the number of persons who have symptoms in a one-month period. Thus, we used prospective health-diary studies conducted in the United States between 1964 and 1991.²⁶⁻²⁹ The use of health diaries has been shown to increase the likelihood that respondents will report most of their symptoms.²⁶⁻²⁸ Few such studies have used the one-month reporting period chosen for this study, and we know of none that have used a nationally representative sample. Our estimate is based predominantly on two studies²⁶,²⁷ that involved relatively large samples and a reporting period of three weeks²⁶ or four weeks²⁷ staggered throughout the calendar year to avoid seasonal confounding. These studies are complementary in other ways. One sampled children and young adults,²⁷ and the other focused on adults over the age of 65 years.²⁶ One sample was urban and racially mixed,²⁷ and the other was predominantly rural and white.²⁶ Definitions of terms and data sources are summarized in the Appendix.

Analytic Strategy

We estimated the number of persons per 1000 members of the civilian, noninstitutionalized U.S. population in 1996 who had experienced the health care events shown in Figure 2 during a one-month period. We used data from the Medical Expenditure Panel Survey to calculate the numbers of persons who had visited a physician’s office, an emergency department, or an outpatient clinic; had received home health care; or had been hospitalized. For each survey participant, we computed the number of months in which each type of event occurred, divided this number by 12, and multiplied this quotient by the survey weight. The product was summed for all records, multiplied by 1000, and divided by the number of persons in the U.S. population in 1996.

To estimate the number of persons who had visited a primary care physician, we first calculated the proportion of all visits to a physician’s office reported in the 1996 National Ambulatory Medical Care Survey that involved family physicians, general practitioners, general internists, and general pediatricians. We then
Figure 1. Monthly Prevalence Estimates of Illness in the Community and the Roles of Physicians, Hospitals, and University Medical Centers in the Provision of Medical Care. Data are for persons 16 years of age and older. Reprinted from the 1961 report by White et al.\textsuperscript{1}

Figure 2. Results of a Reanalysis of the Monthly Prevalence of Illness in the Community and the Roles of Various Sources of Health Care. Each box represents a subgroup of the largest box, which comprises 1000 persons. Data are for persons of all ages.
multiplied this proportion by the number of persons per 1000 who had visited a physician’s office. Similarly, we calculated the proportion of all hospital admissions that were accounted for by academic medical centers, using data from 1996 from the American Hospital Association. This proportion was multiplied by the number of persons per 1000 who had been hospitalized during a one-month period (calculated from the Medical Expenditure Panel Survey) in order to estimate the number of persons per 1000 per month who had been hospitalized at an academic medical center. These procedures for estimating the number of persons visiting a primary care physician and having an inpatient stay at an academic-medical-center hospital are based on the assumption that the number of persons is independent of the number of visits or inpatient stays.

The Gallup survey weights were summed for all persons who had considered seeking health care and who had received care from a complementary or alternative medical care provider. The resulting number was multiplied by 1000 and then divided by the U.S. population for the year 2000.

Roghamm and Haggerty found that 77 percent of young adults and children report one or more symptoms in a four-week period,27 and Stoller and Forster found that 82 percent of older adults report symptoms in a three-week period.28 Two other diary studies involving adults26,29 have shown that older persons report more symptoms than do younger persons. To estimate the number of persons with symptoms, we assumed that the results of these studies represent the range for the numbers of persons experiencing symptoms of illness or injury within an average month. We took the midpoint of the range as a point estimate.

RESULTS

Of 1000 men, women, and children in the United States, we estimated that on average each month, 800 experience symptoms, 327 consider seeking medical care, 217 visit a physician in the office (113 visit a primary care physician and 104 visit other specialists), 65 visit a professional provider of complementary or alternative medical care, 21 visit a hospital-based outpatient clinic, 14 receive professional health services at home, 13 receive care in an emergency department, 8 are hospitalized, and less than 1 (0.7) is admitted to an academic-medical-center hospital (Fig. 2). These results are not nested (i.e., they are not subgroups of one another); all are based on a denominator of 1000.

Table 1 illustrates how the relations in the ecology model can vary. It shows that the number of persons receiving care each month in different settings varies according to age, sex, and race. More adults than children, more women than men, and more whites than blacks receive care in physicians’ offices and hospital outpatient clinics. More adults than children and more women than men receive care in their homes. Similar numbers of whites and blacks receive care at home or in the hospital. Use of the emergency department does not vary according to age, sex, or race.

DISCUSSION

As White et al. reported in 1961, we found that each month a large portion of the population of the United States has health problems. Almost 25 percent visit a physician’s office, and approximately one third that number visit a complementary or alternative medical care provider. The number of persons who receive professional care at home is similar to the number who receive care in an emergency department. Less than 1 person in 1000 is admitted to an academic-medical-center hospital.

Remarkably, with children included in the analysis, the estimated proportions of persons reporting symptoms, visiting a physician, receiving care in a hospital, and receiving care in an academic medical center have changed little in 40 years. This lack of change may represent stability of these proportions, perhaps because the interactions between people and the health care system are driven by preferences and needs that persist despite changes in the organization of health care. It is also possible that various developments in the health care system have had offsetting effects. For example, an

### Table 1. Medical Ecology in Terms of Type of Care According to Age, Sex, and Race.*

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>OFFICE VISIT</th>
<th>OUTPATIENT CLINIC VISIT</th>
<th>HOME HEALTH CARE VISIT</th>
<th>EMERGENCY DEPARTMENT VISIT</th>
<th>HOSPITAL STAY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>no./1000 (95% CI)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Age†</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>&lt;18 Yr</td>
<td>167.3 (161.0–173.6)</td>
<td>8.2 (7.0–9.4)</td>
<td>2.2 (1.4–3.0)</td>
<td>12.8 (11.7–13.9)</td>
<td>3.5 (2.7–4.3)</td>
</tr>
<tr>
<td>≥18 Yr</td>
<td>2548.3 (229.0–240.0)</td>
<td>25.8 (24.0–27.6)</td>
<td>17.7 (15.6–19.8)</td>
<td>13.0 (12.2–13.8)</td>
<td>10.3 (9.6–11.0)</td>
</tr>
<tr>
<td>Sex‡</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>179.3 (173.4–185.2)</td>
<td>17.5 (16.0–19.0)</td>
<td>8.7 (7.0–10.4)</td>
<td>12.5 (11.6–13.4)</td>
<td>7.5 (6.7–8.3)</td>
</tr>
<tr>
<td>Female</td>
<td>252.6 (246.1–259.2)</td>
<td>24.6 (22.5–26.7)</td>
<td>18.1 (15.7–20.5)</td>
<td>13.3 (12.4–14.2)</td>
<td>9.5 (8.7–10.3)</td>
</tr>
<tr>
<td>Race§</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>150.7 (142.3–159.1)</td>
<td>15.5 (12.5–18.5)</td>
<td>14.9 (10.8–19.0)</td>
<td>13.0 (11.3–14.7)</td>
<td>7.9 (6.3–9.5)</td>
</tr>
<tr>
<td>White</td>
<td>280.9 (225.0–236.8)</td>
<td>22.7 (21.1–24.3)</td>
<td>13.6 (11.8–15.4)</td>
<td>13.1 (12.3–13.9)</td>
<td>8.7 (8.0–9.4)</td>
</tr>
</tbody>
</table>

*Data are for persons who made at least one visit or were hospitalized at least once in a one-month period. CI denotes confidence interval.
†Data are for males and females of all races.
‡Data are for all races and all ages.
§Data are for males and females of all ages.
increase in the proportion of older persons with chronic diseases may have resulted in more office visits and hospital stays, but cost containment by hospitals and the shifting of care to outpatient departments and patients’ homes may have moderated these effects.

The inclusion in the ecology model of children and additional settings provides a broader, still useful framework for thinking about the organization of health care, medical education, and research. For example, most measures of the quality of health care that are currently in use were developed for hospital settings, and much of the recent interest in medical errors has focused on the safety of patients in hospitals.31,32

The ecology model makes apparent the opportunities that would be missed by limiting quality and safety programs to hospitals. It highlights the need for comprehensive medical-information systems that span all sites of care. The model also shows the need for alternative types of research laboratories, such as practice-based research networks,33 which allow the study of patients where they receive their care.

There are important limitations of the ecology model and the methods we used for this analysis. The model may appear to be nested, leading to the misinterpretation that a small box is derived from an adjacent, larger box. Our estimates have not been adjusted for the effects of age, race, ethnic group, or other variables. The model does not establish causal pathways. We did not estimate the frequency of referral to specialists because of limited data and current ambiguities in how a referral is defined.

Unlike other results calculated from contemporary, nationally representative data sets, our estimate of the number of persons who have symptoms per month is based on the best health-diary data we could locate that could be organized into a monthly time frame. The usable studies spanned decades and had different sampling frames. Errors may also have arisen from the use of data on office visits and admissions to estimate the number of persons who visit a primary care physician’s office and the number hospitalized in an academic medical center, respectively. Although the public data used were averaged over the entire calendar year 1996, so that there was no need for seasonal adjustment, the data from the Gallup survey lacked seasonal adjustment.

Our findings are supported by similar estimates based on different sources. For example, data from the 1996 National Health Interview Survey indicated that there were 7.9 and 8.1 admissions per 1000 persons for 30-day and 31-day periods, respectively; these estimates are consistent with our estimate of 8 persons hospitalized per 1000, which is based on data from the Medical Expenditure Panel Survey. Also on the basis of data from the National Health Interview Survey, 6.9 persons per 1000 (the same for adults and children) used the emergency department during a two-week period. Our estimate of emergency-department use during a one-month period, based on data from the Medical Expenditure Panel Survey, was 13 per 1000 for both adults and children.

Of the respondents who reported acute conditions in the 1996 National Health Interview Survey, 68.8 percent sought care in physicians’ offices. Of the Gallup-survey participants who considered seeking medical care during a one-month period (327 per 1000), 66.4 percent actually visited a physician’s office.

In conclusion, there have been marked changes in the organization and financing of medical care since the 1961 study by White et al.1 Substantial progress in the collection and reporting of health-related data has made it possible to update and expand the study, with the use of data only from the United States. The new estimates are remarkably similar to the estimates made 40 years ago.

Larry A. Green, M.D.
George E. Fryer, Jr., Ph.D.
Robert Graham Center
Washington, DC 20036

Barbara P. Yawn, M.D.
Olmsted Medical Center
Rochester, MN 55904

David Lanier, M.D.
Agency for Healthcare Research and Quality
Rockville, MD 20852

Susan M. Dovey, M.P.H.
Robert Graham Center
Washington, DC 20036

Supported by the Robert Graham Center, the Olmsted Medical Center, and the Agency for Healthcare Research and Quality.

