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Evaluating Community Participation in Health Care Decision-Making: The Case of the Airdie/North Rocky View Health Needs Project

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EVALUATING COMMUNITY PARTICIPATION IN HEALTH CARE DECISION-MAKING: THE CASE OF THE AIRDRIE/NORTH ROCKY VIEW HEALTH NEEDS PROJECT

by

Aleisha Dawn Harrington

(Bachelor of Arts, First Class Honours in Psychology, University of Calgary, 1999)

THESIS

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Abstract

Rising health care costs combined with limited health resources have made it essential for health agencies around the world to identify successful and affordable ways to prevent disease and promote health. Several national and international documents have proposed that increased community participation in health matters is one potential approach. While many of these reports detail the benefits of and need for community participation in health care decision-making, they provide little information as to how this should be achieved. The result has been a myriad of interpretations, interventions and practices of community participation. According to several scholars, evaluations are needed that assesses these approaches to determine what works, what doesn't and why, as well as demonstrate that the assumed benefits associated with increased participation are valid.

Drawing upon the principles of illuminative evaluation as well as utilizing qualitative interviewing and a community participation assessment tool, the purpose of this research was threefold. First, it sought to evaluate a community participation project by having participants identify strengths and weaknesses of the process. Second, this research explored the value of this project for community participants and the health agency. Lastly, this study sought to provide feedback and recommendations to the health agency regarding this project.

Findings from the evaluation indicated that for the most part those interviewed felt that the community participation process adopted by the health agency was excellent. Participants identified the reliance on evidence, working together to collect evidence, and the project manger as real strengths of the process. Although participants felt the process implemented by the health agency was a success, reactions to the outcomes of the project and how it ended were surprisingly negative. Several interrelated factors seemed to contribute to these feelings the first being the different expectations that participants had for the project. Other factors, such as a lack of funds to carry on with subsequent phases of the project; life issues and priorities emerged that took precedence over health needs; and the announcement that a southern community located outside of Calgary was getting a urgent care facility, also contributed to feelings of dissatisfaction towards the project's outcomes and ending. Even though the results of the project did not exactly meet expectations, respondents did feel that the initiative achieved some larger benefits such as opening up a dialogue between the two groups, which increased understanding and awareness of each other's perspectives regarding health care provision. For community members there was also the sense that the information collected during the project legitimized their concerns about. Based on the findings, suggestions and recommendations are put forth that may improve future community participation projects such as the need to clarify goals and expectations; the role of context; the challenge of sustaining participation and the importance of communicating back to communities the impact of their participation.

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To my advisor, Dr. Juanne Clarke. Your input, wisdom and willingness to listen kept me going and challenged me to go deeper.

To my parents, Jack and Cora. I would never have been able to do this without your patience, love, humor, and support.

I also owe a special debt of gratitude to the participants who took time out of their busy schedules to meet with me and share their stories about community participation.

Dedication

I would like to dedicate this work to my husband David and my new daughter Ava.

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Chapter One: Background

1.1 INTRODUCTION TO THE ISSUE

> *"The conclusion is inescapable: public participation is not only valuable but also essential to the achievement of health for all Canadians."*
>
> (Epp Report, 1986)

In Canada, national and provincial documents have been increasingly advocating for greater participation of local communities in the planning, development, and allocation of health services and resources (Epp Report, 1986; Fyke Report, 2001; Kirby Report, 2002; Lalonde Report, 1974; Romanow Report, 2002). Driving these calls are demands by citizens for more accountability and transparency in the spending of public funds and the belief that participation will facilitate numerous benefits, such as a less costly and more efficient health system (Charles & DeMaio, 1993; Church, Saunders, Wanke, Pong et al., 2002; Frankish, Kwan, Ratner, Wharf-Higgins & Larsen, 2002).

Interest in engaging communities in health care decision-making has spurred many health agencies to begin experimenting with different participation techniques. Although several Canadian health organizations have developed frameworks that seek to guide participation practices by outlining key concepts, values, principles, levels, techniques and planning steps (Calgary Health Region, 2002; Health Canada, 2000; Winnipeg Regional Health Authority, 2004; Vancouver Island Health Authority, 2003), these documents say very little about evaluating these initiatives or how this might be accomplished.

The lack of direction around evaluating community participation practices has resulted in little systematic knowledge about “what does and does not work when it comes to designing public involvement processes; what impact these processes have on participants, decision makers and decision-making or how these processes are shaped and constructed by the different contexts within which they are implemented” (Abelson, Forest, Eyles, Casebeer, Martin & Mackean, 2007, p. 2115).

The paucity of evaluations of community participation practices is concerning for several reasons. First, without evaluations how do we know that community participation practices are achieving the expected benefits anticipated by community participation theorists? Second, without evaluations how can we be sure that health agencies are implementing appropriate and effective strategies? Lastly, without evaluations how do health agencies know if these practices are meeting the needs of the communities they are seeking to involve? According to several authors what is needed are in-depth analyses of community participation projects, at the local level, that share both positive and negative experiences in order to clarify what works, what does not and why (Abelson, 2001; Rifkin, 1986; Zakus & Lysack, 1998).

Therefore the aim of this research was to address the need for evaluations of community participation in healthcare decision-making. This was accomplished by assessing a community participation project that took place between the Calgary Health Region and the community of Airdrie/North Rocky View. More specifically, this research sought to identify the project’s strengths, weaknesses, benefits and limitations, from the perspective of participants, in order to learn from and potentially inform future participation projects.

1.2 PERSONAL LOCATION

When working as a summer research assistant for the Calgary Health Region, I came across a final report on a project that occurred between the Calgary Health Region and the community of Airdrie/North Rocky View, which sought to engage the community in a collaborative process to look at and analyze their need for after-hours medical care services. As a passive recipient of health care, I was struck by these peoples' willingness to take on such an active role (i.e. collecting and interpreting data) in making decisions about healthcare services and began to wonder what that experience had been like for the participants. Reference was made in the final report regarding the intent to conduct an evaluation of the project so I approached a co-worker to ask about the findings. She informed me that an evaluation had never been done due to a lack of funds. I began to think that conducting an evaluation of this project would make an excellent thesis topic for my Masters degree in Community Psychology, primarily for two reasons. First, a fundamental concept within the discipline of Community Psychology is the notion that "communities should participate in defining the problems or issues that affect them, and in deciding how to resolve them" (Dalton, Elias & Wandersman, 2001), p.17). By undertaking this research I would be contributing to my understanding of the different ways this can be accomplished. Second, evaluation research had been strongly encouraged in my course work and was identified as being critical to achieving several of the disciplines' goals such as optimizing the wellbeing of individuals and communities, facilitating psychological competence and empowerment, preventing disorder, and promoting constructive social change (Dalton, Elias & Wandersman, 2001). Therefore, this research would provide me with an opportunity to apply the knowledge I had gained about conducting evaluations as well as develop practical skills in this area.

1.3 THESIS OUTLINE

This work is divided into 5 chapters. In the remainder of Chapter 1 the literature on community participation in health care decision-making is reviewed to explore how it has been conceptualized, why it is being advocated for in the health sector, what it is expected to achieve, and why evaluations of these practices within the health sector are needed. Chapter 2 further details the purpose of this evaluation, the evaluation approach taken to assess the community participation project and how the research was conducted. In Chapter 3 the project that was the focus of this evaluation is described in detail. Chapter 4 presents the findings generated from the research study while Chapter 5 makes recommendations based on these findings and provides suggestions for future research.

1.4 REVIEW OF THE LITERATURE

1.4.1 What is Community Participation?

Although increased community participation is a central feature of many health care reforms, a precise definition of this concept remains elusive. This is due in large part to the multiple meanings associated with the terms *community* and *participation.* Take *community* for instance. Within the health sector several definitions of community have been identified. Most common include: (a) a group of people sharing a geographical space; (b) a group of people sharing a common interest, identity, or interaction; (c) a group of people who share a common health problem or concern; or (d) the general public or lay people (Meleis, 1992; Smithies & Webster, 1998). Jewkes and Murcott (1996), in an analysis of the meanings of community expressed by health promotion workers, refer to the work of George Hillery who in 1951 conducted a review of sociological research and found 94 interpretations of community (p.557).

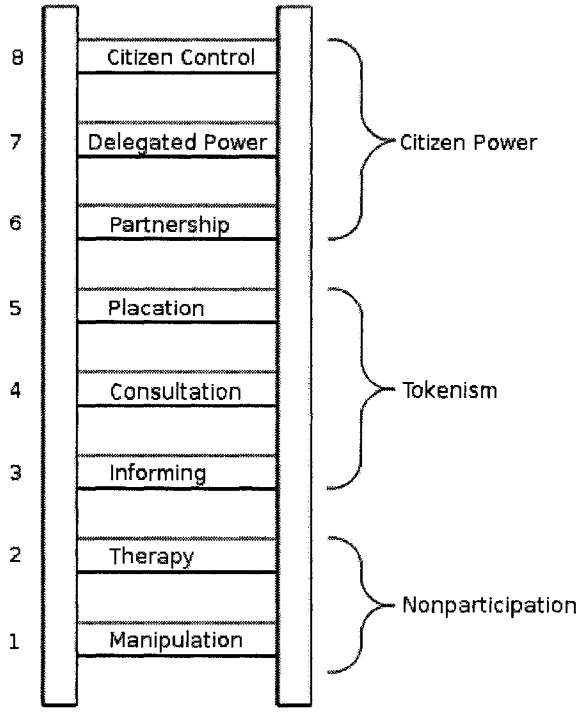
According to several authors how *community* is conceptualized will depend on who is doing the defining and the context in which participation will occur (Church et al. 2002; Olico-Okui, 2004; World Health Organization, 2002). For example, an epidemiologist will most likely construe community to mean those at risk for a certain disease or illness while an anthropologist might interpret community as a group of people who share a cultural heritage.

Like community, *participation* also has several meanings. According to Kahssay and Oakley (1999), two distinct interpretations of participation are apparent in the health literature. The first sees participation as a means or intervention to achieve a specific outcome, such as local cooperation with a proposed health program or following health advice from a doctor. The other form views participation as an end in and of itself, or rather a process in which people over time develop the skills, knowledge and confidence to improve and gain control over the conditions that affect their lives.

