

*RESEARCH AND PRACTICE NOTE /
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**THE BC CANCER AGENCY PRIMARY
PREVENTION PROGRAM: USING
NEGOTIATED ACCOUNTABILITY TO
EVALUATE A COMMUNITY-DETERMINED
HEALTH INITIATIVE**

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Abstract: The British Columbia Cancer Agency Centre for the Southern Interior Prevention Program operated from 1997 to 2005, resulting in community-determined cancer prevention initiatives specific to unique local needs. These initiatives included community events and forums, school food and nutrition activities, physical exercise initiatives, environment and air quality programs, early childhood education, tobacco counselling programs, and cancer prevention-related publications. The external evaluation of the program used the concept of negotiated accountability to strengthen collaborative evaluative practices. In this article, we present evaluation findings and provide a detailed example from one partner community.

Résumé : Le programme de prévention créé par la British Columbia Cancer Agency – Centre for the Southern Interior (BCCA-CSI), qui fonctionnait de 1997 à 2005, a donné lieu à la mise en place

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d'initiatives communautaires pour la prévention du cancer spécifiques aux besoins locaux uniques. Ces initiatives comprennent événements et forums communautaires, activités centrées sur les aliments et la nutrition dans les écoles, exercice physique, programmes sur l'environnement et la qualité de l'air, éducation à la petite enfance, programmes de lutte contre le tabagisme, et publications sur la prévention du cancer. L'évaluation externe du programme a utilisé le concept de la responsabilité négociée pour renforcer des pratiques d'évaluation collaborative. Dans cet article, nous présentons des résultats d'évaluation et fournissons un exemple détaillé d'une des communautés participantes.

INTRODUCTION

The British Columbia Cancer Agency Centre for the Southern Interior (BCCA-CSI) Prevention Program operated from 1997 to 2005. The program was shaped by the tenets of communicative action, thereby introducing a critical element to the participatory process (Habermas, 1984). Resulting initiatives were both community-determined and specific to unique local needs (Baillie, Bassett-Smith, & Broughton, 2000). It was of equal importance that these initiatives be evaluated within a similar rubric.

METHOD

While the external evaluation of the program was instigated by BCCA administration and program funders, all stakeholders negotiated the development of an evaluation framework that could adequately address their own information needs.

Interview questions were both qualitative and quantitative in nature and were derived from validated interview instruments used in other settings (Australian Centre for Health Promotion, 2000; Gardner, 2003; Gibbon, Labonte, & Laverack, 2002; Health Canada, Population and Public Health Branch, 2004; Laverack, 2001). A review of relevant academic, peer-reviewed literature and a process of repeated review and approval involving all parties helped to identify the seven core community capacity domains that composed the interview guide. Each domain was then defined by a series of indicators or characteristics. As a part of the interview process, interviewees were asked to rate the extent to which each indicator was represented or implemented in the cancer prevention activities in which they were involved.

Participation (Table 1) is the active involvement of people in improving their own and their community's health and well being.

Table 1
Participation Indicators

- Involve community organizations in cancer prevention programs
 - Encourage people with diverse interests and perspectives to participate in program work
 - Include community members in defining and resolving needs
 - Implement procedures to ensure participation from all people during community meetings or events
 - Identify barriers to participation in cancer prevention programs
 - Devise ways to overcome barriers to participation
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Leadership (Table 2) includes developing and nurturing both formal and informal leaders during the course of a program to provide support and direction, address conflict, encourage community involvement, facilitate partnerships, and garner community resources.

Table 2
Leadership Indicators

- Involve formal leaders (e.g., elected officials) in cancer prevention programs
 - Encourage and support the involvement of informal leaders
 - Define key roles and responsibilities of community leaders involved in programs
 - Develop reporting guidelines to ensure leaders are accountable
 - Shape and cultivate the development of new leaders
 - Connect and link with other leaders on a regular basis
 - Are open and receptive to innovative ways of doing things
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Skill and Knowledge Development (Table 3) allows people to apply and share existing skills, transfer knowledge, and develop new skills.