Address reprint requests to Dr. Green at the Robert Graham Center, Policy Studies in Family Practice and Primary Care, 2025 Massachusetts Ave., NW, Washington, DC 20036.

REFERENCES


APPENDIX. DEFINITIONS OF TERMS AND SOURCES OF DATA.

<table>
<thead>
<tr>
<th>TERM</th>
<th>DEFINITION</th>
<th>SOURCE OF DATA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Final estimate</td>
<td>The number of persons per 1000 who had each type of event</td>
<td>Medical Expenditure Panel Survey, Gallup survey, National Ambulatory Medical Care Survey, American Hospital Association data base</td>
</tr>
<tr>
<td>Person</td>
<td>A civilian, noninstitutionalized member of the U.S. population, regardless of age, sex, race, or ethnic group</td>
<td>U.S. Census Bureau</td>
</tr>
<tr>
<td>Month</td>
<td>Each of the months in calendar year 1996, or the 30 days immediately preceding interview conducted in April and May of 2000</td>
<td>Medical Expenditure Panel Survey, Gallup survey</td>
</tr>
<tr>
<td>Symptom</td>
<td>Any discomfort, illness, or injury</td>
<td>Medical Expenditure Panel Survey, Gallup survey</td>
</tr>
<tr>
<td>Considered seeking health care</td>
<td>For adults, an affirmative response to the question, “In the last 30 days, have you considered or thought about seeking medical care for any health problem, even though you may not have actually visited a health care professional?”</td>
<td>Journal articles, Gallup survey</td>
</tr>
<tr>
<td>Visit to a physician’s office</td>
<td>A visit to the office of any doctor of medicine or osteopathy, including the 3.5 percent of reported visits that were actually telephone calls</td>
<td>Medical Expenditure Panel Survey, Gallup survey</td>
</tr>
<tr>
<td>Visit to a primary care physician’s office</td>
<td>A visit to the office of a family physician, general practitioner, general internist, or general pediatrician</td>
<td>Medical Expenditure Panel Survey, National Ambulatory Medical Care Survey</td>
</tr>
<tr>
<td>Visit to a complementar or alternative medical care provider</td>
<td>For adults, an affirmative response to the question, “In the last 30 days, did you receive any alternative medical treatment, such as chiropractic care, acupuncture, massage therapy, or some other type of alternative medical care?”</td>
<td>Gallup survey</td>
</tr>
<tr>
<td>Emergency department visit</td>
<td>A visit to the emergency department</td>
<td>Medical Expenditure Panel Survey</td>
</tr>
<tr>
<td>Outpatient clinic visit</td>
<td>A visit to a hospital outpatient department</td>
<td>Medical Expenditure Panel Survey</td>
</tr>
<tr>
<td>Home health care</td>
<td>Health care services provided at a person’s home by a health care professional</td>
<td>Medical Expenditure Panel Survey</td>
</tr>
<tr>
<td>Inpatient hospital stay</td>
<td>A stay of any duration after admission to a facility licensed or registered as a hospital by a state to provide diagnostic and therapeutic services for a variety of medical conditions, both surgical and nonsurgical</td>
<td>Medical Expenditure Panel Survey</td>
</tr>
<tr>
<td>Inpatient stay at an academic-medical-center hospital</td>
<td>A stay of any duration after admission to a hospital owned by or affiliated with a university that has an allopathic or osteopathic medical school and a school or training program for at least one other profession, as defined by the Association of American Medical Colleges</td>
<td>Medical Expenditure Panel Survey, American Hospital Association data base</td>
</tr>
</tbody>
</table>

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SPECIAL COMMUNICATION

Participatory Action Research Designs in Applied Disability and Rehabilitation Science: Protecting Against Threats to Social Validity

Tom Seekins, PhD, and Glen W. White, PhD

From the Department of Psychology and the Research and Training Center on Disability in Rural Communities, The University of Montana, Missoula, MT; and Department of Applied Behavioral Science and the Research and Training Center on Independent Living, University of Kansas, KS.

Abstract

Researchers and disability advocates have been debating consumer involvement in disability and rehabilitation science since at least 1972. Despite the length of this debate, much confusion remains. Consumer involvement may represent a spirit of democracy or even empowerment, but as a tool of science, it is necessary to understand how to judge its application. To realize consumer involvement as a design element in science, researchers need a framework for understanding how it can contribute to the scientific process. The thesis of this article is that a primary scientific function of consumer involvement is to reduce threats to the social validity of research, the extent to which those expected to use or benefit from research products judge them as useful and actually use them. Social validity has traditionally not been treated with the same rigor as concerns for internal and external validity. This article presents a framework that describes 7 threats to social validity and explains how 15 forms of consumer involvement protect against those threats. We also suggest procedures for reporting and reviewing consumer involvement in proposals and manuscripts. This framework offers tools familiar to all scientists for identifying threats to the quality of research, and for judging the effectiveness of strategies for protecting against those threats. It may also enhance the standing of consumer involvement strategies as tools for protecting research quality by organizing them in a way that allows for systematic criticism of their effectiveness and subsequent improvement.

The purpose of applied research in disability and rehabilitation is to develop empirically derived solutions to problems experienced by people with disabilities.1-3 Researchers apply a wide range of scientific methods to develop solutions that may include mechanical and electrical technologies, medical and pharmacologic treatments, and behavioral and social technologies (including laws, policies, programs, and treatment techniques). To be considered truly successful, findings from the research must actually be used.

Over the past 30 years, researchers and advocates have debated the role of people with disabilities in the conduct of disability and rehabilitation science.4-11 This debate has tended to focus on the concepts of participatory action research (PAR).12-13 The broader fields of medicine and health focus on concepts of patient-centered outcomes research and community-based participatory research.14 While these discussions have been useful, researchers need a structured framework to realize consumer involvement as a design element in science.15

The thesis of this article is that a primary scientific function of consumer involvement is to reduce threats to the social validity of research, the extent to which potential adopters of research products judge them as useful and actually use them. This article briefly reviews the history of consumer involvement in disability and rehabilitation research, introduces and defines the concept of social validity, compares social validity with internal and external validity, and describes threats to social validity. Importantly, it presents a framework for judging the extent to which different forms of consumer involvement protect against threats to the social validity of research. It also reviews several forms of consumer involvement as a means of explicating the scientific function of consumer involvement.

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History of Consumer Involvement

The idea of involving end users in research is neither new nor unique to disability and rehabilitation science. The agricultural research and extension service has long involved a partnership among farmers, ranchers, agricultural workers, field agents, and researchers. Rogers and Shoemaker\(^6\) report on the lessons learned by agricultural researchers in the 1920s when they did not involve farmers in the development and dissemination of hybrid seed corn. Early on, it was tried in the Southwestern United States. Despite the increased yield in corn, farmers quickly rejected it. It seems that the corn meal produced from processing the corn was not suitable for making tortillas. Research and development had indeed produced a more efficient variety of corn, but it produced flour that had limited value to intended consumers. From this and similar experiences, agricultural researchers began to consider consumer concerns in research, development, and dissemination.

A recognized parallel in disability and rehabilitation science is the abandonment of assistive technology by people with disabilities.\(^17-21\) There are numerous reports of elegant assistive devices that had been demonstrated as effective and reliable by engineers, but which were discarded because they did not meet consumers' needs. This has led rehabilitation engineers to call for the involvement of consumers in the development of assistive technologies.\(^22\) The involvement of consumers in disability and rehabilitation research began at least by the early 1970s.\(^33\) For example, Remmers\(^24\) presented a paper at the 1972 meeting of the National Association of Rehabilitation Research and Training Centers in which he stated that people with disabilities want to participate in any decision-making process that affects their lives, and suggested that consumers could become a positive force in rehabilitation research.

In the late 1970s, the emergence of the independent living movement, with its roots in civil rights and consumerism, asserted that people with disabilities should control all aspects of their lives, from medical care to employment choices.\(^25,26\) By extension, this included controlling research that used resources targeted at issues of importance to them.

The literature on consumer involvement in disability and rehabilitation science has grown steadily since then.\(^27\) A particularly important contribution to the debate was the identification of PAR as a means of conveying a spirit of such involvement and possible methods for achieving it.\(^28\) Still, confusion remains about the nature and purpose of PAR; some argue that it is a philosophy, others that it is a method, and still others that it is a grab-bag of procedures, and, of course, some argue for its use and others against it. Given the importance of consumer involvement to the funding and practice of disability and rehabilitation science, efforts to clarify its purpose and characteristics are warranted.\(^29\)

Social validity

Wolf\(^10\) defined social validity as the extent to which potential adopters of research results and products judge them as useful and actually use them. Social validity involves judgments of the importance of research goals, the acceptability of procedures, and the significance of impact by those expected to use its results or to benefit from them. Wolf argued that when behavioral researchers attend to the social validity of their research, the probability that their research would be supported by the public or be used to solve problems increases.

Threats to social validity

A primary concern in the scientific study of behavioral and social phenomenon, as well as medicine and engineering, has been the internal and external validity of the research results.\(^33\) To incorporate consumer involvement as a design element in science, researchers need tools for assessing threats to social validity and assessing the effectiveness of strategies for protecting against those threats. Such tools are needed by those who review research proposals in the design stage (e.g., human subject protection committees), by those who formally review proposals to make funding recommendations, and by journal editors and peer reviewers when reviewing research reports for publication. They are also useful for policy-makers, program managers, and professional service providers who are considering the implementation of a finding, and for consumers judging whether to adopt a new approach.

Framework for assessing protection against threats to social validity

Campbell and Stanley’s classic description\(^32\) of and rules for judging internal and external validity of experimental and quasi-experimental research designs provides a framework for organizing and evaluating social validity. Table 1 lists 15 commonly used consumer involvement procedures and assesses the degree to which they can help protect research against 7 distinct threats to social validity. First, several threats to social validity are explained with selected examples of how consumer involvement helps protect against the threat. Next, several forms of consumer involvement are described and their method of protection explained.

Threats to the social validity of applied research

As with threats posed to internal and external validity of research designs, there are numerous threats that challenge the social validity of applied research. These include threats posed by: (1) selecting irrelevant topics for research, (2) a lack of clarity about important consumer goals, (3) misunderstanding the acceptability of research methods, (4) misunderstanding the range of intervention acceptability, (5) ignoring criteria that potential adopters would use to judge the significance of outcomes and impacts, (6) misinterpreting results, and (7) lacking generality of findings in real-life application. Table 1 lists these threats and summarizes the degree to which different forms of consumer involvement may help protect against those threats. The following sections describe the column headings for table 1.