To Rifkin (1996), these different views of participation reflect two distinct paradigms. The first, of which she refers to as the "target-oriented frame" (p. 81). This approach has roots in the biomedical model of health and illness and views health improvements to be possible by either getting people to follow the advice of medical doctors or to buy into a particular health program. The second paradigm she called the "empowerment frame" (p. 81). This paradigm emerged from the post war and ex-colonial period and views poor health as a result of the unequal distribution of resources. In this line of thinking, improvements in health requires that structural changes occur at the local level, which can only be achieved as excluded or marginalized groups, such as the poor, gain access to information and resources (p. 82).

Drawing upon these different perceptions of participation, Sherri Arnstein (1969), contended that participation is best understood as a continuum that ranges in the degree to which community members are allowed to become involved in and have control over the decision-making process. She developed a typology that identified eight different levels of participation (see Figure 1.). The lower end of the continuum is characterized non-participatory, as the objective of participation is to educate or cure rather than provide an opportunity for community input.

Figure 1. Arnstein's ladder of citizen participation



The middle rungs are described as tokenistic because community members are allowed to have a voice but have little decision-making authority. The higher levels of the ladder represent citizen power as community members have increasing degrees of decision-making clout.

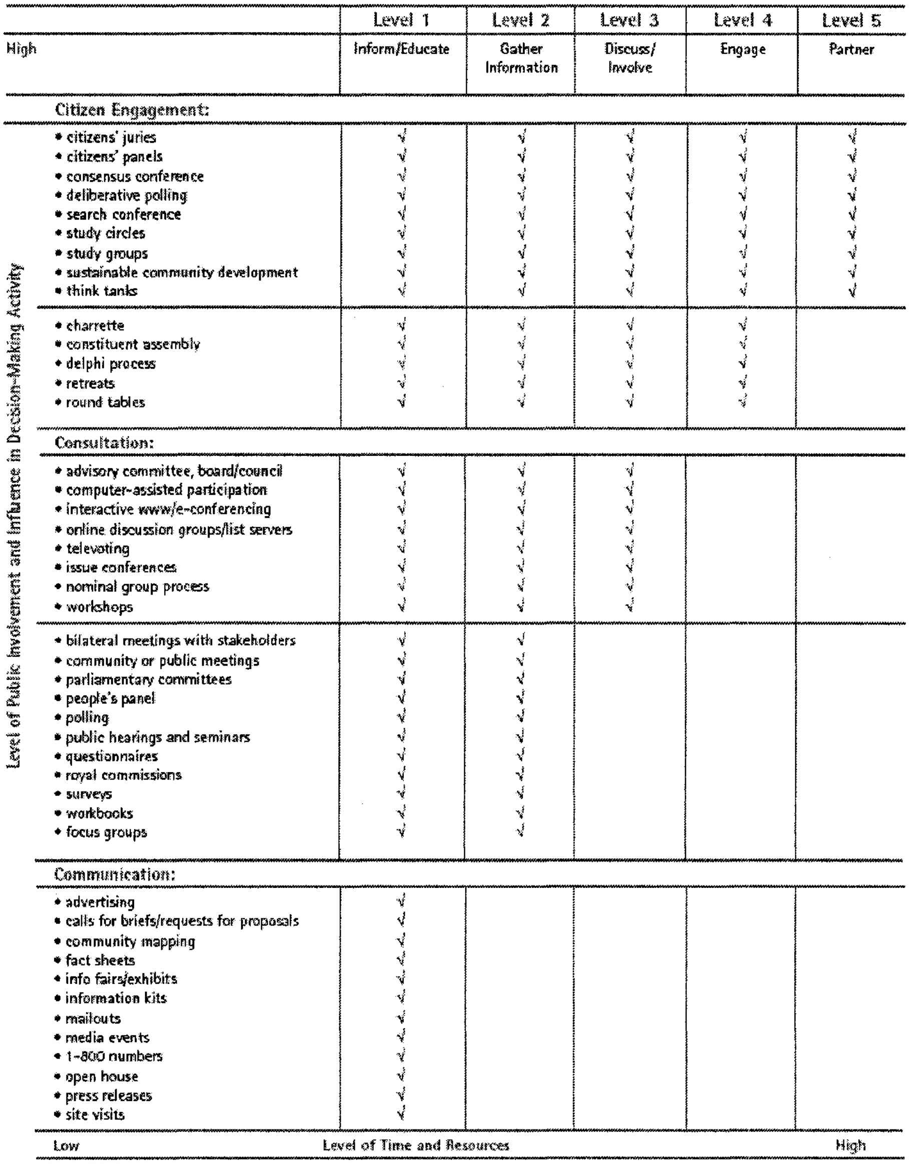
Since 1969, numerous people have adapted her work, modifying the names and numbers of the rungs (Charles & DeMaio, 1993; Health Canada, 2000; Rowe & Frewer, 2005).

It is important to stress that these continuums are not meant to represent a good versus bad dichotomy but rather to illustrate that certain situations will require different levels of participation and that it is not always feasible or appropriate to aim for the "top rung of the ladder" (World Health Organization, 2002, p. 15).

The level of participation sought is influenced by a number of factors. According to the Public Health Agency of Canada (2002), factors that will impact on the level of participation selectedd include: (a) the nature and complexity of the issues; (b) the goal and phase of the policy-making processes; (c) the expected level of participant influence and involvement; (d) participant profiles (i.e. the mix of citizens versus group representatives); (e) the previous experience of facilitators with public involvement techniques; (f) time lines, financial costs, human resources, and expertise; (g) the degree of intersectoral collaboration required; and (h) the level of support for public involvement processes from stakeholders and partners. Other factors that could affect participation suggested in the literature include: the level of awareness participants have of belonging to the "community" (Meleis, 1992); the level of homogeneity of the defined community (Woelk, 1992); a history of common struggle (Bracht & Tsourous, 1990); whether health is a priority or concern of the community (Brownlea, 1987; Rifkin, 1986); and a political, economic and sociocultural climate that supports community participation (Zakus & Lysack, 1998). Given these factors, the Public Health Agency of Canada (2002) suggests that higher levels of participation are warranted when issues involve potential conflicts in values or identity, difficult choices or tradeoffs, or have a major impact on citizens.

Recognizing that different situations will require different degrees of participation, health agencies have developed a plethora of methods to engage community members in the decisions that affect their health. To enhance clarity, these various methods have been grouped into three broad categories – communication, consultation, and engagement - based on the flow of information and the intensity of interactions required between sponsors (i.e. policy makers, government, organizations) and the communities they seek to involve (Rowe & Frewer, 2005). The **communication** category represents activities that are designed to inform rather than elicit input on an issue or decision. Information flow is characterized as unidirectional (from the sponsor to the community) and the intensity level is fairly low, as the groups do not interact with one another. Within the **consultation** category, participation methods seek to obtain the community's opinions and views on a topic or issue in order to inform a decision. The flow of information is still considered unidirectional but is reversed (from the community to the sponsors). The intensity level for these activities is higher than for communication as some interaction between the groups is needed. Methods in the last category, **engagement**, are designed to generate a dialogue between community members and sponsors in which to deliberate an issue. Information flow is described as bidirectional and activities are quite labour intensive as sustained contact between the two groups is generally required. Figure 2. illustrates how different participation methods can be sorted using these three categories.

Figure 2. Health Canada's Public Involvement Continuum Matching Actions to Needs (2000)



		Level 1	Level 2	Level 3	Level 4	Level 5
High		Inform/Educate	Gather Information	Discuss/ Involve	Engage	Partner
Level of Public Involvement and Influence in Decision-Making Activity	**Citizen Engagement:**					
	• citizens' juries	√	√	√	√	√
	• citizens' panels	√	√	√	√	√
	• consensus conference	√	√	√	√	√
	• deliberative polling	√	√	√	√	√
	• search conference	√	√	√	√	√
	• study circles	√	√	√	√	√
	• study groups	√	√	√	√	√
	• sustainable community development	√	√	√	√	√
	• think tanks	√	√	√	√	√
	• charrette	√	√	√	√	
	• constituent assembly	√	√	√	√	
	• delphi process	√	√	√	√	
	• retreats	√	√	√	√	
	• round tables	√	√	√	√	
	Consultation:					
	• advisory committee, board/council	√	√	√		
	• computer-assisted participation	√	√	√		
	• interactive www/e-conferencing	√	√	√		
	• online discussion groups/list servers	√	√	√		
	• televoting	√	√	√		
	• issue conferences	√	√	√		
	• nominal group process	√	√	√		
	• workshops	√	√	√		
	• bilateral meetings with stakeholders	√	√			
	• community or public meetings	√	√			
	• parliamentary committees	√	√			
	• people's panel	√	√			
	• polling	√	√			
	• public hearings and seminars	√	√			
	• questionnaires	√	√			
	• royal commissions	√	√			
	• surveys	√	√			
	• workbooks	√	√			
	• focus groups	√	√			
	Communication:					
	• advertising	√				
	• calls for briefs/requests for proposals	√				
	• community mapping	√				
	• fact sheets	√				
	• info fairs/exhibits	√				
	• information kits	√				
	• mailouts	√				
	• media events	√				
	• 1-800 numbers	√				
	• open house	√				
	• press releases	√				
	• site visits	√				
	Low	Level of Time and Resources				High

So what is community participation? Given the various ways in which both *community* and *participation* can be conceptualized, it has come to mean many different things to different people and is in constant flux as people and situations change (Rifkin, 1986).

In essence though, community participation in health care is generally understood to mean:

> a process whereby people, both individually and in groups, exercise their right to play an active and direct role in the development of appropriate health services, in ensuring conditions for sustained better health, and in supporting the empowerment for health development. (World Health Organization, 1991, p. 14)

Again, how community participation is expressed will vary depending on the context and people involved.

1.4.2 Why Community Participation in Health Care?

The literature has identified a number of social and political influences that have prompted increased demand for community participation in health care. An important catalyst was a shift in "Development" thought and practice in the 1970's.

The 1950's and 1960's saw an increase in community initiatives, especially in Third World countries, to help alleviate mounting social and economic problems (Jewkes & Murcott, 1998; Kahassay & Oakley, 1999; Rifkin, Lewando-Hundt & Draper, 2000; Sawyer, 1995; Smithies & Webster, 1998). During this period, the accepted practice was one in which external agencies/professionals designed, delivered, and directed all programs and services (Kahassay & Oakley, 1999). It was assumed that by introducing Western technology and ideas into Third World countries, increased wealth and prosperity would be achieved thus reducing poverty and illness (Sawyer, 1995). By the 1970's, this model of development was under attack. The anticipated outcomes from this professionally driven approach, such as reduced inequalities, had yet to be achieved and, as some scholars observed, the gap between the 'haves' and 'have-nots' was in fact increasing (Esteva, 1992; Foster, 1982). It was argued that the reason this model of development failed to improve the human condition was that it had ignored the needs and concerns of the people for whom services were developed (Kahassay & Oakley, 1999; Rahnema, 1992). A new model was proposed that actively sought direct involvement of previously excluded people in development efforts and encouraged strengthening the abilities of people in order for them to take control of their situations.

