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Recommended Citation

Lofters, Aisha; Virani, Tazim; Grewal, Gurpeet; and Lobb, Rebecca, "Using knowledge exchange to build and sustain community support to reduce cancer screening inequities." *Progress in Community Health Partnerships: Research, Education, and Action*. 9, 3. 379-387. (2015).

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Progress in Community Health Partnerships: Research, Education, and Action, Volume 9, Issue 3, Fall 2015, pp. 379-387 (Article)

Published by Johns Hopkins University Press

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Using Knowledge Exchange to Build and Sustain Community Support to Reduce Cancer Screening Inequities

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Submitted, 14 January 2014, revised 18 August 2014, accepted 2 September 2014.

Abstract

Background. “Knowledge exchange” (KE) refers to the interaction between knowledge users and researchers toward a goal of mutual learning and collaborative problem solving.

Methods. Using a case study approach, this article describes how researchers leading a multiphase community engagement project, the Peel Cancer Screening Study (PCSS), used KE to engage a community advisory group (CAG) of knowledge users to build community support for interventions to reduce cancer screening inequities for South Asians in Peel Region, Ontario, Canada.

Results. As a result of KE activities (concept mapping, a CAG launch meeting, regular CAG meetings, workgroup meetings, a community report), there is currently a resident-

targeted, community-level program being implemented and a provider-targeted intervention that is funded, with both ethnospecific and health service organizations involved. The process of KE received positive evaluations from advisory group members.

Conclusions. The experiences of the PCSS illustrate the benefits of KE for researchers and community members.

Keywords

Health disparities, community-based participatory research, health promotion, community health partnerships, neoplasms, Canada

In Ontario, Canada's most populous and ethnically diverse province, considerable evidence suggests that immigrants from South Asia (Bangladesh, India, Pakistan, and Sri Lanka) are underscreened for breast, cervical and colorectal cancer despite existing organized provincial screening programs.^{1–8} For example, Lofters et al.⁸ found that cervical cancer screening rates were lowest for South Asians among immigrant groups compared with Canadian-born women, both for women aged 18 to 49 years (adjusted rate ratio 0.81; 95% CI, 0.80–0.82) and 50 to 66 years (adjusted rate ratio, 0.67; 95% CI, 0.65–0.69). These inequalities in screening are of particular concern from a public health perspective given

that South Asians are one of Ontario's and Canada's fastest growing immigrant groups.^{3,7,9}

According to the 2011 Canadian Census, Ontario's Peel Region has a population of 1.3 million people, and the largest South Asian population in the province. Peel also has lower cancer screening rates than the rest of Ontario, with particularly low rates in areas with a sizeable South Asian population.¹⁰ Accordingly, our research team initiated the PCSS, a multiphase community engagement project aimed at building community support for the development of effective, sustainable screening interventions for South Asians.

The community-based participatory research model encourages researchers and communities to partner together on the input, process, and outcome of research studies.¹¹ KE is an important component of community-based participatory research, the goal of which is to increase the uptake of this research by communities.^{11,12} Specifically, KE refers to the interactions between knowledge users and researchers where the goals are mutual learning and collaborative problem solving.¹³ Incorporating KE into health research can maximize the impact that research has on policy and practice, facilitate the production of relevant, priority-driven work, close the gap between knowledge generation and uptake, and foster ongoing meaningful partnerships between knowledge users and researchers.^{14–18} Using a case study approach, this article describes how PCSS researchers used five KE activities (Figure 1) to engage knowledge users and to build community support for implementation of interventions to reduce inequities in cancer screening. Knowledge users were public health organizations, primary care providers, health system entities that promote cancer screening, community service agencies that could or do provide outreach and education to increase cancer screening, and community members from the target ethnic groups. Ethics approval for the study was received from the St. Michael's Hospital Research Ethics Board.