Threats posed by selecting irrelevant issues

The first threat to social validity involves selecting an issue or problem for research that lacks importance or relevance to a constituency. Many researchers are interested primarily in theoretical, methodologic, or measurement issues. For research with
Table 1: Levels of protection against threats to social validity offered by various forms of consumer involvement

<table>
<thead>
<tr>
<th>Preinvolvement</th>
<th>Lack of Clarity of Issue or Problem Selected</th>
<th>Misunderstanding About Range of Acceptable Criteria for Interventions or Approaches</th>
<th>Ignorance of Judging Significance of Outcomes and Impacts of Research Methods</th>
<th>Generality of Findings in Real-Life Applications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theory-derived data mining or methods research</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>2</td>
</tr>
<tr>
<td>People with disabilities as data points</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>2</td>
</tr>
<tr>
<td>Advisory committees</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
</tr>
<tr>
<td>True PAR</td>
<td>High</td>
<td>High</td>
<td>High</td>
<td>Low</td>
</tr>
<tr>
<td>Emancipatory research</td>
<td>High</td>
<td>High</td>
<td>High</td>
<td>Medium</td>
</tr>
<tr>
<td>Organizational development</td>
<td>High</td>
<td>High</td>
<td>High</td>
<td>Medium</td>
</tr>
<tr>
<td>Community development</td>
<td>High</td>
<td>High</td>
<td>High</td>
<td>Medium</td>
</tr>
<tr>
<td>Action research</td>
<td>High</td>
<td>High</td>
<td>High</td>
<td>Medium</td>
</tr>
<tr>
<td>Quasi-PAR</td>
<td>High</td>
<td>High</td>
<td>High</td>
<td>Medium</td>
</tr>
<tr>
<td>Focus groups</td>
<td>Medium</td>
<td>Medium</td>
<td>Medium</td>
<td>Low</td>
</tr>
<tr>
<td>Researcher translation</td>
<td>Medium</td>
<td>Medium</td>
<td>Medium</td>
<td>Low</td>
</tr>
<tr>
<td>Agenda setting surveys</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
</tr>
<tr>
<td>Best practices research</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
</tr>
<tr>
<td>Research teams</td>
<td>Medium</td>
<td>Medium</td>
<td>Medium</td>
<td>Low</td>
</tr>
<tr>
<td>Researcher with disability</td>
<td>Medium</td>
<td>Medium</td>
<td>Medium</td>
<td>Low</td>
</tr>
<tr>
<td>Consumer consultants</td>
<td>Medium</td>
<td>Medium</td>
<td>Medium</td>
<td>Low</td>
</tr>
<tr>
<td>Product champions</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Partners in advocacy</td>
<td>High</td>
<td>High</td>
<td>High</td>
<td>High</td>
</tr>
</tbody>
</table>

Abbreviation: NA, not applicable.

such a focus, the actual content of study may be arbitrary except to the extent that it provides a heuristic mechanism for developing or testing methods and measures. It may be as useful to such researchers who are studying time-sampling procedures to study the sitting behavior of an office secretary as to examine the study behavior of a child with a learning disability. In fact, for some purposes, the selection of a secretary’s sitting behavior may be more convenient and provide a better opportunity to study the issue (i.e., observation procedures) of interest to them.

Several forms of consumer involvement can protect against the threat posed by selecting irrelevant issues or problems to address. For example, Seelink et al.33 first conducted an extensive literature review to identify a range of secondary conditions that might be experienced by adults with disabilities related to mobility impairments. This review led to the identification of 26 conditions. Next, they conducted a series of focus groups and an open-ended survey of adults with disabilities. This led to the identification of 14 additional conditions they had not found in the literature. Later research led to the finding that 10 of the top 15 conditions were those identified by consumers but not found in the literature review.34 Had consumers not been involved in the early stage of this research, it is unlikely that the consumer-relevant issues would have been selected for research and development.

Threats posed by lack of clarity of important goals

Researchers can select important issues for study but miss the mark by focusing on socially unimportant goals. Clark et al.35 present a series of studies that outline procedures for increasing the likelihood that important issues and goals will be addressed. In the first study, they reported canvassing parents to determine child-rearing problems in need of solutions. These parents indicated that shopping with young children often posed significant problems. Next, they surveyed parents about desired goals in shopping, and the acceptability of using rewards and punishers. Third, they worked with 2 families to develop and test procedures (eg, instructions and contingencies) for achieving satisfactory shopping trips. This led to 3 separate procedures, which were experimentally evaluated, and the rejection of a fourth approach, because it appeared to be incompatible with parental practices. Extended evaluations under experimental controls replicated the effectiveness and consumer satisfaction with the intervention. The advice package was later commercially disseminated.36

Threats posed by choosing unacceptable methods

A third threat to social validity involves the use of research methods that would be deemed unacceptable by those who participate in the research or to those who might adopt the resulting products. Santelli et al.37 describe a partnership between researchers and consumers—in this case, parents of children with disabilities—in which the participants negotiated a clear delineation of tasks. The researchers agreed to give direction on research design and methods, take primary responsibility for developing study instruments, implement the intervention, run statistical analyses, interpret and summarize the data, and publish the results.
in peer-reviewed journals. The consumers agreed to provide information about parent-to-parent organization, suggest modifications to the research design and research methods and therefore the study would be more comfortable for parents, recruit participants, and write about the findings in a way that would be clearly understood by other parents.

Threats posed by misunderstanding the range of acceptable interventions

Innovation is a hallmark of applied research. Designing an innovative, socially valid intervention is tricky business, however. Researchers must consider not only the potential effectiveness of procedures and the acceptability of research methods but must also consider whether the innovation itself will be acceptable to potential adopters. Research in community development and appropriate technology suggest a number of dimensions along which consumers or participants in research might inform the choices that affect the characteristics of an innovation. These include dimensions such as simplicity, cost, contextual compatibility, and flexibility. In general, consumers or potential adopters can provide information about the type and form of an intervention that may be most attractive and most feasible.

Consumers can be involved in the development and selection of strategies and intervention approaches in several beneficial ways. For example, Klett et al worked with a group of consumers to develop a research primer for better understanding disability research. However, during the initial meeting with about 20 consumers recruited from a center for independent living (CIL), it became apparent that these individuals were not very interested in understanding how the research process works. Rather, they wanted to know more about how disability research could actually help improve their lives. As a result of these discussions the researchers changed their project objectives to accommodate the consumers’ interests and request. The resulting product was a consumer-directed booklet that shows consumers a step-by-step approach on how to conduct their own research to make positive community change for people with disabilities.

Ignorance of criteria for judging significance of impact

A fifth threat to the social validity of research is failure to understand the criteria that potential adopters and beneficiaries use to judge the significance of the impact expected from the research. Researchers can focus on important problems and do so in a way that is acceptable, but fail to understand the criteria that would convince potential adopters to believe that the use of the research results would be meaningful to them. Many researchers who use statistical analyses to detect differences fail to consider the clinical or practical significance of results. While statistical differences can be particularly important in testing theory, because they can help detect small differences, small differences are usually of less interest to practitioners who are looking for information or techniques that make a meaningful difference. Potential consumers can help focus attention on the criteria for practical significance.

Threats posed by misinterpreting results

A sixth threat to the social validity involves misinterpreting results. This can occur when researchers either draw conclusions that are biased or fail to notice implications. Involving people with disabilities in the discussion of research findings can emphasize such practical implications. Similarly, consumers might raise issues for further systematic investigation and development that researchers working alone might miss. Consumers might also help identify subtle limitations in study methods and procedures that researchers might miss as well.

Generality of findings in real-life application

The contributions by consumers or potential users of research are considered to be data in a research project or study. As such, they are subject to threats similar to those posed to the collection of other data. One of these is the threat posed by selection bias. Any consumer or potential user has his or her individual perspective on a range of issues. These may not reflect a representative sample of a researcher’s intended constituency. A classic example involves the conflict between the medical and disability-rights models in disability and rehabilitation research. For example, much debate has been made about whether resources should be allocated to finding a cure for various ailments that lead to disability or finding better ways to promote community integration and participation of those experiencing disabilities (i.e., the independent living model).

Many more subtle biases exist, including biases that would lead informants to want to please the researchers, thus undermining the intent of consumer involvement.

A special case of this threat involves the generality of findings and recommendations from one cultural group to another. Clay analyzed cultural variables in considering the application of independent living interventions and procedures to American Indians. She identified aspects of IF. philosophy that were both compatible and incompatible with American Indian culture. Involving representatives from culturally diverse groups can help protect against assumptions that an approach that is effective in one context will work in every cultural context.

Strategies of consumer involvement and how these protect against threats to social validity

As experimental designs protect against threats to internal and external validity, consumer involvement in research can also protect against threats to social validity. Following Campbell, White, and colleagues, there are 3 levels of consumer involvement: pre-PAR designs, true PAR designs, and quasi-PAR designs. The far left column of table 1 displays these 3 levels of consumer involvement and the forms of consumer involvement within each level. These are each briefly discussed subsequently.

Preinvolvement

Consumer involvement is a process not an outcome. Research with no or minimal amounts of direct consumer involvement may still have social validity. This may be referred to as preinvolvement. Three forms of preinvolvement are subsequently described.

Consumers as subjects of research

White et al describes the role of consumers who simply provide data and refers to this as nonparticipatory subject-based research. In this case, the authors describe no implementing mechanisms for PAR, because consumers or potential users have no other role than providing data (eg, answering a questionnaire). The approach, as
Social validity described here, provides no protection against threats to social validity.

Theory-derived data mining or methods research
This form of research involves analysis of already collected data, such as U.S. census data. A critical aspect of this type of research is that the questions addressed are derived from a theory or conceptual system. If, for example, questions of interest were derived from requests made by policy-makers, program managers, or advocates, then that would reflect consumer involvement in selecting the issue. Theory-derived data mining appears to fall into the category of nonparticipatory research described by White.13

Advisory committees
White13 describes advisory committees as an implementing mechanism for user-sensitive PAR research. By this, the author means that involvement in research is typically limited to the initial stages of research and that the extent of involvement even at this stage is limited in degree. Presumably, consumers might help select issues for study, suggest potential audiences and users, and offer suggestions about strategies. The researchers are free to accept, modify, or even reject this advice. Consumers have control only to the extent that they can refuse to participate, or are willing to comment on the research and the responsiveness of the researchers to others in the networks they represent.