A second major contributing factor to the increasing demands for community participation in healthcare decision making was the recognition of the limits of medical care in achieving global health.

With the discovery of germs and their role in infection and disease, the potential for the medical sciences to battle disease and death seemed infinite. The priority of medicine throughout the late 1800's and early 1900's was on developing technology, procedures and drugs that targeted and eliminated these organisms (Konner, 1993). Increasingly, resources were invested into medical care and hospital services (Crichton, 1997). During this period "hospitals and health professionals felt that they were doing the best for their patients by providing them with direct medical treatment" (Greenwalt & Beery, 2002, p. 11). By the 1970's, this medical care approach to health care delivery was being questioned. The radical health improvements anticipated from medical science had yet to be realized. New diseases were emerging and old diseases once thought eradicated were reappearing in new drug resistant strains (Konner, 1993). In addition, chronic illnesses, such as heart disease and diabetes that require some level of health care management across time were rapidly rising, especially among the poor (World Health Organization, 2002). Many of these "chronic" conditions are related to how people live their lives, such as ingesting fatty foods, smoking cigarettes and abusing alcohol. Treatment and prevention of these conditions usually requires people to modify certain behaviours to maintain their health. Unfortunately, as Greenwald and Berry note, "most health care providers are only trained to cure illness rather than assist individuals in changing their lifestyles" (2002, p. 12).

In addition to personal health practices, it was realized that health is largely determined by a number of complex interactions between social and economic factors, many of which fall outside the control of the health sector, such as income and social status (Public Health Agency of Canada, 2002). Take poverty for example. The poor have limited resources to purchase proper food, sanitation, housing, etc., thus increasing the likelihood of becoming ill, reducing their capacity to work to better their circumstance and perpetuating the cycle over again (World Health Organization, 2002).

To date, twelve determinants of health have been identified by the Public Health Agency of Canada (2002):

1. Income and Social Status
2. Social Support Networks
3. Education and Literacy
4. Employment/Working Conditions
5. Social Environments
6. Physical Environments
7. Personal Health Practices and Coping Skills

8. Healthy Child Development
9. Biology and Genetic Endowment
10. Health Services
11. Gender
12. Culture

The impact of non-medical factors (determinants) on health raised questions as to medical professionals' ability to tackle all health-related issues. It also raised doubts as to their legitimacy in making health care decisions for the communities they served (Charles & DeMaio, 1993; Kahssay & Oakley, 1999; Zakus & Lysack, 1998).

A third and related factor influencing the growing demand for community participation in health care decision-making was the rising cost of health care provision caused by increased demands for medical services and development of biomedical technology (Konner 1993). Canada's health care system, like those in many other nations, is structured on the belief that medical care would soon eradicate disease and the need for universal health care coverage would decrease (Crichton, 1997). The escalating cost of health care provision combined with new fiscal realities, such as growing national deficits, have prompted governments to seek new and affordable ways in which to organize and deliver health care services (Church, Saunders, Wanke, Pong et al., 2002).

Other factors identified in the health literature as contributing to increased calls for community participation include: growth of the consumer movement in the public sector (Charles & DeMaio, 1993); social movements such as women's liberation, patient rights and self help movement (Smithies & Webster, 1998); a more educated and informed public that is dissatisfied with current practices

(Health Canada, 2000); and controversial reforms, mismanagement scandals, and difficult decisions needing to be made about limited health resources (Abelson, Forest, Eyles, Smith, Martin & Gauvin, 2003; Charles & DeMaio, 1993; Frankish et al., 2002).

1.4.3 Community Participation in Health Care: Expectations

In 1978, the World Health Organization (WHO) in collaboration with the United Nations Children's Fund (UNICEF) declared that radical changes needed to be made to the ways in which health care was delivered if all people of the world were to receive basic health services (WHO, 1978, Declaration of Alma-Ata). They proposed a new model of health care delivery, called Primary Health Care, which stressed health over illness, prevention over cure, and the needs of the people over the needs of health professionals (Kahssay & Oakley, 1999). Critical to this strategy was the involvement of people "not just in the support and functioning of health services but more importantly in the definition of health priorities and allocation of scarce health resources at the district level" (Kahssay & Oakley, 1999, p. 4). By including people in the decisions that affect their health, the WHO argued that numerous health and social benefits could be achieved (Rifkin, 1986).

First, if communities participated in the development of health programs they would be more willing to contribute resources such as time and money to these initiatives thus offsetting the cost of providing services. Also, community input would result in these projects capturing the felt needs of communities leading to health services and resources being used more appropriately (p. 246).

Second, as communities participate in health care projects they "develop their capabilities and skills to negotiate for and seek the resources and the changes they require to improve their lives" (Kahssay & Oakley, 1990, p. 7). This in turn empowers individuals to gain increased control over the factors affecting their lives, which research has shown enhances peoples' health, well-being and quality of life (Israel, Checkoway, Schultz, & Zimmerman, 1994; Wallerstein, 1992)

Third, as people work together they build social networks and capital that help combat exclusion, counter prejudice and discrimination as well as reducing conflict and building trust, which in turn can lower mortality, morbidity and disease (Maloff et al., 2000; Smithies & Webster, 1998). According to Robert Putnam (2000) "of all the domains in which [he has] traced the consequences of social capital, in none is the importance of social capital so well established as in the case of health and well being" (p. 326).

Lastly, by becoming involved in and exploring the consequences of certain unhealthy behaviours, people would be more likely to "change their attitudes about and actions towards the causes of poor health" (Rifkin, 1986, p. 246) thus preventing many illnesses and the use of costly medical care.

Since the Declaration of Alma Ata, community participation in health care decision-making has increasingly been advocated in several international and national documents as the means by which radical improvements in health can be achieved (Jewkes & Murcott, 1996). These perceived benefits have led many health agencies to pursue community participation.

Although these benefits of community participation in health care decision making are widely accepted, several authors maintain that "the health literature is seriously lacking in empirical studies that demonstrate these benefits" (Zakus and Lysack, 1998, p. 2) and that the "anticipated merits of lay participation should be evaluated rather than assumed" (Charles and DeMaio, 1994, p.890).

1.4.4 Community Participation in Health Care: Caveats

Not everyone is convinced of the overwhelming merits of community participation and some express concern about current attempts to incorporate it into various health policies. Foster (1982) contends that there is a tendency to romanticize communities as homogenous entities that live harmoniously together and co-operate for the common good. He asserts this is an erroneous assumption and points to situations in which community leaders have used information and resources meant for the entire community to enrich themselves and their families (p. 190). This situation is exacerbated in times of poverty and limited resources. Morgan (2001, p. 226) echoes Foster's concerns arguing "that planners should not treat 'community' as a benign entity with shared goals and values because the relationships within particular communities can isolate or even harm some individuals and groups" such as women, disabled, elderly, poor, homosexual, certain religious orders and castes.

Others question the belief that community participants are representative of the community. Community participation takes a great deal of time, energy and effort. These factors may act as barriers to low income, stigmatized, vulnerable or oppressed populations (Meleis, 1992; Zakus & Lysack, 1998). Participation also requires several abilities such as a strong personality, verbal and literacy skills, mediation and negotiation skills, analytic and problem solving skills thus shutting out those who most need to be empowered and who are most likely to be affected by the decision (Maloff, Bilan, & Thurston, 2000). Therefore, those who are most able to commit to the rigors of participation and have the necessary skills are the least representative of the larger community.

There is also increasing evidence that there are limitations to communities' willingness to participate in health care decision-making. For many people, health care is not a priority unless they are ill or if their interests are affected such a closing of a hospital or loss of a service (Abelson et al. 2003; Rifkin, 1986). Several authors have also found that people are more comfortable with consultation roles in which they provide input about health care needs, values, and preferences of the community versus rationing or technical decision-making (Ableson, Lomas, Eyles, Birch, Phil, & Veenstra, 1995; Litva, Coast, Donovan, Elyes, Shepherd, Tacchi et al. 2002; Lomas, 1997).

Many academics have cautioned against viewing community participation processes as inherently good (Brownlea 1987; Cooke & Kothari, 2001; Morgan, 2001; Rahnema, 1992). Within participation practices there are power imbalances especially around knowledge. This can result in community participants not being able to question the authority of professionals, professionals disregarding the input of community members, and professionals or organizers providing selective information in order to influence the decision in their favor or to retain their power and influence (Brownlea, 1987; Charles & DeMaio, 1993; Zakus &

Lysack, 1998). Frequently community participation has been used as a cosmetic label to make what is being proposed or done appear good when in actuality it is masking manipulative, self-serving or corrupt endeavors (Morgan, 2001). This point is powerfully illustrated when Rahnema (1997) writes: “After all, slogans of participation have accompanied the events which led to the physical or mental destruction of millions of innocent people in Germany, the USSR, Cambodia, India, Iran, Iraq and elsewhere” (p. 126).

Given the above factors, scholars argue that community participation can no longer remain an act of faith. Community participation needs to be critically examined to clarify what it is, what is motivating it, what can realistically be expected, and when it is appropriate and for whom (Brownela, 1987; Cooke & Kothari, 2001). Until these issues are addressed participation practices run the risk of being mechanisms of coercion, co-option, and control rather than vehicles for empowering excluded members of society.

1.4.5 Evaluating Community Participation

With more and more health agencies encouraging greater community participation in health care decision-making, the need to assess the impact and effectiveness of these initiatives has increased. Several different strategies for measuring and evaluating community participation activities have been proposed in the literature.

As the field of medicine is strongly linked to the scientific paradigm, evaluation approaches of community participation practices in health care have largely been quantitative in nature (Rifkin, Lewando-Hundt & Draper, 2000).

Initial attempts to assess participation focused on assigning numbers to certain activities (Schmidt & Rifkin, 1996), such as counting how many community participants took part in a project, the degree of decentralization achieved or the number of mechanisms available for the expression of community input (Meleis, 1992; Rifkin & Kangere, 2002). While these approaches are useful in demonstrating the uptake of participation within the health sector, several authors caution that mere presence does not always equate with feelings of satisfaction, influence, empowerment, understanding or even participation (Frankish, Kwan, Ratner, Wharf-Higgins & Larsen, 2002; Schmidt & Rifkin, 1996).