Table 3
Skill and Knowledge Development Indicators

- Draw upon the skills, knowledge, and expertise of community members to increase the potential for program success (e.g., proposal writing, media skills)
 - Provide the program team and community members with learning opportunities related to the program (e.g., workshops or in-services)
 - Have procedures in place to share and disseminate program information (successes, challenges, outcomes) to agencies and the communities at large
 - Provide program team members, community members, and/or program beneficiaries the opportunities to acquire or improve the following skills:
 - Problem solving
 - Advocacy
 - Fund raising
 - Program planning
 - Research (data collection and analysis)
 - Evaluation
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Resources (Table 4) are obtained from both within and outside the community and include time, money, leadership, volunteers, information, technical expertise, and facilities.

Table 4
Resources Indicators

- Identify and access resources within the community to support cancer prevention programs
 - Identify and access resources outside the community (e.g., provincial government, regional health authorities, and nonprofit foundations)
 - Pool or share resources with other community groups or agencies
 - Generate trust and cooperation within the community (i.e., social capital) in order to promote program goals
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Partnerships and Networks (Table 5) bring diverse populations and interests together to address joint issues and synergistically achieve goals.

Sense of Community (Table 6) is fostered through community programs that reflect trust, commitment, and caring.

Community Infrastructure (Table 7) addresses the social determinants of cancer risk behaviours.

Table 5
Partnerships and Networks Indicators

- Bring agencies and groups together to express joint views and address concerns related to cancer prevention
 - Have a structure process in place to facilitate and maintain partnerships and networking (e.g., interagency meetings)
 - Have community channels that support working together (e.g., newsletter)
 - Enjoy reciprocal links, that is, give as well as receive support from other groups and organizations
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Table 6
Sense of Community Indicators

- Are readily recognized by community members, that is, people are aware of who you are and the work you do in cancer prevention
 - Use a variety of methods to inform the community about programs (e.g., meetings, electronic mailing lists, media, newsletter)
 - Demonstrate a high level of concern, respect, and generosity for community members
 - Be aware of and respond to important social, political, and economic changes that affect the community
 - Support and reflect community history, norms, and values
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Table 7
Community Infrastructure Indicators

- Have contributed to community structures (e.g., new facilities, resources, information access)
 - Have contributed to new organizations or networks that work together to address the issues that affect them
 - Have fostered change or improvement in health-related policies in the community
 - Have increased the ability and confidence of the community to undertake cancer prevention initiatives (e.g., collective efficacy)
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Interviews were conducted with approximately 60 community representatives who were currently or had been involved with the planning and/or implementation of the resulting cancer prevention activities in each partner community. Data were analyzed both quantitatively and qualitatively. Additionally, program documents were reviewed to provide additional information and context.

CASE STUDY

Nestled in the Selkirk and Monashee mountain ranges are the regions of Greater Trail and Castlegar, having a combined population of 28,000. Sharing this location is Teck Cominco Ltd.'s Lead Zinc Smelter Complex. The program began here in 1999, when BCCA-CSI met and worked closely with a diverse group of representatives from the community to discuss the possibility of establishing a local cancer prevention program.

In an effort to gain an understanding of the attitudes, beliefs, and practices held by community members in relation to cancer and cancer prevention, qualitative surveys were conducted with local residents. Findings revealed a prevailing attitude among community members that the occurrence of cancer could not be prevented or reduced by the individual's own health behaviours and choices and a belief that cancer and ill health were matters of fate. Further, there was a common perception that there was a higher than average incidence of cancer in the area and surrounding their community. Within this context, a steering committee made up of residents from the Greater Trail and Castlegar area was established in November 1999, and the first community coordinator was hired by the committee in January 2000.

GREATER TRAIL AND CASTLEGAR EVALUATION FINDINGS BY DOMAIN

Participation

The majority of respondents believed that the program involved community organizations to the fullest possible extent and fully encouraged people with diverse interests and perspectives to participate, with just over three quarters believing the program fully includes community members in defining and resolving local needs.