Many research centers describe consumer involvement strategies that involve consumer participation on advisory boards. These advisory boards may serve to guide the research of a large program or focus on a single project. The composition and processes of such advisory boards vary dramatically and may address programmatic, political, research, dissemination, as well as consumer issues. Further, the preparation and experience of members may vary substantially. Their awareness of research procedures and design, and their frequency of meeting may also vary. Typical advisory committees help set direction or consent to research activities, and may periodically review progress. Depending on the openness of researchers, this form of consumer involvement can provide low to moderate levels of protection against threats to social validity. Researchers might be expected to report the issues (ie, threats to social validity) and contributions addressed by an advisory committee. Major recommendations rejected by researchers should be reported, along with a rationale for doing so.

True PAR

True experimental designs use randomized assignment to control for threats to internal and external validity. True PAR involves total control of the research by those affected. As with random assignment, this protects against threats to social validity, but not necessarily to the generality of findings.

Emancipatory research

White et al15 describes emancipatory research as full participation and control over the research process. Emancipatory research is based on the understanding that emerged from efforts such as those of the Mondragon in Spain.49 That community took charge of its development by learning and employing empirically grounded scientific methods to local economic development. The intent of such research is to focus almost exclusively on the issues of importance to the members of the community or even smaller subgroups (eg, a business). It is emancipatory in the sense that the participants control the selection of issues for study, the methods used, and the evaluation of success, set free from influence by others who are not members of that community.

In this vein, the National Institute on Disability and Rehabilitation Research funded the Community Research for Assistive Technology project (grant no. H133A010702) to explore the potential of true PAR. This project examined disparities in assistive technology use in employment.20,51 The work was conducted by the California Foundation for Independent Living Centers.

Organizational quality improvement

Research and development can be done within an organizational context as well as a community. The difference between continuous quality improvement and emancipatory research involves the structure, authority, and even ownership of resources. Owners, managers, and supervisors typically have a greater say in setting an organization’s applied research agenda. Still, the values, goals, resources, and customs of the organization are very likely to be reflected in the applied research and development activities that are targeted at its own improvement. Here, it is important to distinguish between organizational development and research that is focused on developing or improving products and services that it offers to its consumers. Threats to the social validity of the latter form of product-oriented research are not protected by organizational developmental procedures. Rather, specified consumers must be involved to do so.

Community development action research

Community development action research is similar to emancipatory research in that its focus is on locating and democratic, and it is typically directed by a group of community leaders who engage an external consultant to orchestrate a research and development process. The range of issues and processes are generally outlined by a steering committee. Community members are typically engaged as stakeholders to help define specific issues, generate debate, select alternatives, implement alternatives, and judge their success. The larger and more diverse the community, the more consumer involvement must be achieved through representation rather than direct participation. Still, many design features can be considered, such as the extent to which a new approach (ie, intervention, policy, or reorganization of relations) fits with local customs and resources.

Drum et al52-54 designed a community development approach to address local access barriers. This methodology, called the Community Engagement Initiative (CEI), builds on Hahn’s theory on the institutional creation of disability and more traditional community development.55 The CEI process engages disability advocates in promoting community dialogue to resolve accessibility problems. The main steps in the CEI method include: (1) a facilitated town hall meeting involving persons with disabilities and their families in which they identify barriers to participating in their community, (2) a facilitated meeting between representatives from the community’s leadership and town hall participants to review community assets and barriers, and (3) a barrier mobilization process. The CEI methodology has achieved promising results in resolving a range of access barriers.

Quasi-PAR

As with experimental designs in applied field settings, most consumer involvement designs combine several procedures in
order to address specific concerns at different stages of research. Ten procedures are subsequently outlined. Others are possible.

**Focus groups**

The technical use of focus groups has grown in the past several years. In disability and rehabilitation research, focus groups typically refer to one or a few small groups of individuals whom the researchers select for reasons of convenience, representation of a constituency, or potential use of results from a line of inquiry. Focus groups are seen as temporary project advisory groups to help address specific or narrow questions. For example, Seekins et al. reported using focus groups of individuals with disabilities related to physical and sensory impairments to help identify and define secondary conditions experienced by adults with such conditions. As mentioned, these focus groups helped identify 14 conditions not identified in the literature review. Further research with larger numbers of participants using survey methods built evidence of the generality of these consumer identified issues. As such, focus groups provide modest protection against threats posed to the issues they address. Confirmation through multiple groups or surveys enhances these protections.

**Researcher translation from network participation**

Popular publications by people with disabilities about issues of importance to them offer insight into issues of importance, acceptability of methods, and criteria that people with disabilities might use to assess the significance of impact of a program. Reviews of this literature are equivalent to reviews of technical literature. Similarly, researchers can participate in conferences that emphasize perspectives, goals, and standards that are held by people with disabilities (eg, national or state conferences of such organizations, such as the Association of Programs for Rural Independent Living, National Council on Independent Living, and Society for Disability Studies, meetings of state traumatic brain injury associations, state and national meetings of the National Alliance for the Mentally Ill, and other similar groups).

Participation in consumer-run organizations can also provide timely and critical information. With experience, researchers can learn to translate both direct and subtle calls for different forms of research on various topics of importance. As with focus groups, these forms of consumer involvement provide low to moderate protection against threats to social validity to the topics addressed. Focus groups or surveys that confirm such interpretations enhance protection.

**Agenda setting surveys**

Perhaps one of the most widely used procedures for consumer involvement in disability and rehabilitation research is the concerns report method. The concerns report method has been demonstrated to be a particularly useful method of building a broad, consumer-oriented research agenda. It has been used to set research agendas reflecting interests of people with disabilities living in rural communities, vocational rehabilitation counselors, CILs, individuals with mental retardation, individuals with psychiatric disabilities, and Peruvians with disabilities.

The concerns report method combines several different procedures of consumer involvement. Researchers use literature reviews and focus groups to generate a concerns menu, often composed of several hundred issues. Next, additional consumer representatives use these menus to select and develop items for a concerns survey. Surveys are then distributed among a large, defined constituency represented by the participants in the focus groups. Resulting data are summarized as potential strengths and problems, and subsequent focus groups discuss these results to explore the nature of the most important issues. Such structured discussions often recommend studies that will build on or protect strengths and solve problems. This method provides exceptional protection against threats to social validity posed by irrelevance of issues selected and lack of clarity about important consumer goals. It also provides reasonable protection against threats posed by misunderstanding of the range of acceptable interventions, and ignorance of criteria for success. Because the process does not typically provide for discussion of research methods, it does not provide direct information about the acceptability of research methods. Finally, if the concerns survey data are collected from a representative sample, they also provide some protection against threats posed to the generality of findings and products.

**Best practices research**

From a social perspective, the purpose of a great deal of applied research is to identify strategies for improving the quality of life for people experiencing similar conditions (ie, to identify replicable solutions to common problems). One approach to this task is to conduct best practices studies. This means observing what people and organizations are currently doing to address a common issue and comparing the outcomes of those approaches.

As these programs continue to be used, it may be presumed that they address important problems in an acceptable way, and offer some degree of effectiveness and user satisfaction. Further, there is a presumption that they are compatible with local culture and resources. Some best practices research projects focus primarily on these latter dimensions. As such, users have chosen to implement and maintain these practices. From a behavioral perspective, the choice to adopt an innovation is seen as a function of antecedent and consequent events—the contingencies of reinforcement act to sustain the practice. This constitutes a type of PAR or the results of it, regardless of the origin of the idea.

An important aspect of best practices research is to match the characteristics of target settings with needs to those with successful practices. Potential users in a target setting should at least have acknowledged the problem they face, if they have not initiated the request for information about alternative practices. Researchers must also be able to show similarities and differences between settings that might function to facilitate or impede use. For example, Clay compared characteristics of the IL philosophy and service model as it fits into the general social context and, more specifically, into American Indian tribal context. The author identified features of compatibility and incompatibility that might influence tribal adoption of IL programs. One point of incompatibility, for example, involved the role of advocacy. Advocacy (both for individuals and people with disabilities in general) is a cornerstone of the IL model. Conversely, within many tribal cultures, individual issues are expected to be subordinate to issues of tribal sovereignty: what is best for the tribe as a whole. Researchers and program developers who take such issues into account protect their work from threats posed by a lack of understanding of the acceptability of research methods and misunderstandings about the range of acceptable interventions.

**Research teams**

One of the most intensive forms of consumer involvement occurs when researchers and representatives of potential users collaborate on a research project. This process involves a dynamic and ongoing interplay between research collaborators, or what White
et al. identify as consumer empowered teams. The consumer collaborators function as members of the research team during the course of the project and may be paid as members of the project. This form of consumer involvement may be more effective in the design and testing of an innovative program or treatment technique. For example, Balcazar et al. reported a project in which members of a local consumer advocacy group worked hand in hand with researchers on the development and evaluation of a consumer advocacy system. In such instances, the role consumers play often fades away and they become collaborating members of the research team. It provides good protection against threats posed by misunderstanding of the range of acceptable intervention approaches and ignorance about criteria for judging success.

People with disabilities as researchers

There are many researchers in the field of applied disability and rehabilitation science who experience disability themselves. The participation of these research leaders in the design, conduct, and use of research may be seen as a form of PAR. In this case, one or more individuals with personal experience with disability and research experience has significant control over the research process and the allocation of resources in that process: an approximation of the White et al. definition of true-PAR. These researchers with disabilities may pursue issues they have seen as important in their personal experience, as well as ones that relate to their professional interest. For example, one of the authors had problems in dealing with his insurance company paying for a wheelchair and spent numerous hours in trying to get the equipment paid for, as specified in the insurance plan. As a result of this experience, White et al. created a guide for others with disabilities on how to successfully advocate for their rights through writing action letters that could articulate their disability concerns and serve as a paper trail to monitor response or nonresponse of the targeted individual or organization. This guide, later renamed the action letter portfolio was created, evaluated, and the results later published for others to replicate. This form of consumer involvement provides good protection against all threats to social validity except those that involve the generality of findings. Specifically, researchers with disabilities represent a small and potentially select sample of the population. While their extensive personal experience with disability, and their expertise as researchers, provide them with insights into issues of importance and the subtleties of selecting important goals, they may be less familiar with aspects of the different contexts in which results are to be applied. Despite this, such researchers often use additional forms of consumer involvement to protect against biases and use their own experience to augment that information, and thus, further enhancing the social validity of their work.