Given these limitations several scholars turned their attention towards identifying principles that characterize good community participation (Rowe & Frewer, 2000, 2004; Webler, 1995). Much of this work has been conducted in the fields of science, technology and environmental policy and has focused on identifying process criteria by which participatory mechanisms could be judged (Rifkin, Muller & Bichman, 1988; Rowe & Frewer, 2000, 2004; Webler, 1995).

According to Abelson et al. (2003, p. 244), four broad evaluation criteria can be identified in this literature. The first criterion they describe is that of *representation* or the degree to which participation processes involve a representative sample of the affected population. A second key criterion, labeled *procedures,* focuses on the process structures of participation and the degree to which they are conducted in an appropriate, unbiased, timely, respectful, and transparent way. *Information* is the third criterion and concerns the appropriateness, quality and accessibility of the content used in participatory processes. The last criterion, called *outcomes,* encompasses how the input provided by community participants is incorporated into the decision-making process.

The first three criteria assess the effectiveness of participation methods by comparing them to the ideals of participation, such as giving voice to marginalized groups or increasing their access to power. The last category judges participation methods by identifying what problems participation is meant to remedy (i.e., educating the public; incorporating public values, assumptions and preferences into decision-making; increasing the substantive quality of decisions; fostering trust in institutions; reducing conflict; making decisions cost-effectively) and determining the degree to which these have been achieved. Using these criterion scholars have tried to rank or score various participation methods (see Beierle 1999, Rowe & Frewer, 2000, 2004).

Although the criterion approach to evaluation does provide us with more information about various participation methods, such as how they compare or differ from one another, their strengths and weaknesses, and which may be better at achieving certain goals for participation than others, there are limitations. First and foremost is that these assessments still rely mostly on quantitative dimensions. Several scholars argue that participation is an abstract concept which cannot be reduced to mere numbers and is heavily influenced by factors like culture, historical, social, economic and political environments which are not easily quantifiable and can interact in unexpected ways on processes and outcomes (Abelson & Gauvin, 2006; Rifkin, Lewando-Hundt & Draper, 2000;

Rifkin, Muller & Bichmann, 1988). Second, as participatory exercises typically involve diverse groups of people, there may be many different interpretations as to what constitutes a successful process. These differing perspectives of success can also dramatically influence perceptions of the process as well as the outcomes achieved (Chess, 2000). Another major limitation of these approaches is that they tell us very little about what participants thought about the process, what made it successful or unsuccessful according to them or how it could have been improved upon (Meleis, 1992, Abelson et al., 2003). This is problematic for those looking to develop more appropriate and effective participation processes (Abelson et al., 2003).

Recognizing that community participation is a dynamic and variable concept that does not reduce neatly into numeric equations, researchers have suggested using qualitative methods to evaluate participation. According to Oakley (1991) qualitative evaluation has numerous advantages for assessing community participation practices. First, it allows the project to be seen within the context of its environment and allows for the exploration of relationships between participants and activities. Second, it is based on inductive analysis in which the evaluator seeks to understand the process rather than imposing predetermined expectations. Lastly, it provides an opportunity for individuals and groups to voice their experiences and views of participation processes. The perspective of participants of community participation processes is surprisingly absent in the health literature (Martin, Abelson, & Singer, 2002). This is concerning as without people's perspectives how do health agencies know what the community wants and expects from participation processes (Abelson et al., 2003)? Currently, qualitative approaches to evaluating community participation are still evolving and have been struggling to gain acceptance in fields like medicine which have strong ties to the positivist tradition (Oakley, 1991; Rifkin, Lewando-Hundt & Draper, 2000).

Despite the availability of these different evaluation frameworks, researchers note that there is a paucity of evaluations of community participation in health care decision-making in the literature (Abelson, Forest, Eyles, Smith, Martin & Gauvin, 2003; Abelson & Gauvin, 2006; Rowe & Frewer, 2000, 2004).

Several explanations for the lack of evaluations of community participation endeavors have been presented in the literature. These include:

- The concept of community participation is complex and value laden which has resulted in multiple, differing and sometimes competing interpretations, goals, and methods, making research into this topic complicated (Rosener, 1981; Thurston, MacKean, Vollman, Casebeer, Weber, Maloff & Bader, 2005)
- Many projects that seek to engage communities in the decisions that affect their health do not clearly articulate the intended goals, objectives, and outcomes for participation or evaluation which makes researching these initiatives difficult (Rowe & Frewer, 2004).
- Given the diverse goals for participation and the different people involved in these initiatives (community members and sponsors), there

are differing opinions as to what makes a process successful or effective (Chess, 2000; Rosener, 1981; Rowe & Frewer, 2004).

- The plethora of participation mechanisms and the diverse contexts in which they are carried out makes comparisons problematic (Abelson et al., 2007; Rowe & Frewer, 2004).
- Decisions arising from participation activities may take many years to materialize which makes it challenging to identify and measure impact (Abelson & Gauvin, 2006).
- Organizations lack the resources, expertise, time and commitment to carry out evaluations and possibly fear that negative feedback will result in loss of funding or criticism (Abelson & Gauvin, 2006).

According to Rifkin (1986) the lack of evaluations of community participation practices is potentially problematic as "unless we take the lessons we have learned so far and seek to apply them to programs, we risk letting health care become once again a bottomless pit of resource absorption and a commodity out of reach of those who need it most" (p. 249).

1.5 SUMMARY

Community participation is a fluid concept. It has been interpreted in many different ways, expressed in many different forms, and can be influenced by a variety of factors. Although numerous health and social benefits are assumed possible through participation, only anecdotal evidence exists that substantiates these views (Zakus & Lysack, 1998). Several authors have noted cases in which it resulted in more harm than good. Numerous strategies for assessing the effectiveness of participation practices have been suggested in the literature but to date there is no agreed upon approach which has hampered evaluation efforts (Rowe & Frewer, 2000, 2004). Given these issues, several authors contend that what is needed are in-depth analyses of community participation projects, at the local level, that share both positive and negative experiences in order to clarify what works, what doesn't and why (Abelson, 2001; Rifkin, 1986; Zakus & Lysack, 1998).

Chapter Two: Methodology

2.1 INTRODUCTION

In the previous chapter, the literature was reviewed to provide a context for this research. The review examined why community participation in health care decision-making is being sought, how it has been defined, what it is expected to achieve and how it is being implemented in practice. From the literature, a need for evaluations of community participation initiatives became evident. This chapter begins with a discussion of the rationale and purpose of this research. Next, the evaluation model and design are presented. The setting in which the research was carried out and the participants who took part in the evaluation are then briefly discussed. Lastly, the methods used to conduct the evaluation and analyze the results are described.

2.2 RESEARCH RATIONALE

> Too often in the past the road to participation has been paved with good intentions only to lead up to time consuming and wasteful dead-ends which result in disillusionment and resentment for all concerned.
>
> (Brian Batson in Wilcox, 1994, p. 1).

As more and more health agencies around the world are encouraging increased community participation in health care decision-making, the need to separate rhetoric from reality is great. Evaluations of community participation practices have the potential to do just that. According to Mark, Henry and Julnes (2000, p. 3).

> Evaluation assists sensemaking about policies and programs through the conduct of systematic inquiry

> that describes and explains the policies' and programs' operations, effects, justifications, and social implications. The ultimate goal of evaluation is social betterment, to which evaluation can contribute by assisting democratic institutions to better select, oversee, improve and make sense of social programs and polices.

2.3 RESEARCH PURPOSE

The purpose of this research was to evaluate a community participation project that took place between a local health authority and one of its constituent communities from the perspective of the participants. Specifically this research sought to:

1. assess the strengths and weakness of the process selected to engage the community in health care decision-making;
2. identify potential benefits and limitations of this process/project; and
3. make recommendations to the Health Authority regarding this participation strategy.

2.4 EVALUATION APPROACH

2.4.1 Evaluation Model: Illuminative Evaluation

According to Patton (1990) there are a wide variety of evaluation models available which are designed to "help evaluators know what steps to follow and issues to consider in designing and implementing a study" (p.115). As this research sought to explore peoples' thoughts and experiences of taking part in a community participation project in an effort to better understand what worked (or didn't) and why, an illuminative model of evaluation was adopted.

In 1972, Malcom Parlett and David Hamilton questioned the usefulness of traditional evaluation models, which draw heavily from the experimental and psychometric paradigms, for understanding educational programs. They argued that these contexts are complex and constantly evolving which makes them difficult to control, define, or objectively measure (the cornerstones of traditional approaches) and attempts to do so have resulted in "studies that are artificial and restricted in scope" (p. 10). Parlett and Hamilton proposed a different approach to evaluation in which the "attempted measurement of educational products is abandoned for the intensive study of the program as a whole: its rationale and evolution, its operations, achievements and difficulties" (p. 10). The aim of illuminative evaluations is to discover and document the factors and issues that are meaningful and important to the participants in a particular situation rather than how well a program performs against standard measures of evaluation.

Parlett (1981) outlined the role of the evaluator in illuminative model as being:

> ...an orchestrator of opinions, an arranger of data, a summarizer of what is commonly held, a collector of suggestions for change, a sharpener of policy alternatives. Illuminative evaluators do not act as judges and juries but, in general, confine themselves to summing up arguments for and against different interpretations, policies, and possible decisions (p.223-224).

To achieve this end, Parlett and Hamilton (1972) advocate a "progressive focusing" approach to evaluation (p. 18). To begin the evaluator becomes familiar with or knowledgeable about the context/setting in which the evaluation is to take place. As understanding grows, relevant issues can be parceled out and expanded upon through discussion. In the last phase the evaluator seeks to explain findings and patterns within the broader context.

According to Parlett and Hamilton (1972), illuminative evaluations can be characterized as:

- *Process-oriented*: the focus is on increasing knowledge and understanding of a program rather than measurement and prediction.
- *Holistic*: evaluators attend closely to the various contexts of a program being evaluated and seek to portray the program as a working whole.
- *Inductive*: evaluators try not to impose any predetermined expectations onto the program but let them emerge from the setting.
- *Naturalistic*: the focus of the evaluation is on identifying and describing what happens in a program not on measuring outcomes.
- *Context Sensitive*: realize that different variables, such as values and beliefs, interact with and influence how a program is implemented and understood.
- *Responsive*: evaluators work closely with all to provide a genuinely helpful report. This might take many different forms and draw on many diverse sources and methods, but is designed to interest, to inform, and to add to people's understanding.