KE ACTIVITIES

Concept Mapping (January 2011 to August 2011)

At the initiation of our study, we developed relationships with three key stakeholder organizations, namely the provincial authority for cancer screening programs, Peel Region's designated public health organization, and a local South Asian community service organization that delivers culturally tailored health promotion services. These initial community partners represented provincial, regional, and local levels of organizations respectively. We leveraged these partners' connections in the community to recruit 53 participants for a concept mapping exercise. Details of this work are described elsewhere.¹⁹ Briefly, concept mapping is a participatory research method that engages community members to brainstorm, sort and rate ideas.²⁰ Participants included primary care providers and representatives from 17 health service, community service, and public health organizations. Importantly, 24 participants were South Asian immigrant residents of Peel, with a diversity of languages spoken and religious beliefs.¹⁹ Using concept mapping, we derived a community-generated list of barriers to cancer screening among South Asians. The exercise also built support for and spread the word on PCSS throughout the community.

Figure 1. Knowledge Exchange Activities Engaged in by the Peel Cancer Screening Study Community Advisory Group

CAG Launch Meeting (September 2011)

Face-to-face interactive exchange is a key KE strategy.^{14,21} Accordingly, in September 2011, we held a meeting that brought together researchers, primary care providers, and organizational representatives. The represented community service, public health, and health service organizations either served South Asians, provided health promotion services, or both in Peel. The goals of the meeting were to share the identified barriers, initiate discussion on addressing these barriers, and launch a CAG of organizations who would identify and adapt evidence-informed intervention strategies to address the barriers.

Although CAGs often consist of laypeople who have some common trait,²² we aimed to establish a CAG composed of a broad range of organizations of different sizes and expertise as a way of engaging preexisting community resources and creating synergistic effects.²³ Our intent was that these organizations would play an integral role in the development of interventions and, by being part of this process, would have a commitment to participate in, and ultimately lead, implementation. We aimed to ensure that community service organizations would be overrepresented on the CAG because our earlier research informed us that they would know best what interventions would be accepted within the community, would be critical for community buy-in, and had the best perspective on the experiences and beliefs of the South Asian immigrant.^{19,24} The vision of the CAG that emerged from the launch meeting was that of a group that would provide infrastructure for the community to have a voice in developing interventions and advise the research team about suitable processes for gathering information to develop interventions. The vision of the screening interventions that emerged was that of an integrated, sustainable resident- and provider-focused program, relying on resources of larger health organizations while community service organizations played a central role in outreach and implementation, with all contributing equally to intervention development.

The launch meeting also provided the research team the opportunity to introduce our newly hired research coordinator to the community. We sought to hire a qualified candidate from Peel's South Asian community who was fluent in multiple South Asian languages. The chosen coordinator met

these criteria, and importantly, had a preexisting relationship with some local community partners.

CAG Meetings (October 2011 to August 2013)

The first meeting of the CAG was held shortly after the launch meeting in October 2011. Four subsequent meetings were held every 4 to 8 weeks until April 2012. Many members had attended the launch meeting, and additional members included representatives from other relevant organizations, brought in on the recommendations of meeting attendees. Importantly, many CAG members were also South Asian, particularly those who were community service organization representatives, and were thus able to both represent their organization and provide a personal perspective.¹⁹ As we had hoped, smaller community service organizations were well-represented. Twelve organizations were represented in the CAG, representing a four-fold increase in our number of partner organizations from the pre-implementation phase.

A terms of reference for the CAG was initiated in December 2011 and finalized by the group in March 2012, emphasizing that this was a living document that could be revisited regularly. The terms of reference described the focus on organizational representation in the CAG, provided guiding principles for the collaborative process, and outlined project objectives. We agreed that decisions would be made by consensus, with the group generally looking to the research team for final decisions in times of disagreement. To avoid any potential power imbalances between organizations, we alternated co-chairs for all meetings. One co-chair was always a member of the research team, and for the other, we alternated between smaller community service organizations and larger health organizations. We similarly alternated locations for our meetings between the two organization types. At each meeting, we tried to ensure that every attendee's opinions were heard and understood, sometimes requiring direct questioning of members who had not spoken previously. We also invited CAG members to provide electronic feedback before and after each meeting.