Consumer consultants

Some research programs engage technical experts to assist in tasks such as experimental design, measurement, or statistical analysis. Similarly, some experts can serve as consultants on both consumer involvement strategies and social validity. Experts may consult on both the process and the content of research. While expertise may inform researchers about both, experts may have their own biases. Multiple consultants enhance protection but may begin to approximate focus groups comprised of experts. The benefits of expert consumer consultations include efficiency, experience in the content area and research process, familiarity with the subtleties and interrelations among a broad range of issues, deeper understanding of the interaction of research and content, and awareness of linkages to other areas of research and other researchers working on related topics.

Product champions and disseminators

After research and development of a particular innovation, adopters may recognize the particular value of the research product. If convinced of the research effectiveness, these constituents may then work to help disseminate it by providing testimonials or more intense training and technical assistance in its use. While this approach does not involve consumers in the design and conduct of the research, those who choose to support the research outcomes are applying similar judgments to the evaluation of the results. As such, they are also likely to display a favorable opinion of the social validity of the research product. Of course, these product champions may face actual or apparent conflicts of interest, if they are paid for this role.

Partners in advocacy

It may be more proper to say that researchers become partners with consumers in advocacy, because the consumer representatives are more often the leaders in such efforts: they choose the issues, develop the strategies, and may call on researchers as members of a strategic effort. Still, consumer-initiated advocacy efforts steer the issue agenda and articulate goals. Research that addresses issues and goals in this manner may be said to enjoy some protection from threats to its social validity posed by those concerns. For example, the National Council on Independent Living initiated an advocacy effort to increase funding for CILs, the Drive for 75. Their goal was to increase funding for CILs by $75 million. Innes et al. conducted an independent study to examine the distribution of CILs around the nation and estimated that it would take approximately $72 million to achieve minimal but universal access to their services in all counties of the United States. These research data, showing independent confirmation of the National Council on Independent Living’s estimate, were used as one of the advocacy points in the Drive for 75. It is important to note, however, that research conducted to address an advocacy issue may not always support the position of advocates.

Discussion

This paper describes a method to organize and understand consumer involvement in research within a scientific framework. Specifically, we present the case that involving those who are expected to use and benefit from the products of research is a design element that protects research findings from threats to its social validity. This framework offers tools familiar to all scientists for identifying and managing threats to the quality of research, and for judging the effectiveness of the strategies for protecting against those threats. It also organizes the various procedures in a way that allows for systematic criticism of their effectiveness and subsequent improvement. Finally, it provides tools for improving the design of research from the beginning.

Peer review of research proposals and reports of research findings are a critical step in the advancement of science. Yet, there are few guidelines for reporting consumer involvement procedures in proposals or publications. For example, style guides such as the American Psychological Association’s Publications Manual offer no advice on reporting consumer involvement nor do such standards as the Consolidated Standards of Reporting Trials checklist.

www.archives-pmr.org
Just as funding agencies and journal editors are concerned about the methods used to protect against threats to internal and external validity, they might also develop expectations that researchers address how they plan to protect against threats to social validity in their research proposals and manuscripts. Proposal reviewers should consider how the researchers selected the problem to address, the goals to achieve, the methods used, and the criteria for judging success. Researchers may build the case for the social validity of their work in several ways. As with any other aspect of research, the reviewer must judge the extent to which it meets standards. Judging the effectiveness of the procedures to maximize social validity is no exception. The framework proposed here offers a tool that can be consistently applied by reviewers with diverse backgrounds, such as those often found on review panels.

Stylistically, aspects of consumer involvement may be reported in different ways. First, for example, if consumer support for a line of research comes from established consumer literature, or interpolation of information gathered through conferences or other meetings, it might best be cited in the introduction of a manuscript. Similarly, data that support the importance of the issues, such as that collected from consumer surveys, should be presented in the introduction. Otherwise, the consumer-involvement procedures may be best incorporated into the methods section of a manuscript. For example, the characteristics of participants in a focus group might be reported in the section traditionally labeled subjects. The actual operation of the focus group might be described in the procedures section. Third, limitations to social validity of the research should be articulated in the discussion section, just as limitations to the reliability and validity of the data would be discussed there. Finally, if no process was used to protect against threats to social validity of the research, an author might be expected to acknowledge this limitation and provide a clear rationale for its absence in the discussion section.

Conclusions

This article presents a framework for judging the effectiveness of strategies of consumer involvement in protecting applied research studies against threats to its social validity. It is not an exhaustive list or a cookbook. Rather, it offers a tool to those who are designing or reviewing research. Reviewers of research must rely on their experience and insights to make judgments of the merit of particular research methods and results. This applies to judgments about the internal, external, and social validity of applied research.

Consumer involvement may represent a spirit of democracy or even empowerment, but as a tool of science, it is necessary to understand how to judge its application. To advance this tool, however, it is important for researchers to report their efforts to protect against threats to social validity and for their peers to critique their methods.

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Q7

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Corresponding author
Tom Seikins, PhD, 52 Corbin Hall, University of Montana, Missoula, MT 59812. E-mail address: ruraldoc@ruralinstitute.umt.edu.
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Using concept mapping in the knowledge-to-action process to compare stakeholder opinions on barriers to use of cancer screening among South Asians

Rebecca Lobb1,2*, Andrew D Pinto1,3 and Aisha Lofters1,3

Abstract

Background: Using the knowledge-to-action (KTA) process, this study examined barriers to use of evidence-based interventions to improve early detection of cancer among South Asians from the perspective of multiple stakeholders.

Methods: In 2011, we used concept mapping with South Asian residents, and representatives from health service and community service organizations in the region of Peel Ontario. As part of concept mapping procedures, brainstorming sessions were conducted with stakeholders (n = 53) to identify barriers to cancer screening among South Asians. Participants (n = 46) sorted barriers into groups, and rated barriers from lowest (1) to highest (6) in terms of importance for use of mammograms, Pap tests and fecal occult blood tests, and how feasible it would be to address them. Multi-dimensional scaling, cluster analysis, and descriptive statistics were used to analyze the data.

Results: A total of 45 unique barriers to use of mammograms, Pap tests, and fecal occult blood tests among South Asians were classified into seven clusters using concept mapping procedures: patient’s beliefs, fears, lack of social support; health system; limited knowledge among residents; limited knowledge among physicians; health education programs; ethno-cultural discordance with the health system; and cost. Overall, the top three ranked clusters of barriers were ‘limited knowledge among residents,’ ‘ethno-cultural discordance,’ and ‘health education programs’ across surveys. Only residents ranked ‘cost’ second in importance for fecal occult blood testing, and stakeholders from health service organizations ranked ‘limited knowledge among physicians’ third for the feasibility survey. Stakeholders from health services organizations ranked ‘limited knowledge among physicians’ fourth for all other surveys, but this cluster consistently ranked lowest among residents.

Conclusion: The limited reach of cancer control programs to racial and ethnic minority groups is a critical implementation issue that requires attention. Opinions of community service and health service organizations on why this deficit in implementation occurs are fundamental to understanding the solutions because these are the settings in which evidence-based interventions are implemented. Using concept mapping within a KTA process can facilitate the engagement of multiple stakeholders in the utilization of study results and in identifying next steps for action.

* Correspondence: lobbr@wustl.edu

1 Centre for Research on Inner City Health, Keenan Research Centre, Li Ka Shing Knowledge Institute, St. Michael’s Hospital, 30 Bond St, Toronto, ON MSB 1W8, USA
2 Division of Public Health Sciences, Department of Surgery and Alvin J. Siteman Cancer Center, Washington University School of Medicine, 660 S. Euclid, Campus Box 8100, St. Louis, MO 63110, USA

Full list of author information is available at the end of the article

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Background

In Canada, cancer is the leading cause of mortality [1]. Ontario, the most populous province in Canada [2], has organized screening programs to promote the early detection of breast (est. 1990), cervical (est. 1997) and colorectal (est. 2007) cancers [3]. In order to maximize reach, these programs use evidence-based interventions (EBIs), including targeted invitations, facilitated appointment booking, reducing out-of-pocket costs [4,5], as well as public education and communication of test results to patients and providers [3]. Overall, self-reported recent use of mammograms (73%) and Pap tests (73%) in Ontario are similar to the country as a whole [6,7], and self-reported rates of fecal occult blood test (FOBT) use (50%) are higher in Ontario compared to other provinces [8]. However, the Ontario cancer screening programs have limited reach to immigrant populations compared to Canadian-born residents [9-15], which diminishes the effectiveness of these programs [16] and potentially leads to health inequities.

South Asians, including those from India, Pakistan, Afghanistan, Bangladesh, and Sri Lanka, are among the fastest growing immigrant groups in both Canada and Ontario [17]. Immigrants from South Asian countries are particularly vulnerable to being inadequately screened for all three types of cancer because they generally have incomes lower than the national average [18], and awareness about cancer screening in their countries of origin is typically poor [19-21]. Loffers et al. found that among immigrant groups cervical cancer screening rates were lower for South Asian immigrant women compared to Canadian-born women and immigrants who arrived before 1985, both for women aged 18 to 49 years (adjusted rate ratio (ARR) 0.81, 95% confidence interval (CI) 0.80, 0.82) and for women aged 50 to 66 years (ARR 0.67, 95% CI 0.65, 0.69) [22]. Another study found that a lower percentage of India-born Canadian residents compared to European-born Canadian residents had ever performed a breast self exam (58.6% versus 75.2%, respectively) [23]. Although South Asian specific colorectal cancer screening data are not available, screening rates for colorectal cancer are lower for all immigrant groups as compared to Canadian-born residents [24].

Studies that explored barriers to use of mammography, Pap tests, and FOBTs among racial and ethnic minority groups, including South Asians, have primarily focused on the perspectives of women who are eligible to receive these services and occasionally the perspective of the healthcare provider [23,25-34]. Relatively little is known about how stakeholders from various organization types view barriers to use of mammography, Pap tests, and FOBTs among racial and ethnic minority groups. Implementation frameworks suggest that successful implementation of EBIs is associated with organizational characteristics (e.g., readiness to adopt, leadership, culture), and the context in which organizations exist (e.g., legislation, continuity of funding, inter-organizational works) [35-40]. Therefore, by identifying organizational perspectives on barriers to cancer screening for racial and ethnic minority groups we can begin to understand how organizational factors might influence implementation of EBIs [41]. This knowledge can be used to design studies that will examine the effect of implementation strategies to improve organizational delivery of and resident participation in cancer screening programs for medically underserved populations. We report on research that is part of a multi-phase project with the overarching goal to reduce inequities in cancer screening for South Asian immigrants to Ontario by identifying effective strategies for increasing use of EBIs. In this manuscript, we describe concept mapping that was used to compare barriers to the use of mammograms, Pap tests, and FOBTs among South Asians from the perspective of stakeholders from organizations and South Asian residents, and discuss how results from concept mapping are being used within a knowledge-to-action (KTA) process to inform future phases of the project.