Although much of the work around illuminative evaluations has taken place in educational settings, with its sensitivity to context, process and experiences, it was viewed as an appropriate fit to understanding community participation practices as well as achieving the objectives of this research.

2.4.2 Evaluation Design: Case Study

As case studies offer an intensive description and analysis of a phenomenon or social unit, such as an individual, group, institution or community they are well suited for the aims of illuminative evaluation. With its emphasis on the individual and the particular, case studies offer large amounts of rich detailed information that permits the researcher to effectively understand and identify significant factors that are characteristic of the phenomena (Berg, 1998). According to Morgan (2001) case studies are vital for investigating participation as, "participation is contingent upon local contexts" (p. 226). While she asserts that "case studies cannot be used to predict what will happen in a different context", they are useful to planners experimenting with community participation in other settings by assisting them in identifying potential factors that might influence participation.

As the purpose of this study is to explore peoples' experiences of community participation in healthcare decision-making to better inform future practices, a case study research design was considered appropriate.

2.5 CASE SETTING

The case that was the focus of this study took place between the Calgary Health Region and the community of Airdrie/North Rocky View. The Airdrie/North Rocky View Health Needs Project sought community participation in determining the need for after-hour medical services (i.e. a hospital or urgent care centre) in the area. The project began in December of 2000 and concluded twelve months later. The project is described in depth in the Third Chapter.

2.6 PARTICIPANT SELECTION

Participants for this study were purposefully selected from members of the Airdrie/North Rocky View Health Needs Project's steering committee and working groups. To recruit participants into the study, the Airdrie/North Rocky View project manager was asked to contact the twenty-five steering committee and working group members to inform them that an evaluation was being conducted on the project (See Appendix A for the project manager's letter). The purpose of having the project manager make first contact was to facilitate entrance and reaffirm that they were under no obligation to the Calgary Health Region to participate in the study. The evaluator then contacted the twenty-five members individually by email and telephone, explained the purpose and requirements of the research and invited them to participate (see Appendix B for evaluator's invitation to participate). Twelve people agreed to participate in the study.

2.7 METHODS

According to Parlett and Hamilton, "illuminative evaluations - like the innovations and learning milieux that they study - come in diverse forms" (1972, p. 17). The choice of methods to be endorsed within a particular study therefore follows not from research orthodoxy but from the decisions in each case as to the most appropriate techniques. Essentially, the problem being investigated dictates the method. They also recommend that no method be "used exclusively or in isolation", and advocate the use of different data generating mechanisms so that the issue can be viewed from a "number of angles" (p. 17).

Since the Airdrie/North Rocky View Health Needs Project had taken place prior to the evaluator's involvement, several data collection methods, such as observation, could not be used. Therefore, this research made use of two different approaches, semi-structured interviews and a Community Participation Assessment Tool, both of which have been used to access past events or situations in which the researcher is unable to be present (Bjaras, Haglund & Rifkin, 1991; Burgess, 1984). Documents, such as the project's final report, were also used to provide context and background information on the project.

2.7.1 Semi-Structured Interviews

According to Patton (1990) there are three main interview strategies researchers can use (informal, guided, and structured) that "differ in the extent to which interview questions are determined and standardized before the interview occurs" (p. 280). The method chosen for this research was the guided approach or what Smith (1995) refers to as semi-structured interviewing. In this approach the researcher generates a schedule or set of questions to be asked prior to the interview, which will act as a guide during the interview, ensuring that certain topics are covered. The wording and order of questions is flexible which allows for a more natural flow of conversation to occur between the interviewer and respondent. According to Smith (1995) semi-structured interviews allow the researcher to probe, clarify, and follow up interesting avenues that emerge or were unanticipated while providing the respondent with space to tell their story in their own words.

2.7.1.1 Schedule Construction

An interview schedule was constructed prior to conducting any interviews. The development of the schedule ensures that basically the same information would be obtained from all participants, thus making analysis easier (Patton, 1990). Generating a schedule also forces the evaluator to think about how the interview might unfold and can help the researcher anticipate possible difficulties and develop solutions (Smith, 1995). Lastly, preplanning allows the researcher to "concentrate more thoroughly and more confidently on what the respondent is saying" (Smith, 1995, p. 13).

In constructing an interview schedule for this research (See Appendix C for the interview schedule), the sequence outlined by Smith (1995, p. 14) was followed. First, the literature on community participation in health care decision-making was explored and a list of themes and questions was developed for use in the interviews. These themes/questions were then arranged into a sequence that allowed topic transitions to be made more naturally, taking into consideration Smith's advice to "leave sensitive topics till later in the interview to allow the respondent to become relaxed and comfortable speaking to you" (p. 13). After sequencing the broader topic areas, specific questions related to each area were developed. Heeding the advice of Patton (1990) and Smith (1995) questions were formatted to ensure they were value neutral, framed in a language the respondent could understand, open-ended and avoided potential dichotomous responses.

2.7.1.2 Conducting Interviews

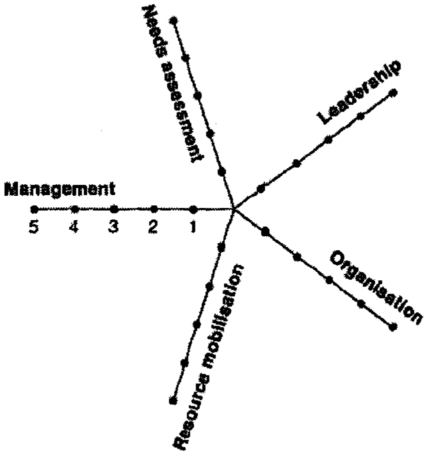
Interviews were conducted one on one and took place in a setting selected by the participant, in order to facilitate comfort. Prior to beginning each interview, participants were asked to read and sign two consent forms[1] (See Appendices D & E). Once the consent forms were signed, participants were asked for their permission to tape record the interview. All participants agreed to being recorded. Interviews began with general questions regarding how participants first heard about the Airdrie/North Rocky View project and what motivated them to participate. Participants were then asked a variety of questions about the purpose of the project, their role and expectations regarding the project, and how they felt about the process. Lastly, questions were asked concerning the impact of the project on participants personally and the community as well as any recommendations they had to improve the process. In order to increase consistency and familiarity of the data, one evaluator conducted all interviews. Interview length ranged from 45 minutes to 2 hours.

2.7.2 Community Participation Assessment Tool

2.7.2.1 Tool Description

In 1988, Rifkin, Muller and Bichman sought to develop a tool that would assist planners in assessing community participation in health programs. Based on a review of over one hundred case studies, the authors concluded that health programs are typically composed of five core processes: needs assessment, leadership, organization, management, and resource mobilization. They go on to argue that for each process, participation can range from little to high involvement. By combining the five processes and the idea of a participation continuum, they created the Community Participation Assessment Tool (see Figure 3). To use the tool participants are asked to plot the level of participation they perceive for each of the five factors, with 1 being low community participation and 5 being high. Once all the points are plotted, they are connected with each other to produce what the authors call a "broad picture of the extent and scope of participation in a program" (p.935). Rifkin et al. (1988) stress that this tool is not a measure of "good" or "bad" participation but rather a descriptive tool that allows planners to show how wide or narrow the process of participation is at any given time.

Figure 3. Diagram of the Community Participation Assessment Tool developed by Rifkin, Muller and Bichmann (1988).



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[1] As this research was being conducted within the Calgary Health Region, a second consent form was required.

The authors suggest that the tool can be used in three ways. First, it can be used to compare differences in participation at different times in the same program. Second, it can be used to compare differences in participation as perceived by different assessors of the same program and finally to compare differences in perceptions of participation by different participants in the program.

2.7.2.2 Using the Tool

Upon completion of the interview, participants were each given a blank Community Participation Assessment Tool. Participants were informed as to what the tool was for and what each of the five processes represented. They were then asked to place an X on the number between 1 and 5 that they felt best represented the level of participation for each process. If participants were unclear as to the process definitions, probing questions, as outlined by Rifkin et al. (1988) were provided (see Appendix F for factor descriptions and questions). Time to fill out the tool ranged from 5 to 20 minutes.

2.8 ANALYSIS

2.8.1 Data Management

2.8.1.1 Interviews

According to Patton (1990, p. 379) the "data generated by qualitative methods are voluminous" and therefore it is vital to develop a process for managing potentially large amounts of information. This advice was heeded for this research study. Once interviews were completed, tapes were labeled immediately with the date, time and participant code. Tapes were transcribed verbatim into Microsoft word then transferred into the qualitative software program Nud*ist 11 for storage and analysis.

2.8.1.2 Community Participation Assessment Tool

Once participants had filled out the assessment tool, the participant code was marked on the page along with the date to later match the tool to the interviewee. Paper versions of the tool were then inputted into Microsoft Word for storage and comparison. Each tool was also assigned a specific color to differentiate between community members and health authority participants.

2.8.2 Data Analysis

2.8.2.1 Interviews

Data generated from the interviews was analyzed using interpretive phenomenological analysis (Smith, 1995). According to Smith this approach attempts to understand what the person is saying but recognizes that in order to do this the researcher must draw upon their own interpretive resources. Using Smith's outline, the plan for analysis was to:

1. Read over one transcript several times.
2. Use the left-hand column to note anything that was perceived interesting or significant about what the respondent was saying.
3. Use the right hand column for key words or themes that describe what is being interpreted from the text.
4. On a separate sheet of paper, list the key words/themes that were generated and begin to look for connections between them.
5. For each theme, indicate where in the transcripts this instance can be found.

6. Repeat this process for each transcript, adding, expanding, eliminating, and collapsing themes.
7. Develop a master list of themes and subcategories and their location in the text. This master list will be used in the writing up of research findings.

2.8.2.2 Community Participation Assessment Tool

The Community Participation Assessment Tool was used in two ways. First, participants' diagrams were compared to their transcripts to see if their visual representations were consistent with their verbal accounts. Second, the tool was used to see if there were any significant differences in perceptions of participation between community and health region participants. This was accomplished by plotting community members' mean scores for each of the five factors onto a blank diagram using a blue color. The health region participants' mean scores were then added to the same diagram but with a red color.