The knowledge exchanged at the meetings evolved over time. Initial meetings were used to establish the terms of reference, provide further information about cancer screening through guest speakers, and review research goals. The research team set agenda items, but we used an emergent

approach so that each meeting's discussion informed the agenda for upcoming meetings. Meetings were also used to plan research activities that the research team would be responsible for, such as mapping target areas of Peel with low screening rates and a high prevalence of South Asian residents, and conducting a local organizational network analysis to determine current communication, collaboration and referral patterns. Details about these study outputs have been published elsewhere.^{10,25}

Workgroup Meetings (Jun 2012 to September 2012)

In June 2012, in anticipation of a slowdown in study progress owing to the upcoming summer months, and to shift focus from information sharing to the process of selecting and developing interventions, the CAG decided to form two workgroups. Each group would be tasked with creating logic models, one for a resident-level intervention and one for a provider-level intervention that clearly outlined the inputs, participants, activities, and short-, medium- and long-term outcomes of each intervention. Membership was high, with eight organizations represented in the resident-level intervention workgroup and eight in the provider-level workgroup, with significant overlap in membership. Workgroups met approximately every 3 weeks over 3 months with all five meetings taking place by teleconference to accommodate their frequency. We hoped that empowering the workgroups to make decisions would increase productivity, trust and ownership and continue to enhance each partner's investment in the project.^{26,27}

Resident-Level Intervention. As a result of workgroup activities, our research team and CAG formed a partnership with a national cancer-focused nonprofit organization and with the region's cancer program (both of whom were active CAG participants), who are now jointly funding a lay health educator program. The program involves recruitment and training of members of the South Asian community who will convey cancer screening messages to their friends, family, and neighbors, and at community gatherings and places of congregation. Advisory group members felt strongly that a lay health educator program would be adaptable and acceptable to the target communities. Importantly, this intervention was also supported by research evidence.^{28–31} The CAG continues to be the advisory group for implementation of this program, providing general guidance, helping to recruit

lay health educators, and providing space for the educators to conduct sessions.

Provider-Level Intervention. During the summer of 2012, the provider-focused workgroup did not make the same level of progress. We suspected this was largely owing to many workgroup members being unfamiliar with the primary care setting. Ultimately, at the suggestion of the research team, this workgroup agreed that the research team would continue to work on the development of the provider-focused intervention with the input of a few key CAG members (representatives from the regional cancer program and local physician leads) and bring an almost fully developed proposal back to the CAG. Therefore, through the fall and winter of 2012, the research team developed an application and successfully submitted for further funding by the Canadian Cancer Society Research Institute. This provider-focused intervention emphasizes the adaptation of evidence-based interventions to increase cancer screening using a plan–do–study–act framework.^{32–35} The relevant CAG members noted above were collaborative partners on this application.

Community Report (October 2013)

In the spring of 2013, the research team began production of a community report that summarized our work to date. The intent was to disseminate our research findings to a broad audience of stakeholders in a format that they could use to strengthen other programs and collaborations. The development of the report was a collaborative process, conducted in consultation with a research communications coordinator to assist with accessibility and readability, and with iterative feedback from a small group of interested CAG members. This process provided an opportunity for mutual learning, as the research team reflected with CAG members on progress made to date and on how the research outputs we had produced (a community-generated list of barriers, geographic maps, network analysis) could be useful to the community at large. We viewed the list of barriers as *what* needed to be addressed, the geographic maps as telling us *where* interventions should be focused, and the network analysis as telling us *who* should be working together. Importantly, CAG members emphasized that community service organizations often do not have the resources on their own, financial or otherwise, to lead interventions. Therefore, we guided the writing of the report in this

manner, and made efforts to highlight throughout the document how organizations could potentially work together to improve screening rates. The community report was provided to all CAG members, distributed to other relevant organizations in Peel Region, and published online in fall 2013.³⁶

CAG PROCESS EVALUATION

Recognizing that the CAG in its current incarnation was coming to an end, the research team conducted an evaluation of the CAG process. The evaluation focused on members' understanding of the study objectives, perceptions of the extent to which objectives were met, participatory processes, new collaborations that had been undertaken as a result of CAG membership, and whether CAG participation increased their organization's capacity to participate in implementing cancer screening programs for South Asian residents..