Methods

Implementation framework

The multiple phases of our project are guided by the KTA process that conceptualizes a relationship between knowledge creation and an action cycle to translate research into ‘real-world’ settings. KTA views knowledge creation as occurring through a funnel that includes the multitude of primary studies or information on a topic at the widest end, knowledge synthesis in the middle, and knowledge products (e.g., EBIs) at the most narrow end. The action cycle is the process that leads to the implementation of EBIs. Based on numerous theories and frameworks of implementation, the action cycle consists of the following activities: identify a problem; identify the EBI relevant to the problem; adapt the identified EBI to the local context; assess barriers to using the EBI; select, tailor, and implement strategies to promote use of the EBI; monitor EBI use; evaluate the outcomes of using the EBI; and sustain ongoing use of EBI. The KTA process is dynamic and is accomplished through iterative exchanges between researchers and the end-users of research [37,42].

Following an adapted KTA process, our project consists of a pre-implementation phase and three phases of implementation (Figure 1) [37]. In the pre-implementation phase, we identified low rates of cancer screening among South Asians in Ontario and implementation strategies that are effective to increase use of mammograms, Pap tests, and FOBTs. We developed relationships with three key stakeholders in our target setting including Cancer
Care Ontario, the provincial authority for cancer screening programs in Ontario; the Medical Officer of Health in the region of Peel, an area of 1.2 million residents with cancer screening rates lower than other regions of Ontario [11], and a high concentration of immigrants from South Asia [43]; and the Executive Director of Punjabi Community Health Services, a community service organization that delivers culturally tailored health promotion services to South Asians in Mississauga and Brampton, the largest cities in the Peel region. These organizations were our initial community partners from the provincial, regional, and local levels respectively. Following funding from the Canadian Institutes of Health Research, we completed phase one (concept mapping) and launched phase two of the study. Knowledge gained from concept mapping is described in this paper. Future papers will describe findings from our current activities (phase two) and future activities (phase three).

Study design
Concept mapping is a participatory research method that has been widely used for program planning [41,44-46]. This mixed methods approach uses qualitative procedures to generate data and quantitative methods to analyze data [41,44]. Concept mapping involves six steps: preparation, brainstorming, sorting and rating, analysis, interpretation, and utilization [47]. We conducted the preparation step in the pre-implementation phase of our project in collaboration with our initial community partners. During preparation we clarified the core issue to be addressed through concept mapping, developed the focus statements for brainstorming and rating sessions, and identified potential participants. The brainstorming, sorting, rating, analysis, and interpretation steps in concept mapping were conducted in phase one, and are described in this paper. The utilization step of concept mapping in which we are using concept mapping results to guide the selection, tailoring and implementation of interventions is being conducted in phase two of our study (Figure 1). Study activities have been approved by the St. Michael’s Hospital Research Ethic Board.

Participants
To achieve a broad sampling of ideas about barriers to cancer screening for South Asians, we recruited 53 participants for brainstorming including potential decision makers, program implementers, and program participants from Brampton and Mississauga using a snowball sampling process that was initiated by our community collaborators. Punjabi Community Health Services recruited 24 South Asian immigrants to Canada through personal networks and existing health promotion programs. We recruited residents who spoke English, Punjabi or Urdu, the most common languages spoken among South Asians in Peel [43]. Translated invitation letters and consent forms were used for non-English speaking participants. South Asian resident participants ranged in age from 18 to 49 years (66%) to 50 to 69 years (34%), were male (36%) and female (64%), and spoke English (45%), Punjabi (38%) and Urdu (17%) as a primary language. Residents’ religious beliefs included Muslim (n = 4), Sikh (n = 14), Hindu (n = 5) and Christian (n = 1). Cancer Care Ontario’s Regional Primary Care Lead helped recruit 10 South Asian primary care physicians. A total of 13 organizations participated in
brainstorming. Of the 13, seven were community service organizations (entities that routinely provide outreach and education to South Asian residents for the purpose of relocation assistance, health promotion, etc. but do not plan or provide cancer screening services), and six were health service organizations (public health, provincial health service program delivery, local clinical service delivery). Representatives from community service (seven senior managers, two health promoters, one case manager, one volunteer outreach coordinator) and health services organizations (four senior managers, two public health nurses, one project coordinator, one diversity support specialist) were identified through a collaborative effort by all partners.

From the group of participants in the brainstorming sessions, we invited residents that spoke English, primary care providers, and organizations to participate in sorting and rating. We also extended sorting and rating invitations to potential participants that were referred to us by participants in the brainstorming sessions. The 46 community members that participated in sorting and rating included South Asian residents (n = 15, eight men and seven women), five primary care providers and 17 organizations (11 community service, 6 health service). Representatives from community service organizations included: nine senior managers, two settlement counselors, one community services coordinator and representatives from health service organizations included: eight senior managers, two health promoters, one community services coordinator, one project coordinator, one diversity support specialist, one public health nurse). They ranged in age from 18 to 49 years (70%) to 50 to 69 years (30%), and were female (70%) and male (30%). The lower number of participants in sorting and rating was due to lower participation by primary care providers and our decision to not recruit Punjabi and Urdu speaking residents because of budget constraints.

Brainstorming
During brainstorming, participants worked in groups to generate statements in response to the focus prompt, ‘A barrier to use of mammograms, Pap tests, or fecal occult blood tests among South Asians in Peel is __________?’ We conducted ten brainstorming sessions. On the recommendation of our community partners, we held separate sessions for male and female residents, led by facilitators representing the same gender as participants, to minimize the discomfort of discussing personal health issues in a group. Brainstorming sessions in Urdu and Punjabi were led by lay facilitators from the community who had been trained by research staff. Following these sessions, the statements collected in Urdu and Punjabi were translated to English by qualified translators. The session with representatives from community organizations was held separately from the session with representatives from health service and public health organizations. The brainstorming sessions generated 290 statements. Two authors (RL and AP) used an independent review process with iterative meetings for comparison analyses to synthesize statements that were ascertained from multiple brainstorming sessions, reduce ideas to eliminate redundancy, and edit statements for clarity. The final list of statements included 45 unique barriers to use of mammograms, Pap tests, or FOBTs among South Asians in Peel.

Sorting and rating
The majority of participants completed sorting and rating in-person with the exception of eight representatives from organizations who completed sorting and rating using the web-based Concept Systems software version 4.0175, Concept Systems, Inc. (Ithaca, NY). During sorting and rating sessions, the participants worked on an individual basis to sort statements into conceptually similar groups. Following the sorting activity, we administered four rating surveys to participants. Three surveys asked participants to rate each barrier based on, ‘How likely is it that addressing this barrier would increase the use of [specific test] among South Asians?’ where the specific tests were mammograms, Pap tests, and FOBTs. A fourth survey measured the feasibility of addressing each barrier based on, ‘How strongly do you agree with the statement, It would be easy for the Peel community to remove this barrier within two to three years?’ Response options were on a continuous scale for surveys one to three (1. extremely unlikely – 6. extremely likely) and survey four (1. strongly disagree – 6. strongly agree).

Analysis
The analysis for sorting, rating, and comparison of ratings was also performed using the Concept Systems software. The software uses multi-dimensional scaling to create a point map based on sorting data. The point map shows the spatial relationships among statements with the goodness of fit indicated by a stress value. The stress value associated with our analysis was 0.2641, a value within acceptable limits for goodness of fit (<0.365) [16]. Details of the multi-dimensional scaling analysis are described in detail elsewhere [44,45]. Next, the software uses hierarchical cluster analysis to create a cluster map that partitions the statements on the point map into conceptual domains [44,45,47]. ‘No simple mathematical criterion is available by which a final number of clusters can be selected’ [45], p.13, because the ‘best’ number of clusters ‘depends on the level of specificity desired and the context at hand’ [48], p.316. Instead of using a statistical criterion to determine the final number of clusters, we asked experts in cancer control planning to examine different cluster solutions to interpret the best number of clusters and grouping of statements. This approach is standard for concept mapping [44,45,47]. It is important to note that the spatial position of the
statements never change in the cluster map because the statement’s position is determined by the multi-dimensional scaling. However, the clusters, formed by circles around the statements, can be influenced by asking the concept system software for a specific solution (e.g., ten-cluster, nine-cluster, etc.) or by using the software to place a specific statement in a specific cluster. The flexibility with deciding the final groupings for the statements invites the community to take ownership of the data and create information from the data that is meaningful to them [44,45,47]. Using the software, we created a visual display of the clusters (concept maps) with the statement numbers assigned by the concept mapping system. We computed the average ratings for each barrier and each cluster of barriers, and estimated the simple linear correlation in average ratings for groups using the Pearson correlation coefficient ($r^2$). We report average ratings across subgroups of residents, and representatives from community service and health service organizations.

Interpretation

We used a research-processing stage and participant-processing stage to interpret the final number of clusters and grouping of statements [47]. The research-processing stage consisted of two study investigators (RL and AP) examining different cluster solutions and observing the clusters that were merged from the upper limit of clusters (n = 10) to the lowest limit (n = 5) [44,48]. The study investigators decided to present a seven-cluster solution to stakeholders in the participant-processing stage because the statements within the clusters were conceptually similar to each other and discrete from statements in other clusters (Figure 2a) [44].

The participant-processing stage consisted of an interpretation session during which study investigators (RL and AP) presented the seven-cluster solution to nine community leaders (one primary care physician, four representatives from community service organizations, and four representatives from public health and health service organizations). Four residents who attended earlier sessions were also invited to the interpretation session but were not able to attend due to work or school related commitments. Consistent with other concept mapping studies, community leaders examined each statement and discussed whether the number of clusters and statements within the clusters were most appropriate for program planning [44,45,47]. The community leaders agreed with the seven-cluster solution and the names for the clusters. Although, they expressed the opinion that some barriers could be representative of more than one cluster and suggested that we move two barriers to other clusters. As a result of this suggestion, we moved the barrier ‘education programs do not offer materials that are well translated and culturally appropriate’ (statement 34) from the cluster labeled ‘health education programs’ to ‘ethno-cultural discordance with the health system,’ and the barrier ‘patient is concerned about the cost associated with tests’ (statement 11) from ‘patient’s beliefs, fears, lack of social support’ to the cluster labeled ‘costs.’ By moving these statements the final concept map (Figure 2b) had overlapping clusters. While concept mapping ideally strives for a clustering solution that does not have overlapping clusters [44], the researchers felt it was more important to have the final map represent the community leaders’ viewpoints since they were ultimately the ones who would use the data.