2.9 VERIFICATION

The verification of data is an integral part of the analysis process and for this research was established through:

1. Methodological triangulation: the use of multiple methods to study a single problem.
2. Saturation: ensuring that qualitative information is rich and detailed enough to ensure key themes have not been missed.
3. Source triangulation: ensuring that more than one perspective is obtained.
4. Audit trail: tracking how conclusions were reached from the data.

5. Low inference descriptors: staying close to participant's accounts (i.e. use of direct quotes).

(Adapted from Johnson, 1997, p. 283; Taylor & Botschner, 1998, p. 90)

2.10 ETHICAL CONSIDERATIONS

As the Calgary Health Region and the community of Airdrie/North Rocky View have an on-going relationship, special attention needed to be paid to ethical issues. In order to protect all participants in this research, several precautions were taken:

1. All participants in the study were required to sign two consent forms, which had been reviewed and approved by two ethical boards.
2. Participants were encouraged to use general terms rather than making references to particular people or specific instances.
3. Participants were assigned a numerical code which was used on all documents and the master list containing names and codes was stored in a secure location that only the evaluator had access to.
4. Participants were provided with the option to read over their transcripts and the findings to ensure that any identifying markers were excluded.
5. All hard data were stored in a secure locked cabinet that only the evaluator had access to.
6. All computer data were stored on a personal computer to which only the evaluator had the access code.

Chapter Three: Case Description

3.1 INTRODUCTION

In the previous chapter, the approach to evaluation was detailed and the methods used to carry out this research presented. In this chapter, the Airdrie/North Rocky View Health Needs Project that was the focus of this evaluation is described in depth, which according to Thurston et al. (2005) is important, as it will make the integration and utilization of findings more accessible to other investigators.

3.2 CASE DESCRIPTION

3.2.1 Background/Socio-Political Context

The development of the Airdrie/North Rocky View Health Needs Project did not occur in a vacuum and in order to understand why the project came about, it is important to locate it within its historical context.

Between 1971 and 1993 the Airdrie/North Rocky View area experienced a ten-fold increase in population, which placed a great deal of stress on the public health facility located in the City of Airdrie (Porr, Wanke, & Besner, 2000). When the Calgary Health Region assumed responsibility for providing health services to the Airdrie/North Rocky View area in 1994, the Region agreed that a new facility was needed in Airdrie to meet the growing needs of the community.

Around the time of the decision to build Airdrie a new public health facility, Alberta's health care system was undergoing a major reform as a result of drastic reductions on health care spending by the Ministry of Alberta Health. The Calgary Health Region was expected to reshape health care delivery in their area while meeting expenditure reduction targets (Porr, et al., 2000). They began to explore new approaches to care delivery that would "deliver accessible and appropriate health services at an affordable cost" (Porr et al., 2000, p.16). The Calgary Health Region adopted a primary health care model, which emphasized health promotion and disease prevention over acute illness care, recognized that health is strongly influenced by factors outside the control of the health system such as income, education, and employment and is responsive to community health needs. The development of a new public health facility in Airdrie provided the Calgary Health Region with an opportunity to promote a primary health care approach to health service delivery. The new facility would offer a variety of public health services as well as house three social service agencies thus "bringing together the various sectors concerned with the broader determinants of health of individuals and communities." (Porr et al., 2000, p.4).

When the community was consulted about services the facility should provide many residents felt that the new facility should offer evening or twenty-four hour medical services. For many years, residents of the Airdrie/North Rocky View area have been lobbying for a hospital claiming that there is a lack of available medical services in the community outside of physician office hours (Porr, Wanke, & Besner, 2000). Residents who require medical services after-hours must travel by highway to emergency departments located in Calgary or Didsbury. Travel times can range anywhere from twenty minutes to more than an hour depending on road and weather conditions. Therefore, when the Calgary Health Region proposed in 1996 to upgrade the existing public health facility in Airdrie, many residents expected some form of after-hours care would be offered (Porr et al., 2000).

Given the climate of health reform and the move towards health promotion and disease prevention models of care, the Calgary Health Region had not considered offering medical services as part of the new centre. Despite their commitment to health reform practices, the Calgary Health Region agreed to look into the issue to determine whether enhancement of after-hour medical care was warranted. After receiving information from local physicians stating that they offered after hour coverage and conducting a telephone survey on health service usage, the Calgary Health Region concluded there was insufficient evidence to support the need for after hour medical services as local physicians provided such care (Porr et al., 2000). Effort was made by the Calgary Health Region to increase the community's awareness of evening services provided by local physicians.

The Airdrie Regional Health Centre officially opened on November 14, 1998. As the Centre represented a new direction in service delivery for the Calgary Health Region a process evaluation was conducted on the first year of operation of the centre. One of the findings of the evaluation was that the community of Airdrie/North Rocky View still perceived a need for after hour health care services. The evaluators recommended that:

> "Greater effort should be made by the Calgary Health Region and the Airdrie Regional Health Centre staff to obtain meaningful input into planning and implementing programs and services for Airdrie and surrounding areas" (Porr et al., 2000, p.77).

Based on the evaluation findings the Calgary Health Region agreed to reinvestigate the issue of after hour services in a way that would "work from an understanding of community needs to identify and develop services that would meet those needs" (Calgary Health Region, 2001, p.31). This led to the community participation initiative that is the focus of this research.

3.2.2 Project Participants

3.2.2.1 Calgary Health Region

Regional Health Authorities (RHAs) were established in Alberta in 1994 to streamline the delivery of health care, making it less fragmented and more responsive to local needs. RHAs in Alberta are responsible for hospitals, continuing care facilities, community health services, and public health programs. They are also responsible for service delivery (Maloff, Bilan, & Thurston, 2000). In Calgary, the RHA is the Calgary Health Region and it is responsible for coordinating health services for a population size of approximately 1,000,000 (See Appendix G for the Calgary Health Region boundaries). The geographic area referred to as Airdrie/North Rocky View falls within the Calgary Health Region's responsibility.

3.2.2.2 Airdrie/North Rocky View

The geographic area of Airdrie/North Rocky View represents a diverse mixture of an urban-rural population of approximately 24,000 (See Appendix H for a map of the Airdrie/North Rocky View area) and includes the communities of Airdrie, Beiseker, Crossfield, Irricanna, Balsac and Kathryn. Located along the Calgary-Edmonton Corridor (Queen Elizabeth II Highway-Provincial Highway #2) it is approximately 32 kilometers north of the city of Calgary (city centre). Although a variety of health and social services are available in the City of Airdrie, it is the only city of its size in Alberta that does not have a hospital.

3.2.3 Project Description

3.2.3.1 Purpose

In December of 2000, the Calgary Health Region and the community of Airdrie/North Rocky View embarked on a community consultation process to review the need for after-hour medical services within the community. Initially, the project was envisioned as a three year project in which year one would see the collection of health needs data and the development of service options, year two would focus on the implementation of the proposed service options, and year three would include monitoring and evaluating the entire project (Calgary Health Region, 2001). A shortage of funds prevented the immediate continuation of phases II and III and therefore this research only reports on phase I of the Airdrie/North Rocky View Health Needs Project.

The purpose of Phase I of the project was to "gather evidence to identify the urgent health care needs and service gaps within the community in order to develop service delivery options that might address these needs" (Calgary Health Region, 2001, p. 7).

3.2.3.2 Process

In December of 2000, a workshop was held in Airdrie, that brought together a group of people from the community of Airdrie/North Rocky View and the Calgary Health Region who were interested in and able to speak to health care issues either as residents and/or representatives of stakeholder organization, in order to discuss the current health care situation and identify issues the community felt needed to be addressed. Four strategic issues emerged as needing further review:

1. Access to after-hours care for urgent care situations;
2. Capacity of the community to serve its primary/secondary health care needs;
3. Respond to the community's need to be heard and understood;
4. Need for new kinds of information.

(Calgary Health Region, 2001, p. 10)

To address these issues a steering committee was struck to oversee the design and coordination of a collaborative process, that would engage the community in defining its health care needs, examine current services and identify service gaps using an evidence-based approach. Four working groups were also established to gather information on the priority areas. The first group was charged with examining the evidence and options for meeting urgent after-hour care needs. The second group was responsible for reviewing current community health care programs and services to identify gaps and opportunities for improvement. The task of the third working group was to collect factual information as to the usage of urgent after-hour care services, while the role of the last working group was to provide short and long-term communication planning and implementation to reach all stakeholders and audiences. In total, twenty-five stakeholders from the community and the Calgary Health Region participated in the steering committee and working groups.

Evidence for the project was drawn from two main sources. First, focus groups were employed to "gather evidence from Airdrie/North Rocky View residents regarding their experiences in accessing general urgent and after-hours health services" (Calgary Health Region, 2001, p. 12). Feedback was gathered from sixty-five residents through seven focus groups held in the community. Each of the seven focus groups represented a different demographic within the community (i.e., parents with children under ten, dependent seniors and residents with disabilities). Second historical health care service utilization data such as emergency department and emergency medical service use was also analyzed to try to gauge what services are currently being used, where people are accessing services, for what reasons and at what time. Data from walk-in clinics could not be accessed.

Although focus groups and health care data were the main source of input, there were several opportunities for residents to voice their concerns and become informed about the project at open houses, the Airdrie Home and Garden Fair, and through a Web Site. Once evidence was collected and analyzed, the steering committee was to "make recommendations to the Calgary Health Region about a range of service delivery options that would adequately address the community's needs" (Calgary Health Region, 2001, p. 9).

3.2.3.3 Findings

3.2.3.3.1 Focus Groups

From the focus groups it was clear that residents from the Airdrie/North Rocky View area perceive after-hour urgent care services in the community to be extremely limited and believe extended services or a 24 x 7 emergency centre is needed. There also seemed to be a lack of awareness that community physicians provided after-hour services and many expressed skepticism that their physician would be willing to provide care after business hours, as most physicians did not live in the area. Local physicians, on the other hand, report offering after-hour care by being on call but that the community rarely makes use of this service (Calgary Health Region, 2001, p. 2).

Other messages that emerged from the focus groups included:

- Need for education and communication about what services are available and where to get information.
- Need for medical advice and support to assist in making decisions as to what to do when faced with a medical concern.
- Need for extended services in the community to deal with minor injuries and illnesses instead of having to go emergency departments.
- Concerns that health professional shortages, increasing acuity in the community, growing population are reducing the ability of the community to care for its own.
- Transportation identified as an issue to accessing services in Calgary especially for seniors and those with disabilities.

