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Representation strategies in public participation in health policy: The Aboriginal Community Health Council

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Abstract

Within Canada’s Aboriginal population, an ongoing health promotion strategy has been the facilitation of community participation in the development and application of health policy. The Calgary Health Region’s Aboriginal Community Health Council has provided a setting for involving the local Aboriginal population in health policy and program development for over a decade. This paper represents the results of a case study to identify the Council’s strategies for this work. Data sources included documents, such as meeting minutes and other reports; key informant interviews with past and present Council members and health region representatives; and participant observation of Council functions. Although direct membership in the Council provided a core approach for representing the community, other strategies were actively utilized to involve the public. These included building links and partnerships with community organizations, networking, consultation activities and the identification of special needs groups.

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1. Introduction

Canada’s indigenous peoples are currently suffering from one of the worst health status records in the Americas [1]. The gap between the health of indigenous people and colonizers is significant in many countries and “tacit acceptance of continuing disparities” is no longer acceptable (p. 405) [2]. A key strategy proposed for improving the health of this population is increasing the involvement of Aboriginal persons in both health care delivery and health policy development [3–5]. This has been a focus of the national Institute of Aboriginal People’s Health [6]. Over the past two decades, there have been a number of programs that have attempted to increase the participation of Aboriginal persons in their own health care [7–10]. These can be seen in the development of university-based recruitment and training programs for Aboriginal health care workers and through the creation of the Community Health Repre-
sentative program, the goal of which is to provide a referral and facilitative link for Aboriginal persons to existing health care services [11]. However, such initiatives have generally limited their focus on service delivery, rather than participation at a health systems level policy.

More recent activities in health policy participation can be seen in the creation of several Aboriginal advisory committees working with government health planners at both a provincial and regional level. In many cases these advisory bodies have been a community driven response to a renewed emphasis on increasing public input and representing the various Aboriginal populations in the development and implementation of health policies. In some cases, this is rooted in the 1979 Canadian Health Policy that recognized "that Indian people may assume responsibility for administering any or all aspects of their community health programs" (p. 12) [12].

A major focus of health care reform in Canada has been the regionalization of health services administration. In the 1990s, 9 of 10 provinces in Canada, where health is a provincial responsibility, regionalized the administration of the health systems [13], thus decentralizing authority from the provincial governments. One of the intentions of regionalizing health services was that the resultant system would be more responsive to the particular health needs of the communities that they served [14]. In many locations, regionalization discourse included a commitment to public participation in health service planning. The movement to increase community involvement has focused on the belief that increased consumer participation will provide the information needed to make systems more responsive [15,16]. In Alberta, Canada, the government legislation creating regional health authorities required each one to have a Community Health Council that would provide input from the general public.

In the Calgary Health Region (the Region), the decision was taken to create the Region 3 Aboriginal Community Health Council (the Council). The Region serves a large geographic area surrounding and including the metropolitan area of Calgary and several First Nation reserves. The Region now serves about 1.6 million people including a diverse Aboriginal population and the fourth largest urban Aboriginal population (about 50,000) in Canada. As described in their mandate, the Council was created to provide representation for the Aboriginal population in the Region’s services:

The primary purpose of the Council is to promote the provision of culturally appropriate health services to Aboriginal people of Region 3 and those from other regions utilizing the services of Region 3 that enhance the ability of the individual and family to achieve optimal spiritual, mental, emotional and physical health.

[17]

Created in 1996, the Council is a unique and long-standing example of public participation initiatives and is the focus of this paper. The study reported here was also included as part of a multiple case study of public participation [18]. Within this multiple case study, we sought to provide a history and development timeline, as well as a description and analysis of the community participation strategies. Reported in the present paper is a portion of the results which focused on the following research question: what strategies for participation in health policy did the Council utilize and what were the strengths and challenges of these strategies? In this paper, we describe the strategies and activities used by the Council to represent Aboriginal persons in the development and implementation of health policies within the Calgary Health Region.

2. Methods

A single case study design using qualitative methods was employed for this study. Permission to conduct this research was first sought and obtained from the Region 3 Aboriginal Community Health Council. This research was also granted ethical review by the Conjoint Medical Ethics Review Board at the University of Calgary.