To ensure objectivity as the research team was embedded in the research process, and to ensure that CAG members would be comfortable speaking frankly in interviews, we hired an evaluations consultant to conduct the evaluation. The consultant contacted advisory group members by telephone to complete semistructured, one-on-one interviews. She completed interviews with 93% of AG members. Interviews were audiotaped and transcribed, and a final summary report was prepared for the research team.

Key Findings From the Evaluation

Overall, members were very satisfied with the KE activities of PCSS. They felt that the right members were involved, and were very happy with the research coordinator, namely with her being from the South Asian community, her organizational skills, and her ability to maintain momentum. The majority of CAG members were able to articulate the group's objectives, felt that adequate attention had been paid to them, and felt that they had been achieved. However, a few members believed that the study did not go far enough in achieving its objectives, and that meaningful outcomes remained to be seen. Regarding participatory processes, many of the members felt they had a strong voice during the process and that the study truly was participatory in nature: "I'm extremely satisfied with the way it was conducted, very open, very participatory." Most CAG members¹¹ were very satisfied with the approach to decision making, felt that consensus was regularly achieved with no major disagreements, and felt

comfortable and supported sharing their ideas. However, a few members felt that there was ambiguity at times on what decisions were made, and that stronger, older, and more experienced voices had often led the discussions. In many cultures, including South Asian cultures, a deep level of respect is often afforded to elders in the community,^{37,38} which had limited some younger participants' perceived ability to articulate their viewpoints. The majority of members remained engaged throughout the study despite the long timeline, and felt that they owned the work that had been done.

The CAG members generally had a sense of responsibility of carrying on with the work initiated by the study and with newly established networks, with only three feeling that they were passive observers. For example, a desired result of participation was the development of greater connections between community-based organizations and the local cancer care system. Many members indeed felt that such new linkages had been facilitated by CAG processes, and wanted to ensure that the developed relationships continued: "The networking we did through the last 3 years through the Peel Cancer Study, that's going to go such a long way to allow us to be more sustainable." Three members did note that there should have been a more effective way to help foster greater partnerships.

With regard to knowledge, the CAG members felt that they gained knowledge of low screening rates for South Asians in Peel, the barriers to cancer screening, the types of interventions that could be used to address the barriers, methods of community engagement, and resource mapping techniques. Members also felt that discussions validated information that was already known to them, which built confidence in their knowledge and trust in the researchers and the study as a whole. Members felt that the study added value to their respective organizations with only two finding there to be no change to their organizational capacity. Although CAG members were well aware of the resident-focused intervention and viewed it as an important outcome, few were certain of the final outcome of the provider-focused intervention: "They mentioned something in one of the meetings that they were doing something to educate the primary care physicians but I'm not sure."

Sustainability was a concern for four CAG members, in particular regarding future funding needs and maintaining long-term linkages between mainstream organizations and South Asian community-based organizations. Toward that

end, the process evaluation revealed that three members of ethno-specific community service organizations had independently formed a health alliance committee whose aim is to collaborate to promote a number of different health messages and be a central point with which similar projects undertaken in Peel Region could be shared and communicated.

DISCUSSION

The experiences of PCSS illustrate the mutual benefits of KE for researchers and community members (Table 1). We built community support in Peel Region, Ontario, to reduce cancer screening inequities for South Asians, an identified vulnerable ethno-cultural group. As a result of KE activities, and active participation and collaboration on the part of CAG members, there is currently a resident-targeted community-level program being implemented and a provider-targeted intervention research project that is funded, with both ethno-specific and health service organizations involved. The success of our activities is also evidenced in our positive evaluation from the CAG.

Although successful in achieving its goal to build capacity to implement evidence-based interventions, this phase of the PCSS had its challenges. First, as noted, the provider-focused workgroup was less vocal on suggestions for moving forward, likely because we failed to notice the low representation of health service organizations. Instead, the workgroup was predominantly composed of community service organizations that had limited expertise on the routine procedures in primary care settings. We should have worked harder to involve the health service organization representatives and incorporate their expertise. We ultimately developed a successful proposal for a provider-level intervention. However, as noted in the study evaluation, we did not appropriately present the entire CAG with the finalized approach and ask for their feedback.³⁹ Although the workgroup had not agreed to an intervention, there was still interest from the CAG in the goal of intervening with primary care providers and we had a duty to inform them of future plans toward that end.