(Calgary Health Region, 2001, p. 16-18)

3.2.3.3.2 Utilization Data

Although every effort was made throughout this project to inform decisions based on evidence, there were challenges in obtaining factual information. For example, many service providers do not maintain client databases in which utilization rates could be determined. In addition, much of the data that are available on clients and service utilization does not facilitate understanding of needs or identifies trends. Despite these shortcomings, statistics collected from Airdrie Emergency Medical Services, Calgary Emergency Departments as well as the *Health of the Calgary Region* annual survey and health providers allowed for some assessment of current service use and trends. Highlights from these sources indicated that:

- Visits to Calgary Emergency Departments (ED) by residents of Airdrie/North Rocky View have grown by 10% over the past three years (population in the community has grown 15% over the same period) compared to 3% by City of Calgary residents.
- The majority of ED visits (54%) are occurring during business hours (between 8 a.m. to 6 p.m.)
- Cases presenting at EDs by residents of Airdrie/North Rocky View, at any time, are for the most part categorized as lower level acuity injuries or illnesses (40%).
- 1,094 Airdrie residents visited one of the rural EDs in 1998/1999 (Didsbury, Strathmore, Olds and Three Hills)
- The 8th and 8th walk-in medical clinic in Calgary reported 346 visits by Airdrie residents.
- Calls to Airdrie EMS have increased by 17% over the past three years.

- 48% of calls to Airdrie EMS occur after-hours
- The majority of after-hour calls to Airdrie EMS need to seen within 6 hours (42% in 2000).
- There is a growing level of acuity in the community as people are postponing entering tertiary care facilities and bed shortages in hospitals have reduced acute care stays. This is increasing the demand for after-hour home care and palliative care services.

(Calgary Health Region, 2001, p. 18-23)

Using these data, an effort was made to try and estimate the number of urgent/non-emergent care situations that could be diverted to the community if supports were available. Calculations were derived from the number of low level acuity visits to Calgary and rural emergency departments, Airdrie Emergency Medical Service calls that were attended but not transported, 8th and 8th medical clinic walk in traffic, and volume of visits that might have waited a day to seek help. From these numbers and based on a population growth projection of 5%, it was estimated for the upcoming year (2002/2003) that 8,289 cases per year or 22 cases per day could be handled in the community if services were made available. It was further projected that of these 22 cases, 11 would occur after doctors' offices had closed (Calgary Health Region, 2001, p. 25-26).

3.2.3.3.3 Results

Based on feedback from the focus groups and review of urgent care service utilization trends, gaps in the community's health needs were identified. Although Airdrie/North Rocky View residents strongly feel that an after-hour or extended hour urgent care facility is needed in the community, the evidence collected from health usage data did not indicate enough demand that would justify the expense of such a facility. Recognizing this, the steering committee began exploring possible service options that would hopefully address some of the health care gaps as well as allow for the continued collection of evidence so that a more accurate picture of the community's urgent care needs could be determined. Four options to enhance community based care were identified by the Steering Committee (Calgary Health Region, 2001).

The first option suggested was the development of a physician's communication plan. Focus groups and interviews with local physicians highlighted some confusion around services and accessibility after office hours. The intent of this initiative would be on increasing awareness of current physician availability, services and hours of operation in the community. Key messages to be delivered included:

- There are physicians in the community accepting new patients.
- Community physicians provide a wide range of services.
- Community physicians provide after-hour services.

(Calgary Health Region, 2001, p. 28)

The second option put forth, a pilot telecare service, would address the community's need for medical advice in the event of an urgent care situation. This telephone-based service provided by Registered Nurses, using professional expertise, clinical judgment and standardized evidence-based protocols, could be offered on an after-hours basis or linked to physician offices thus providing an opportunity to track after-hour needs.

A self-care management program was the third option proposed by the steering committee. This concept also emerged from the focus group sessions in which residents expressed they would like to feel more involved in the management of their health. The program could involve "health promotion and illness prevention programs pertaining to specific topics e.g. injury prevention, mental health, cardiovascular health, respiratory problems, diabetes management etc…" (Calgary Health Region, 2001, p. 29). Different health providers in the community could offer programs with the Calgary Health Region acting as a coordinator.

During interviews with health professionals and community members, concerns were raised about the growing number of people in the community who require home care services. Therefore, the final option put forth by the steering committee was that the Calgary Health Region should review the community's need for home care/continuing care services.

The above service delivery recommendations were submitted to Senior Management at the Calgary Health Region for their consideration in December 2001, and thus ended phase I of the Airdrie/North Rocky View Health Needs project. It was anticipated that by early 2002 the Calgary Health Region would inform the project Steering Committee as to which options would be supported so they could proceed with phases II and III. Unfortunately, funding restrictions imposed by Alberta Health and Wellness combined with the Calgary Health Region projecting a deficit for the fiscal year of 2002/2003, caused the second and third phases of the project to be placed on hold until the commitment of further funds could be secured.

3.3 CASE SELECTION RATIONALE

The selection of the Airdrie/North Rocky View Health Needs Project as the case for investigating community participation in health care decision-making was based on several factors. First and foremost was access. As a summer student working for the Research Initiatives in Nursing and Health Unit of the Calgary Health Region, who had been actively involved in the Airdrie/North Rocky View Health Needs Project, I was able to gain access to information and participants. Another compelling feature of the project was its history. Previous attempts had been made to address the issue of after-hour medical services that did not make use of community participation approaches so I felt that this provided an excellent opportunity to see if community participation made a difference. I also selected this project because it was intriguing. The idea of ordinary citizens being involved in the collection and analyzing of health care data, when health decision-making is usually controlled by health professionals, seemed unusual and sparked my interest in what this experience had been like for participants. A fourth factor was the relevance of this project to my schooling in Community Psychology. Community psychology is concerned with the relationship between social systems and individual well-being in the community context. A fundamental concept within community psychology is the notion that "communities should participate in defining the problems or issues that affect them, and in deciding how to resolve them" (Dalton, Elias & Wandersman, 2001, p.17). Evaluation is also a central feature in community psychology as it is viewed as an essential element of social change and social innovation. This research provided me an opportunity to apply the knowledge I had gained regarding evaluation principles and as well as possibly contribute to furthering understanding of the concept of participation. Lastly, I selected this project because the Calgary Health Region has expressed a commitment to promoting community participation in decision-making and was one of the first health authorities to develop a framework to promote and guide community participation in health care decision-making (Frankish et al. 2002; Maloff, Bilan & Thurston, 2000). By conducting an evaluation of the Airdrie/North Rocky View Health Needs project, I hoped the information collected could possibly be used to inform this framework as well as different participation initiatives occurring in the Region.

Chapter Four: Findings

4.1 INTRODUCTION

In the previous chapter, the case that was the focus of this evaluation was described. This chapter reports the results generated from the interviews and community participation assessment tool.

4.2 INTERVIEWS

4.2.1 Initial Reactions and Expectations

While most reactions to the project were positive and anticipatory, there were a few participants who expressed some initial trepidation about the project because they had either heard about or participated in past assessments. One participant recollected thinking *"hot potato" (Respondent 2)* because she had heard through the grapevine that the Airdrie community had not been happy with previous discussions and was quite disillusioned with the Calgary Health Region. For another participant, who had participated in previous assessments, the reaction was a mixture of hope and skepticism.

> *"It seems like every time we had done a review, over many years, a lot of work goes into it. A lot of energy, a lot of emotions, and then nothing happens. So my reaction was mixed from the perspective of here we go again versus are we finally going to get something done?"(Respondent 7)*

When participants were asked to describe what they thought the purpose of the project had been, two distinct understandings emerged. For some, it was viewed as an opportunity to get something "*concrete*" for the community:

> *"...a place that we could take kids to if they needed stitches or if they needed x-rays or just some sort of emergency treatment." (Respondent 12)*

For others, it was a chance to partner with the community to identify the actual needs of the community and develop strategies to meet these needs.

> *"...it was an opportunity to go in there and not just understand what the needs were but to actually work with stakeholders...build some capacity, and hopefully get the relationship, itself, on a better footing." (Respondent 1)*

These differing expectations of the project's purpose have important implications for participants' perceptions of the ending of the project and the outcomes generated.

4.2.2 Process Strengths

Overall, participants were quite pleased with the process adopted by the Calgary Health Region. One participant went so far as to state that *"it was an excellent process and it has to be done more often."(Respondent 3)* Three factors stood out for participants as contributing to the success of the process.

4.2.2.1 Collection of Evidence

In the past, assessments of Airdrie/North Rocky View health needs had relied on more anecdotal accounts of needs, i.e. from physicians in the form of a letter stating they provided after-hour services and telephone surveys of community members perceptions of care, rather than as one respondent put it *"a solid fact base"(Respondent 1)*. This resulted in what was described as *"two very polarized positions"(Respondent 2)*. The Calgary Health Region maintained that adequate care was available through physicians and Emergency Medical Services while the community contended that services were limited and a hospital was needed. Neither side seemed to be able to *"get beyond these positions" (Respondent 1).*

The reliance on different forms of evidence, rather than just personal accounts, to inform decision-making was considered a true strength of the process. For both sides it was a concrete way to figure out what was really going on in the community and what could be done about it. As one community participant remarked:

> *"Because people will tell you their stories and if you listened to everybody you would swear there is this mass exodus in the evening from Airdrie and surrounding communities and they're all going into Calgary for health care." (Respondent 4)*

Community members felt that the Calgary Health Region staff did an excellent job in talking to a great cross-section of the community and service providers as well as searching out every avenue of information to get the most informed picture of the situation as possible.

Although there were difficulties in obtaining after-hour usage data, seeing the low levels of actual demand compared to perceived need helped community members to begin considering alternatives to a hospital for Airdrie. For Calgary Health Region staff it identified gaps in health services and directions for improving services.

4.2.2.2 Working Together

During interviews with community members, comments were made about past assessments conducted by the Calgary Health Region in Airdrie. Participants recalled how the Calgary Health Region would tell them that all necessary services were available in Calgary, yet on several occasions they cancelled meetings in Airdrie due to poor road conditions:

> *"It really made you kind of jaded as to...you're (Calgary Health Region) telling us one thing 'come to Calgary to get your services' and yet you're not prepared to drive those same roads that we have to put our ambulances on or people who have to get into their vehicles and drive. There was kind of a credibility gap there." (Respondent 5)*

The Calgary Health Region's willingness to work in and with the community made many community members feel that for the first time the Calgary Health Region was genuinely interested in the needs of the Airdrie/North Rocky View area.