2.1. Data collection

To ensure a rich description of the case, data were collected from multiple sources. The first method was a review of documents concerning the operations, activities and policy directives of the Council over a 15-year period (1995–2000). Examples included minutes from meetings, membership lists, program reports and evaluations. The second method was a set of 13 per-
sonal interviews with key informants undertaken between February and November 2000. Individuals who held key positions in the Council and/or who had served in a long-term capacity with the Council were identified for interviews. The selection process was guided by the desire to choose a range of informants who could best capture all points of view with regards to the Council, a strategy identified by Patton [19] as maximum variation sampling. This strategy took into account the diversity of the individuals who participate in the Council’s activities and the diversity of the city’s Aboriginal population. The interview guide included questions on the history and development of the Council, and a series of questions on the Council’s roles, representation strategies and activities. All interviews were audio-taped and conducted by the same individual. The final method was participant observation. In this case, the researchers had the opportunity to observe the operations and activities of the Council through attendance at monthly meetings and retreats between November 1999 and February 2001. Detailed field notes concerning these interactions were taken during and after these events.

2.2. Analysis

Interviews and field notes were transcribed verbatim into Microsoft® Word. Minutes from the Council meetings and a number of other documents were scanned into Microsoft® Word using a text recognition program. All Word documents were checked for accuracy, formatted as needed and transferred into the qualitative software program NUD*IST 4 for storage and analysis [20]. The first step in the analysis process was an extensive review of the data collected for this study. During this review, data sources were viewed individually and units of data were coded based on activities, themes, issues and events. The codes formed a template that was used to answer the research questions. Units of data ranged from phrases to paragraphs to entire documents, as appropriate. The second aspect of analysis involved the task of categorical aggregation [21], during which the coded data were reviewed to collect similar instances in an effort to elicit common themes. Emerging themes were explored between data sources in an effort to search for relationships, consistencies and/or inconsistencies. During this analysis process, the researchers met regularly to discuss the data and results. A summary of results was presented to informants who were asked to provide feedback and clarification. The result of this participant feedback was the correction of minor inconsistencies in dates or titles of Council events.

3. Results

3.1. Community setting

Canada’s Aboriginal peoples do not reflect a homogenous population. Rather, they are a diverse group of communities composed of many nations and backgrounds. This diversity is also characteristic of Calgary’s Aboriginal population, which is comprised of Aboriginal peoples from around the province and the country. Some of the groups represented in the city and the surrounding areas include the Blackfoot, Cree, Metis, Ojibway, Tsu’tina and Stoney nations. As will be discussed throughout this section, the Council is challenged with representing these communities through its operations and activities. During interviews, informants commented on this diversity and identified numerous elements that reflect the multifarious nature of Calgary’s Aboriginal population. Informants also expressed caution in grouping these populations together and the necessity for the Council to recognize and address the diversity within the Calgary Health Region.

When we use Aboriginal community, we use it with a lot of caution. We don’t want people to forget that it’s diverse because if you put everybody in one basket and not recognize the differences, you can do some harm.

(Informant)

The Council has identified being an advocate for the urban Aboriginal population as its role. Within this role, informants saw the Council as being responsible for attempting to represent the needs and opinions of the urban Aboriginal population. As one informant described the role:

To be a voice for the Aboriginal people. To represent . . . to provide representation for the urban Aboriginal population. To address the issues in Aboriginal health and to try to make a difference in those areas and make change.
In its efforts to effectively serve in this role and represent the needs of this dynamic and diverse population, the Council employed a number of strategies. As described below, these strategies ranged from formal membership in the Council to efforts to identify the health needs of the various groups who comprise the city’s Aboriginal population.

3.2. Membership

One of the more direct approaches to representation is through membership on the Council, which is comprised of 18 individuals who are appointed through a nomination and review process. The membership process reflected the Council’s efforts to create a diverse membership group, representative of the Aboriginal population. This was partially accomplished through the requirements defined within the official establishment bylaws of the Health Council and through informal efforts to identify under-represented groups.

When we appoint people or get people to apply to become a member of the Council, the effort is made to try to get a wide representation of various Aboriginal community elements. (Informant)

For example, the Council made efforts to invite both Elders and youth to be part of the Council’s membership. Representation on the Council by agencies and organizations that provide services to the Aboriginal population was in place from the beginning. Informants noted both positive and negative aspects to agencies and organizations playing such a key role in the Council. One informant noted that through this strategy sub-populations can be represented on the Council through an agency member. However, this type of representation was also seen as a potentially limiting factor:

I think one of the limitations is that the majority of the representation is probably agency representation which is limiting because it does mean that those in the general community who don’t, aren’t working in an agency at an administrative level or whatever, that they probably are underrepresented. (Informant)

3.3. Operations

Community participation in the Council’s activities was not limited to formal membership. The operations of the Council also allowed for non-member participation. Council meetings were held in public and anyone could attend these meetings. One informant noted how this characteristic facilitated non-member participation:

It’s by involving people, like the meetings are pretty well open. People can come in to listen to what’s going on. We have guests come in.