Similarly, most respondents believed that procedures to ensure participation from all people during community meetings or events were fully implemented, and that there was strong encouragement to participate in program planning and implementation. However, the criticism was made that those actually involved in planning and implementation tended to be from "middle class and up" and that there was not enough youth involvement in these processes. Just under two thirds of respondents believed that the program fully

identified barriers to participation in cancer prevention programs. A major barrier was the recruitment and retention of volunteers, with several respondents mentioning that “there are only a certain number of volunteers in the community and everyone wants to keep to their own independent group.”

Leadership

While most respondents reported that informal leaders were fully or somewhat encouraged to participate in program activities, almost all respondents commented that there were limited leadership development opportunities. This may reflect the fact that many of the respondents believed that those involved in planning and implementing the program activities were “natural leaders” and “self starters,” but it clearly indicates a serious gap between opportunity and preparation. However, nearly three quarters of respondents believed the program fully defined leadership roles and responsibilities. A few respondents commented that they were not entirely clear about their role/responsibility in the program. Of particular interest is the finding that 86% of respondents believed the program fully developed reporting guidelines to ensure leaders are accountable.

Skill and Knowledge Development

Only half of the respondents believed the program encouraged and provided opportunities for skill and knowledge development to the fullest extent. When asked if team members, community members, or program beneficiaries had been provided opportunities to acquire various skills, 64% of respondents believed that the program fully offered opportunities around problem solving; 73% believed the program fully provided opportunities to develop advocacy skills; 90% believed the program offered opportunities to develop program planning; 36% believed the program offered opportunities to develop research skills; and 20% felt opportunities were extended to acquire evaluation skills.

Resources

All respondents believed that resources within the community to support program activities were fully identified and accessed by the program and generated trust and cooperation within the community to promote program goals. Examples included volunteers, local grocery stores providing fruit and juice boxes, swim passes from the

recreation centres, and office and meeting space for the program. As one respondent stated, "We pool resources within." However, only 44% respondents believed the program fully accessed resources outside the community.

Partnerships and Networks

Most respondents believed the program fully brought agencies and groups together to express joint views and concerns related to cancer and cancer prevention. There was a strong feeling among all of the respondents that a significant number of partnerships had been developed in the community as a result of the program and had fully established structures and mechanisms to facilitate and maintain these partnerships. Most people reported that the program enjoyed reciprocal links with other local groups and organizations.

Sense of Community

All respondents believed that the program fully demonstrated a high level of concern, respect, and generosity for community members. Similarly, all respondents believed it supported and reflected community history, norms, and values to the fullest possible extent.

Community Infrastructure

Half of the respondents believed the program contributed to new organizations or networks that work together to address the issues that affect them, with 36% reporting that the program contributed to community structures to the fullest possible extent and 45% indicating that it had fully fostered change or improvement in health-related policies in the communities. Just over half (58%) of the respondents believed the program had increased the ability and confidence of the community to undertake cancer prevention initiatives.

CONCLUSION

The same negotiated accountability that ensured truly collaborative practices from the inception of the program also allowed communities, administration, and funders to reach a working agreement regarding the framework and scope of an external evaluation. While providing all parties with useful information on program performance and progress, the resulting evaluation also enabled administration and

funders to appreciate the range and depth of the challenges faced by the communities involved and to reconsider the achievements and failures of the program within the rubric of local relevance and effect, rather than purely in terms of approximation to organizational goals and cost effectiveness. Similarly, at a grassroots level, this process was sensitive to the high value placed by the community on a “shift in the feeling that there is something that can be done to prevent cancer,” and the take-home lesson for all was provided by a community member who advised administration, “Don’t assume” when it comes to community development.

These important but subtle aspects may or may not have been detectable using a participatory approach that did not include a critical element. However, including negotiated accountability challenged all parties to continuously consider the values and perceptions they brought to the evaluation table in terms of consequence and responsibility.

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