Results

Cluster descriptions

The final list of barriers, statement numbers, and cluster descriptions are provided in Table 1. The clusters included: patient’s beliefs, fears, and lack of social support (eleven statements); cost (three statements); limited knowledge among residents (seven statements); ethno-cultural discordance with the health system (four statements); limited knowledge among physicians (seven statements); health education programs (four statements); and the health system (nine statements). The concept map (Figure 2b) shows the relationships among these clusters. The close proximity of health system, ethno-cultural discordance, and health education programs clusters on the concept map shows how barriers within these clusters are more related to each other than to barriers in clusters that are further away (limited knowledge among physicians or residents; cost; patients beliefs, fears, lack of social support). The smaller size of the limited knowledge among physicians, limited knowledge among residents and health education clusters indicates that barriers in these clusters were more frequently sorted together than the barriers in larger clusters (health system; ethno-cultural discordance; patient beliefs, fears lack of social support). The overlap in two clusters reflects the community leaders’ opinions on the conceptual overlap among statements in the ethno-cultural discordance and health education clusters.

Cluster ratings

Overall, three clusters consistently ranked highest for all surveys (importance for each of mammography, Pap test, and FOBT and feasibility): ‘limited knowledge among residents,’ ‘ethno-cultural discordance,’ ‘health education programs.’ Clusters of barriers related to ‘cost’ and ‘patient’s beliefs, fears, lack of social support’ consistently ranked as lowest in importance. There were a few instances when subgroups of participants differed in opinions on the three clusters with the highest ratings. ‘Cost’ ranked second among residents for the FOBT survey and ‘limited knowledge among physicians’ ranked third among representatives from health service organizations for the feasibility survey. Residents ranked
limited knowledge among physicians’ lowest for all surveys but this cluster was ranked third for the feasibility survey and fourth for all other surveys among representatives from health service organizations (Table 2).

We found the correlation in ratings for clusters among residents and representatives from health service organizations was substantially weaker compared to the correlation in ratings for clusters for other bivariate comparisons (Table 3). The weakest correlation in ratings for clusters was for residents and representatives from health service organizations for the feasibility survey ($r^2 = 0.24$). Correlations in ratings for clusters among residents and representatives from community service organizations were strong for the cancer screening surveys ($r^2 = 0.80-0.84$), and relatively weak for the feasibility survey ($r^2 = 0.54$). The correlation in ratings for clusters among representatives from community service and health service organizations was $r^2 = 0.77$ or higher for all surveys.

**Discussion**

The limited reach of population-based cancer control programs to racial and ethnic minority groups is a critical implementation issue that requires attention. Many studies have explored barriers to cancer screening from the perspective of women and some have examined the perspectives of primary care providers. However, the perspectives of representatives from stakeholder organizations are equally as important given that successful implementation
Table 1 Concept mapping: community planning to reduce inequities in cancer screening

<table>
<thead>
<tr>
<th>Patient’s beliefs, fears, and lack of social support</th>
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<tbody>
<tr>
<td>14 Fear of emotional or physical discomfort about tests (e.g., pain, invasiveness, embarrassment or reluctance to handle feces)</td>
</tr>
<tr>
<td>42 Fear of the side effects of treatment (e.g., Loss of hair, loss of weight, pain, etc.)</td>
</tr>
<tr>
<td>45 Fear of going to the test alone</td>
</tr>
<tr>
<td>43 Belief about lack of confidentiality</td>
</tr>
<tr>
<td>1 Fear of starting a discussion about cancer or cancer screening with their physician</td>
</tr>
<tr>
<td>41 Fear that cancer will be detected (i.e., Stigma, neglect by family)</td>
</tr>
<tr>
<td>9 Fear about going to hospital</td>
</tr>
<tr>
<td>13 Female patient is not able to access cancer screening unless her partner approves</td>
</tr>
<tr>
<td>12 Religious belief about modesty</td>
</tr>
<tr>
<td>24 Lack of family and friends experienced with cancer screening to endorse participation</td>
</tr>
<tr>
<td>44 Females and their health are worthless in some families</td>
</tr>
<tr>
<td>11 Patient is concerned about cost associated with specialized tests</td>
</tr>
<tr>
<td>28 Patient has difficulty accessing transportation, including cost</td>
</tr>
<tr>
<td>8 Patient experiences loss of time and wages to see the primary care provider</td>
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</table>

Limited Knowledge among Residents

<table>
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<tr>
<th>Limited knowledge about cancer screening tests</th>
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</thead>
<tbody>
<tr>
<td>15 Limited accurate knowledge about cancer and risk factors</td>
</tr>
<tr>
<td>19 Limited knowledge about how to access tests</td>
</tr>
<tr>
<td>16 Limited knowledge about the success of cancer treatment</td>
</tr>
<tr>
<td>18 Limited knowledge about the Canadian health care system</td>
</tr>
<tr>
<td>20 Limited knowledge about using the health system when not sick</td>
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<tr>
<td>7 Patient does not prioritize cancer screening</td>
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</table>

Ethno-cultural discordance

<table>
<thead>
<tr>
<th>Health system does not respect or accommodate the culture and traditional notions of health care among South Asians</th>
</tr>
</thead>
<tbody>
<tr>
<td>35 Not enough primary care providers and technicians from South Asian cultures or who speak South Asian languages</td>
</tr>
<tr>
<td>31 Education programs do not offer materials that are well translated and culturally appropriate</td>
</tr>
<tr>
<td>32 Not enough female primary care providers</td>
</tr>
<tr>
<td>22 Primary care provider does not emphasize the need for cancer screening</td>
</tr>
<tr>
<td>5 Primary care provider does not equally emphasize the need for mammograms, Pap tests, and fecal occult blood tests</td>
</tr>
<tr>
<td>2 Primary care provider perceives a lower risk of cancer among South Asians</td>
</tr>
<tr>
<td>4 Primary care provider is unaware of guidelines for cancer screening</td>
</tr>
<tr>
<td>3 Primary care provider is unaware of cancer screening programs</td>
</tr>
<tr>
<td>10 Primary care provider lacks regard for patients’ personal choice about whether cancer screening should be completed</td>
</tr>
</tbody>
</table>

Table 1 Concept mapping: community planning to reduce inequities in cancer screening (Continued)

<table>
<thead>
<tr>
<th>Education programs</th>
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<tbody>
<tr>
<td>26 Primary care provider does not have financial incentive to ensure cancer screening is completed</td>
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</table>

<table>
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<tr>
<th>Health system</th>
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</thead>
<tbody>
<tr>
<td>25 Do not provide messages through multiple mediums accessed by South Asians (e.g., Newspaper, television, etc.)</td>
</tr>
<tr>
<td>33 Do not offer materials that are easy to understand (e.g., Use pictures to convey message, low reading level)</td>
</tr>
<tr>
<td>36 Do not offer endorsements from credible sources (e.g., places of worship, schools, South Asian cancer survivors)</td>
</tr>
<tr>
<td>39 Education programs sometimes deliver inconsistent messages</td>
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<tr>
<th>Limited knowledge among physicians</th>
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<tbody>
<tr>
<td>26 Primary care provider does not have financial incentive to ensure cancer screening is completed</td>
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</table>

of EBIs is associated with the inner context of organizations (e.g., readiness to adopt, leadership, culture), individuals within organizations (e.g., values, social networks perceived need for change), and the outer context such as sociopolitical factors (e.g., legislations, monitoring and review), funding (e.g., grants and continuity of funding), client advocacy (e.g., consumer organizations, lawsuits), and interorganizational networks (e.g., professional organizations, leadership ties, communication) [35-40]. To date, the research on strategies to improve use of cancer screening shows that greater reach among racial and ethnic groups can be achieved when programs take into account the language and cultural characteristics of the target population, provide support to reduce logistical barriers (e.g., transportation, appointment making), and use multi-level strategies [4,5,34,49]. However, whether these strategies are adopted will depend on organizational perspectives on the related barriers.

Little is known about the perspectives of representatives from health service (e.g., community health centers, primary care providers, hospitals, mammography facilities, public health) and community service organizations (e.g., health and fitness groups, settlement agencies, et al.) on barriers to
We found considerable agreement among residents and representatives from organizations on the importance of the top barriers to cancer screening for South Asians. Notwithstanding the concurrence of these opinions, overall agreement in the ranking of clusters of barriers by residents and representatives from health service organizations was low. In particular, rankings were discordant for barriers associated with ‘cost’ and ‘limited knowledge among physicians,’

use of mammography, Pap tests, and FOBTs among racial and ethnic minority groups. This study contributes new knowledge to implementation research in this area by examining which barriers are viewed by representatives from stakeholder organizations as most important and feasible to address to increase cancer screening among South Asians. We found considerable agreement among residents and