Individuals attending these meetings could also make announcements and/or raise concerns by requesting to be placed on the meeting’s agenda. One informant noted this is a continuation of oral traditions:

And the fact that we have our meetings every third Wednesday of the month, it’s standing, and we all know that, and many times we tell other people you know, if you want to present, ever. The oral tradition of my culture we’re still using that, within that atmosphere.

As a result of this openness, many attendees at Council meetings were observers, and there was regular participation in Council discussions by these individuals. In some cases, observers even served on working committees for the Council’s various initiatives. Many individuals who were observers also became formal Council members at later dates. One informant noted their experience in this regard:

So I was going as an observer, going to sit and listen to the concerns of the people...what was happening...how the Council was helping the community at large. So then I became a voting member.

Finally, the role of an observer was also a method for former members to continue to participate in the Council activities.

The Council could also seek out the participation of specific groups through its activities. In particular, the Council initiated a number of efforts to involve Elders within the workings of the Council. Although a number of Elders served in a formal membership role, the Council also took steps to facilitate

the involvement of Elders in a non-membership role.
For example, the Council provided an honorarium for transportation costs for any Elder wishing to attend a Council meeting. The Council organized an Elders sub-committee to plan activities and gather input from Elders.

3.4. Special populations

The Council’s efforts to represent the needs of different groups were not limited to the direct participation described in the above sections. Often representation was accomplished through the Council’s own initiative to identify and/or take action regarding the needs of a sub-population defined by either age, sex or a health need. Formally, this role was outlined in the establishment bylaws as a function of the Council:

Gathering information and Community input relating to the health and health needs of the Aboriginal Community served by Region 3. [17]

For example, one informant discussed how the Council functioned in this role in addressing HIV/AIDS, describing how the Council gathered information to identify the Aboriginal HIV/AIDS population as having unmet needs in the community and what action the Council needed to take to meet these needs.

Throughout the Council’s history, there were numerous other examples of the Council’s efforts to identify the health needs of different populations. With regards to the paediatric population, the Council played a role in initiatives such as the Head Start Program and research on the need for a Children’s Health Center. Information was also presented during Council meetings on child and youth health issues ranging from immunization to SIDS to employment. In recognizing the health needs of women, the Council supported a proposal for a Calgary Women’s Homeless Shelter, participated in a Women’s Planning Group, and regularly brought information on women’s health issues and services in the city to the meetings. The Council discussed the needs of populations with particular health needs, such as, those with diabetes, renal, transplant, mental health and cardiac patients, the homeless and the disabled.

3.5. Consultation and external participation

Another strategy the Council utilized to represent the health needs of Calgary’s Aboriginal population was participation in various community consultation activities. The Council became involved in these consultations through two routes. In the first, the Council was approached by an outside entity to participate in a consultation initiative. The second route for Council involvement was through the initiative of its own members. Council members brought forward numerous opportunities to participate in consultation initiatives. In some cases, members became aware of these consultations through their employment setting and believed that the Council should be a part of them. The Council was also a part of numerous externally sponsored initiatives that included steering committees, program proposals and research projects. In participating in these consultations and external projects, one or more Council members attended the meetings of the initiative and then provided reports back to the Council. In this way, a two-way information flow was established from the Council to the initiative’s planners. This strategy had the advantage of allowing the Council to branch out in their efforts and to be a part of an initiative that internal resources (i.e., financial and human) may not have allowed. This type of participation, however, required a substantial commitment of volunteer time from members.

3.6. Links and partnerships

Another strategy the Council employed was the development of collaborations or partnerships. The Council developed relationships with numerous community agencies and organizations. One informant described this strategy in the following manner:

They’ve provided a lot of support to community members through community projects. That’s when members would go and support other efforts, like the Calgary urban Aboriginal outreach project was also a partnership. They would partner with other agencies . . .

3.7. Endorsement

The Council was often approached to provide their endorsement for a project. This included proposals
from staff in the Calgary Health Region that affected Aboriginal persons, but it also included individuals or groups from outside of the Region seeking various types of support (e.g., funding and partnerships) from the Council. Endorsement in principle was often provided via a letter from the Council chair.