Second, although our methods of encouraging participation did provide the smaller organizations with a voice, the

Table 1. Benefits of Knowledge Exchange throughout the Knowledge-to-Action Framework

Item	Community Members ^a	Researchers
Learned about practical experience of implementing cancer screening programs in the region.	✓	✓
Made connections with organizations to gather information from South Asian residents.		✓
Learned about existing resources for cancer screening and connections among organizations.	✓	✓
Developed a deeper understanding of data analyzed using quantitative methods.		✓
Increased knowledge about local barriers to cancer screening for South Asian residents.	✓	✓
Increased publications.		✓
Increased grant funding.		✓
Increased visibility of organization.	✓	✓
Increased knowledge about cancer screening.	✓	
Increased knowledge about evidence-based interventions to promote cancer screening.	✓	
Increased collaborative relationships among organizations.	✓	✓
Validated assumptions about areas with the most need for targeted interventions.	✓	
Strengthened organizational capacity to lead other health initiatives.	✓	✓

^a Public health organizations, primary care providers, health system entities that promote cancer screening, and community service agencies that could or do provide outreach or education to increase cancer screening

larger organizations remained more vocal overall. Financial constraints and access to resources differ significantly between types of organizations, which may affect how much power they believe they are able to exhibit, the roles they are able to undertake, and how much time and attention they are able to commit.²⁶ Until the evaluation, we were also unaware of the cultural considerations that led some members to be less vocal than others out of respect to their elders. Had we been aware, we could have taken further action to draw out viewpoints of those younger members, such as targeted electronic communication outside of the meeting setting. This finding highlighted the importance of ongoing and frequent process evaluation from the onset, even if just on an informal basis.²⁶

Our third challenge was keeping community partners engaged. Engaging community stakeholders in the early stages of intervention planning is often easier than maintaining that engagement as time progresses, and it can be difficult to maintain momentum when research moves slower than organizations are used to. At the launch meeting, discussions centered around strategies related to implementation of interventions, but 1 year later, interventions were not yet underway. This affected momentum and led to expressed frustration by some CAG members, particularly those who had not been part of the workgroups. The longer-than-anticipated timeline was noted in the evaluation as a challenge to participation. In response to the CAG members' eagerness to begin implementation, we strove to co-produce interim benefits with the CAG, such as the geographic maps and organizational network analysis. These outputs re-invigorated the group, exemplified that work was ongoing, and led to meaningful progress. We also encouraged member organizations to network with each other, share resources, and collaborate whenever opportunities presented themselves. Regular contact is important to maintain enthusiasm,³⁶ so we tried to ensure that electronic communication was frequent. The community report that

we created was also partially born out of a desire to have the members see concrete evidence of benefits and results of the study and the CAG. Evaluation results indicated that our efforts were generally successful in keeping partners engaged. This success was also indicated in the maintained composition of organizations on the CAG.

To develop effective cancer screening interventions, we took the approach of establishing an organization-based CAG and using KE to establish sustained community support. Through our KE activities, we successfully provided infrastructure for the community to advise the research team about suitable processes and to voice concerns, and we co-produced mutually beneficial knowledge. We encountered challenges throughout, but attempted to address them openly and directly and adapted our approach when appropriate. Organizations represented on our CAG continue to be committed to a South Asian-focused cancer screening program and indeed, some have formed a broader health alliance committee. We expect to continue to develop culturally acceptable community-based interventions with potential to live on past the life of the research study funding.

ACKNOWLEDGMENTS

The work described in this article was supported by the Canadian Institutes of Health Research through a meeting grant, a planning grant and an operating grant. During the course of the work described in this paper, Dr. Aisha Lofters was supported by a Canadian Institutes of Health Research Strategic Training Fellowship (Transdisciplinary Understanding and Training on Research – Primary Health Care Program). Dr. Lofters is supported by a Canadian Cancer Society Research Institute Career Development Award in Cancer Prevention (grant #702114). The authors thank our community advisory group for their contributions to the work described in this paper.

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