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<thead>
<tr>
<th></th>
<th>Overall</th>
<th>Residents&lt;sup&gt;1&lt;/sup&gt;</th>
<th>Community service organizations&lt;sup&gt;2&lt;/sup&gt;</th>
<th>Health service organizations&lt;sup&gt;3&lt;/sup&gt;</th>
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<tbody>
<tr>
<td><strong>Ranking (mean rating) mammogram survey&lt;sup&gt;4&lt;/sup&gt;</strong></td>
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<tr>
<td>Ethno-cultural discordance</td>
<td>1 (4.87)</td>
<td>2 (4.95)</td>
<td>1 (5.11)</td>
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<tr>
<td>Limited knowledge among residents</td>
<td>2 (4.77)</td>
<td>1 (4.96)</td>
<td>2 (5.01)</td>
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<tr>
<td>Health education programs</td>
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<td>3 (4.88)</td>
<td>3 (4.94)</td>
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</tr>
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<td>5 (4.60)</td>
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</tr>
<tr>
<td>Cost</td>
<td>5 (4.24)</td>
<td>4 (4.86)</td>
<td>5 (4.58)</td>
<td>7 (3.53)</td>
</tr>
<tr>
<td>Limited knowledge among physicians</td>
<td>5 (4.24)</td>
<td>7 (4.33)</td>
<td>6 (4.35)</td>
<td>4 (4.10)</td>
</tr>
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<td>Patients’ beliefs, fears, lack of support</td>
<td>6 (4.18)</td>
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<td><strong>Ranking (mean rating) pap test survey&lt;sup&gt;4&lt;/sup&gt;</strong></td>
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<td>Limited knowledge among residents</td>
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<tr>
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<td>5 (4.59)</td>
<td>4 (4.66)</td>
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<td>7 (4.30)</td>
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<tr>
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<td><strong>Ranking (mean rating) fecal occult blood test survey&lt;sup&gt;4&lt;/sup&gt;</strong></td>
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<td>1 (4.78)</td>
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<td>3 (4.64)</td>
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<td>1 (5.05)</td>
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<td>Cost</td>
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<tr>
<td><strong>Ranking (mean rating) feasibility survey&lt;sup&gt;5&lt;/sup&gt;</strong></td>
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<tr>
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<td>1 (4.80)</td>
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<td>3 (4.95)</td>
<td>3 (4.67)</td>
<td>2 (4.56)</td>
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<tr>
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<td>1 (5.10)</td>
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<td>4 (3.82)</td>
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<tr>
<td>Limited knowledge among physicians</td>
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<td>7 (4.48)</td>
<td>4 (4.36)</td>
<td>3 (4.28)</td>
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<tr>
<td>Health system</td>
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<td>5 (4.73)</td>
<td>5 (4.33)</td>
<td>5 (3.81)</td>
</tr>
<tr>
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<tr>
<td>Patients’ beliefs, fears, lack of support</td>
<td>7 (3.87)</td>
<td>6 (4.72)</td>
<td>6 (3.96)</td>
<td>7 (3.14)</td>
</tr>
</tbody>
</table>

1. Residents include male and female immigrants from South Asian countries (e.g. India, Pakistan, Afghanistan, Bangladesh, and Sri Lanka).
2. Community service organizations include administrators and staff from business that routinely provide outreach and education to South Asian residents for the purpose of relocation assistance, health promotion, or other social services but do not provide cancer screening services.
3. Health service organizations include staff from the regional department of public, administrators from health service organizations and primary care providers.
4. Question: How likely is it that addressing this barrier would increase the use of [specific test] among South Asians? Scale 1–6: extremely unlikely, very unlikely, unlikely, likely, very likely, extremely likely.
5. Question: How strongly do you agree with the statement, It would be easy for the Peel community to remove this barrier within 2–3 years? Scale 1–6: strongly disagree, disagree, somewhat disagree, somewhat agree, agree, strongly agree.
which suggest that important factors could be overlooked if only one stakeholder opinion is taken into account when planning health promotion programs. For example, if program developers prioritize implementation strategies to remove barriers to cancer screening based only on the perspective of South Asian residents then the need to address ‘limited knowledge among physicians’ might be overlooked, despite physician recommendation being among the strongest predictors of cancer screening [13,50-54].

We found that residents’ perspectives on which barriers to cancer screening are most important to address and feasible to change are more closely aligned with representatives from community service organizations than health services organizations. This finding could be due to the similar ethnic characteristics of residents and employees of community service organizations. In addition, representatives from community service organizations gain a broader understanding of their clients’ perspectives through ongoing discussions about social and economic factors, even at the level of executive director because of the ‘hands-on’ nature of this role in small organizations. In contrast, communication between clients and representatives from health service organizations tends to be limited to biomedical characteristics of clients, and client contact is limited to clinical and clinical support staff.

Furthermore, our results suggest opportunities for health service and community service organizations to work together to remove ethno-cultural barriers to cancer screening for South Asians. Representatives from both types of organizations ranked the ‘ethno-cultural discordance’ cluster among the top three important barriers for all three cancer screening tests. Yet only representatives from community service organizations ranked ethno-cultural discordance as feasible to address. We interpret this pattern of responses as being reflective of the expertise in community service organizations to address ethno-cultural barriers to cancer screening for South Asians and the lack of this expertise in health service organizations. Community service organizations are generally staffed by employees who are culturally representative of the clients they serve and have skills in interpretation and translation of medical information. In addition, foreign trained medical professionals often work in community service organizations because it is difficult for them to gain accreditation in the Canadian health system [55]. This is among the reasons why health service organizations are generally understaffed in employees who are culturally representative of the populations they serve. Recently, Canada implemented strategies to improve the timely assessment and recognition of foreign trained medical personnel including bridge-to-licensure programs for licensed practical nurses, medical radiation technologists, and physicians [56]. However, this gap in skills among employees of health organizations highlights opportunities for collaboration with community service organizations to remove ethno-cultural barriers to cancer screening for South Asians.

Findings from our study inform the field of implementation science by identifying ways in which stakeholders’ opinions about barriers to use of an EBI can differ. In addition, our analysis highlighted potential strategies by which these differences could be used to address barriers to cancer screening for South Asians. Because our study uses the KTA framework, our findings also contribute to the action cycle through which research is translated to action.

Through the participatory processes of concept mapping our community advisory group has grown from the initial three partners to 12 organizations. In phase two of this study we are engaging in multiple activities with the advisory group to utilize the concept mapping results. First, we discussed potential EBIs, based on the Guide to Community Preventive Services [4,5,57], to address the top three barriers to cancer screening that were identified by the community and barriers in the ‘limited knowledge among physicians’ cluster that were identified as important by health service organizations.

Table 3 Correlations in average ratings for clusters of barriers by key stakeholders

<table>
<thead>
<tr>
<th>Type</th>
<th>Residents</th>
<th>Community service organizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mammogram survey</td>
<td></td>
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<tr>
<td>Community Org</td>
<td>0.84</td>
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</tr>
<tr>
<td>Health Service Org</td>
<td>0.42</td>
<td>0.77</td>
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<tr>
<td>Pap test survey</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Org</td>
<td>0.80</td>
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</tr>
<tr>
<td>Health Service Org</td>
<td>0.50</td>
<td>0.86</td>
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<tr>
<td>Fecal occult blood test survey</td>
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<td></td>
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<tr>
<td>Community Org</td>
<td>0.80</td>
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</tr>
<tr>
<td>Health Service Org</td>
<td>0.31</td>
<td>0.77</td>
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<tr>
<td>Feasibility survey</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Org</td>
<td>0.54</td>
<td></td>
</tr>
<tr>
<td>Health Service Org</td>
<td>0.24</td>
<td>0.78</td>
</tr>
</tbody>
</table>

1. Pearson’s correlation coefficient.
2. Residents include male and female immigrants from South Asian countries (e.g. India, Pakistan, Afghanistan, Bangladesh, and Sri Lanka).
3. Community service organizations include administrators and staff from business that routinely provide outreach and education to South Asian residents for the purpose of relocation assistance, health promotion, or other social services but do not provide cancer screening services.
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From these discussions, we identified resources to support implementation of patient targeted, physician targeted, and health system targeted interventions. For example, a lay health advisor intervention is being developed with support from the Canadian Cancer Society. This intervention will include group education sessions for residents at local community service organizations and potentially South Asian screening clinics or blocked times for appointments with female physicians. Using logic models researchers and members of the advisory group developed a shared understanding of resources, activities, outputs, and outcomes for a multi-level intervention program (patient, provider, and health system level) to increase cancer screening among South Asians in Peel. To further inform the availability of and gaps in resources to support these interventions, we conducted a survey of all community service and health service organizations that provide services to promote cancer screening in Peel. When analyzed, the survey will inform us about the types of services organizations provide to promote cancer screening (e.g., outreach and education, navigation, clinic services), the inter-organizational relationships (e.g., communication, referral, collaboration) that support the delivery of the services, and the gaps in services that we need to fill through additional partnerships and resources. Following our accomplishment of a clearly defined intervention to improve rates of cancer screening among South Asians, we will seek funding for phase three in which we will examine the effect of change strategies on implementation of the multi-level cancer screening program.

Despite the strengths of this study, some limitations should be noted. We had limited participation from primary care physicians in the sorting and rating phase (n = 5) and no participation from residents in the interpretation phase. However, the impact of this limitation is minimal for two reasons. First, we were primarily interested in the organizational level perspective, not specifically primary care provider opinions, and physicians represented 26% (5/19) of the responses from representatives from health service organizations. Second, residents might not have felt comfortable speaking their opinions with a group of community leaders in the interpretation session. Fortunately, the multi-phase nature of our project will allow us to seek input on program development from South Asian residents at another point in the study. The generalizability of our findings to other provinces in Canada, to other countries, or healthcare settings may be limited because the perceptions of which barriers are most important and feasible to address will be influenced by local health policy, infrastructure, and practices. However, the methods used to conduct our study can be applied in other settings, and the general differences in opinion that we observed among stakeholders groups are likely representative of what we would find in other regions.

By using concept mapping, we identified barriers to cancer screening in the region of Peel that can be utilized in latter stages of the KTA process. Equally important was that concept mapping engaged a diverse range of stakeholders from the national level (e.g., Canadian Cancer Society), provincial level (Cancer Care Ontario), regional level (Peel Public Health, regional cancer center) and local level (e.g., hospitals, community health centers, community service organizations) that will make the implementation process relevant, feasible, and sustainable moving forward [42]. Participatory research methods combined with an overarching KTA framework can facilitate the translation of research to action.

Competing interests
The authors declare that they have no competing interests to disclose. Funding for support of Drs. Lobb, Pinto, and Lofters work on this project was provided by the Canadian Institutes for Health Research, and the Ontario Ministry of Health and Long-Term Care.

Authors’ contributions
RL contributed to the theoretical background, conceptualization of the study, supervised the acquisition, analyses, and interpretation of the data, had the final approval of the version of the manuscript to be published. AP contributed to the acquisition, analysis, and interpretation of the data, and provided important intellectual content to the preparation of the manuscript. AL contributed to the conceptualization of the study, analysis, and interpretation of the data, and provided important intellectual content to the preparation of the manuscript. All authors read and approved the final manuscript.

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Author details
1Centre for Research on Inner City Health, Keenan Research Centre, Li Ka Shing Knowledge Institute, St. Michael’s Hospital, 30 Bond St, Toronto, ON M5B 1W8, USA. 2Division of Public Health Sciences, Department of Surgery and Alvin J. Siteman Cancer Center, Washington University School of Medicine, 660 S. Euclid, Campus Box 8100, St. Louis, MO 63110, USA. 3Department of Family and Community Medicine, St. Michael’s Hospital, 30 Bond St, Toronto, ON M5B 1W8, USA.

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