3.8. Networking

Through its members and contacts, the Council played a key role in networking with health authority employees, community members and agencies. One informant noted that the Council used this strategy to identify issues and events:

In beginning to identify an activity or an event that might be of interest … I guess another way of considering it would be I guess a network, a community network that would pass the word along by word of mouth.

By networking, the Council also served as a mechanism through which information on Aboriginal health could be presented and passed to the broader Aboriginal community. All the strategies outlined previously played a role in building networks and exchanging information. As one informant said, the Council served as a conduit for a range of information:

I think the Health Council is the conduit from which wellness and health will be understood, interpreted, researched, where the issues will come forward. It will provide the ground from where the voices of the people will come through.

3.9. Other benefits of public participation

The Council utilized a number of approaches for facilitating the participation of the Aboriginal community. For those who were direct participants in the Council (i.e., members and observers), the impact of the Council was primarily one of individual capacity building. This was a result of the skills acquired through members’ participation in the numerous activities that the Council undertook. This list included proposal writing and review, research and planning processes for a wide range of activities and programs, funding applications and organizational activities required to operate the Council. Working with the Council, and consequently the Region, also provided participants with an opportunity to become more knowledgeable about the health system and to gain first-hand experience with the operations of a large organization. The experience and skills acquired through this participation enhanced potential employment opportunities and provided skills that could be used in different settings. Through this, individuals took skills back to the organizations in which they worked. Some respondents also attributed their organization’s membership on the Council as providing more status and credibility for the organization. This served them well in activities like fund raising.

4. Discussion

The present investigation addressed gaps in the knowledge surrounding public participation efforts among Canada’s Aboriginal populations. Few sector-wide participatory initiatives among urban Aboriginal populations have been described in the published literature. The information provided in this paper may be of benefit to Aboriginal populations and health regions by providing an example of one method to involve the public in the decision-making process. This case has shown that the participation strategies employed by the Aboriginal Community Health Council far exceed attendance at regular monthly meetings. The Council was a dynamic organization extending networks throughout the community.

Some of the potential challenges emanating from the Council’s strategies also reflect the limitations of public participation previously identified within the literature. For example, if the perception of requiring skills, status or knowledge to participate in an initiative is a hindrance for community members [22] to become a part of the Council, some individuals may be excluded. Most of the Council members had professional backgrounds, therefore, a perception that this is necessary was reinforced. One of the Council’s identified challenges was reaching out to and involving the wider public in the Council’s activities. To accomplish this task, the Council may need to employ appropriate techniques to facilitate the participation of those who do not have experience. These techniques need to reflect the daily lives, comfort level and experience of the target community [23].
At the same time the notion of representation is problematic in many ways [18,24,25]. As Contandriopoulos [24] states, “public participation conceived as one particular form of political action distinguishes itself by its very limited recourse to formal representation” (p. 327). The struggle over who speaks for whom, and when, is inherently a political or power struggle. For Aboriginal people this is embedded within a struggle to overcome the results and constraints of colonialism [26] while holding true to traditions of relationship and communality in the midst of social and cultural changes [4]. The issues of representation, self-determination, self-government and governance of health care deserve more attention than possible in this paper.

Potential limitations of this study can be found in the sample obtained in this project. All of the informants in this sample had been involved with the Council for at least some period of time. It stands to reason that their continued involvement would be a result of at least some positive aspect(s) of their experience with the Council. As a result, the sample may have only reflected the opinions of those who have had a positive experience with the Council. The sampling procedure also did not capture the opinions of community members not associated with the Council. Including representatives from this group within the sample may have allowed the researcher to further delineate the Council’s role within the community.

In conclusion, the Council utilized a variety of strategies to represent and address the health needs of Calgary’s diverse Aboriginal population. The Council provided the kind of dynamic and adaptable process that resulted in long-term relationships and opportunities for both proactive and reactive participation in health policy development. The Council showed that “authentic participation is possible” when structures are established to enable it (p. 325) [27,28]. The Council established a good working relationship with various health region staff and health region board members. As Kelly and Brown [29] showed, good communication over time can help build mutual trust and cultural competence. Kirmayer et al. [4] concluded that many programs have failed due to the lack of Aboriginal participation; therefore, initiatives like the Council are positioned to have lasting and important affects on the health status of Aboriginal populations. The challenge is that direct linkages between their work and these positive outcomes will be nearly impossible to make. We must now rely on either the counter-factual, that is, what would the community look like if we did not have the Aboriginal Community Health Council, or a discussion of other options for public participation that might have produced more results [30]. This process will be left to the Council members.

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