> *"The fact was they were out here all the time. Like they had open houses and they were in schools and churches and had surveys going on. They really got a lot of input from the public." (Respondent 9)*

Several participants commented that having a committee, which was co-chaired with a representative from both the community and the Calgary Health Region also contributed to feelings that this was a true partnership rather than a one-sided endeavor.

Working together to collect and interpret health usage information also played a part in participants feeling like their input mattered and that this was not just the Calgary Health Region attempting to rubber stamp a predetermined outcome. The ability to influence the process was considered important to participants because as one participant described:

> *"People want a chance to voice their issues and concerns. They want that opportunity to feel that*

> *they've been heard and then ideally, you're going to be able to get back to those people and say this is what we've done in response to the input you've given us." (Respondent 2)*

Participants frequently mentioned that they enjoyed working together as well as being exposed to diverse people, perspectives, and opinions. Community members learned a great deal about the Calgary Health Region, such as their costing and forecasting strategies as well as the expense of healthcare provision. Calgary Health Region personnel became more aware of the realities faced by those communities located outside the city of Calgary, such as lack of access to transportation into Calgary. Having community members taking part in the process was considered extremely valuable by Calgary Health Region staff:

> *"I think if their voices had not been at the table, we would have had all the so called health care experts thinking that they knew what the issues are and how to fix it yet so often we are so far removed from their reality we don't know what the right answer is." (Respondent 6)*

4.2.2.3 Project Manager

A critical element identified as contributing to the success of the process was the project manager. The administrative support, such as organizing and facilitating meetings, taking minutes, compiling and circulating information, provided by the project manager was considered invaluable. Several participants felt that without the project manager position the project would not have gotten off the ground:

> *"I couldn't have done a level of work that the project manager did. Yet often that is expected that that will happen or that the people on the committee*

> *will do it. They just don't have the time." (Respondent 8)*

Along with the administrative piece, participants also felt that the project manager brought particular qualities to the role such as openness, fairness, passion and objectivity, which made community participants feel that the process was legitimate and truly participatory with no set agenda. As one participant described:

> *"An organization that is under attack can close ranks. So you wonder if this person, because it's the Calgary Health Region, are they going to protect their butts and in the end this is just going to validate everything that they want it to validate. But the project manager was able to totally remove herself from that so you felt that always the most important thing was the project and getting the information that was needed. So I felt always that she was without bias and just the ultimate professional." (Respondent 4)*

4.2.3 Process Challenges: Length

Difficulties in locating and accessing health usage information combined with the challenge of bringing together and coordinating a large group of people impacted the length of the project. While participants recognized how important it was to take the time to gather information and involve people in the process, they identified some drawbacks to having a project that took over a year to complete.

Some felt that the time commitment required for the project limited who could actively take part in the project and raised questions as to how representative of the community participants were. This concern seemed valid as several of the participants interviewed acknowledge not being aware of local health services as their health providers were located in Calgary.

> *"There used to be a doctor-or he may still come out there once a week. I'm not sure about that. We do provide an office and there is some sort of a clinic. I've never been there so I can't really even evaluate it." (Respondent 11)*

Another drawback associated with the length of the project was that key players were lost due to work transfers and organization restructuring. This took a toll on the project's momentum and continuity.

> *"We lost ---- and we saw them as being key in leading some of the health promotion stuff. And again, there were constant staff turnovers. So the fellow, who had been our rep at the end of the project, he left and then there was another guy assigned. Then he wasn't on the project any more, then there were two more people assigned and then they both left." (Respondent 1)*

4.2.4 Project Outcomes and Ending

Despite having a successful process that participants' felt was *above par*, there was a great deal of dissatisfaction expressed towards the outcomes generated and how the project ended. There seem to be several interconnected factors that contributed to these feelings.

4.2.4.1 Expectations

Much of the disappointment towards the project outcomes can be traced back to initial expectations participants had of the project. While community members do agree that the recommendations were an "*improvement in the system over what it was that fills the gap until the next step" (Respondent 5),* most had wanted to see an after-hour care facility built in Airdrie and were frustrated that that was not forth coming:

> *"…everybody's heart and soul was into getting something more substantial for the Airdrie community." (Respondent 12)*

As the driving force for getting involved in the Airdrie Health Needs Project for many community members was the desire for a hospital, once they realized that this would not be feasible their sense of purpose and motivation to continue diminished.

> *"So what do you do next? We've got information and we know in many ways we can't justify a hospital so now what do you do?" (Respondent 3)*

The community's loss of purpose in turn impacted Calgary Health Region staff. Members from the Calgary Health Region had gone into the project with the desire to partner with the community and possibly build the community's health capacity via joint programs between the Calgary Health Region and other community agencies. Once the project was completed, Calgary Health Region staff were disappointed that community members did not seem interested in continuing on in some form such as a health advisory committee, with which the Calgary Health Region could interact.

4.2.4.2 Lack of Funds

A second and related factor contributing to dissatisfaction towards the project's outcomes was the lack of funds to immediately carry on with the 2nd and 3rd phases of the project. One of the major consequences of this was the loss of the project manager who participants had identified as being instrumental in shaping and leading the project. Without the project manager, community members felt confused as to what to do next and the interest achieved in the first phase of the project faltered.

> *"We had one meeting and it became apparent that we weren't sure why we were there or who we were reporting to. Everybody there was really busy so we haven't met again since at this point." (Respondent 8)*

Some people commented that the lack of funds prevented what one participant referred to as *"closing of the loop" (Respondent 2)* or feeding back into the community what effect their involvement had on the Calgary Health Region and what was being done with their recommendations. This left some community members feeling like once again the needs of Airdrie were dismissed.

> *"To me, I'm just disappointed in all the work that was put in on the committee level and what I was doing and what everybody else was doing and at the end of the day, we came away with another book that is sitting on the shelf..." (Respondent 11)*

The lack of a community health council which the Calgary Health Region could communicate with to relay information regarding findings and actions taken was identified as contributing to these feelings.

4.2.4.3 Life

A third factor impacting the project outcomes and ending was everyday life. Participants had jobs and obligations in addition to the project, which in turn affected their attendance and availability. Some people could not be as involved in the project or even afterwards due to workloads or job changes and others lost interest as health care took a back seat to life concerns. This combined with loss of purpose and the delay between phase I and II greatly reduced the potency of the outcomes and desire to continue on independently.

> *"...you only have the capacity for so much in your life. Because you've got your day to day life-things that go on in your family, your job or whatever your interests and that stuff is always out there. You let it [health care concerns] come in when you've got a moment and then you put it back out there where it belongs, and concentrate on the things that are important to you. That goes for this project." (Respondent 10)*

4.2.4.4 Okotoks

The last and probably most significant factor that contributed to feelings of dissatisfaction was the announcement shortly after the project was completed that Okotoks, a community located south of Calgary, which is similar in size and composition to Airdrie, would be getting an urgent care facility. Although the decision to build a facility in Okotoks had been made before the Calgary Health Region assumed responsibility for that area, many community members felt acutely frustrated:

> *"And just as we were finishing this all up, Okotoks announced a center. A 24 hour center. And we're kind of like 'Here we've been going through this whole process for a year or year and half, two years maybe at that point. We still have nothing.' So it's kind of like, 'What are we doing wrong here?' You just think what are we doing wrong?" (Respondent 7)*

4.2.5 Benefits

4.2.5.1 Project Benefits

Although there was dissatisfaction towards the outcomes and ending, participants did believe that the project had made a difference and achieved some positive results for both the community and the Calgary Health Region.

4.2.5.1.1 Greater Awareness/Understanding

Participants expressed that a major advantage of this project was that it opened up a dialogue between the Calgary Health Region and the Airdrie/North Rocky View community. This in turn facilitated a greater understanding and awareness of each other's needs and perceptions.

During the interviews participants commented on feeling that prior to this project the Calgary Health Region was preoccupied with Calgary residents and had little to no understanding of what occurred outside of the city.

> *"I honestly believe that the Calgary Region at that time didn't know – the Board didn't know what happened outside of the city of Calgary." (Respondent 5)*

Participants felt that this project went a long way to highlighting and drawing attention to who the Airdrie/North Rocky View area is and what challenges they face in terms of accessing health care services.

> *"It's kind of like my assumptions about Airdrie weren't valid, based on just my little pieces, right? Until I got out there and there was a whole learning process from my perspective of some of the issues and challenges that they face as well." (Respondent 2)*

Calgary Health Region staff felt the project had created more understanding among community participants about the realities of providing health care and the costs associated with it as well as their reluctance in building hospitals in every town.

> *"It's given me a lot broader knowledge on the stats on the health care side of why they look at things different. And maybe why they don't look at some things on a broader scale for particularly a smaller community. Because the population is not there to justify doing it." (Respondent 3)*

Participants also felt that the project had provided valuable insight into the process of involving communities in health care decision-making and the importance of doing so especially in those areas that are outside the city centre.

> *"...now that we are a Health Region that has more rural communities and communities that are not serviced by the big city center, I'm thinking that there is some learning there that could help." (Respondent 1)*

4.2.5.1.2 Legitimacy of Concerns

For community participants the compilation and documentation of health usage data was considered to be extremely beneficial. Several community members felt it gave a sense of authenticity to their health care concerns because there was now actual evidence to support their claims of service gaps rather than anecdotes.

> *"They are more willing to listen to the person who has done their homework and been dedicated to the cause, rather than one person writing letters to the editor and complaining." (Respondent 10)*

Community participants also remarked that the evidence collected would be of benefit in providing a solid case for more health services in the future.

4.2.5.2 Benefits of Community Participation

Despite the dissatisfaction expressed towards the project outcomes and ending, <u>all</u> participants stated that they would take part in another project like this. While participants acknowledge that these types of projects are often time consuming, they felt they are extremely important because of the feedback and information that is generated.

> *"I mean we have a system that is-everybody says that it's not sustainable. Well what is making it not sustainable? I think there is a lack of understanding on the behalf of the people delivering health care. I think they perceive expectations that may or may not be there. So I think they need to get better in touch with the people that they are providing the service to and vice versa. I think the people who are receiving the service need to accept some responsibility for their health. And that is at an individual and a collective level. So I think that having communities involved in these kinds of exercises can only help, in terms of that two way understanding and I guess empowering both sides." (Respondent 6)*

4.2.6 Project Impact

While participants felt that the project had impacted them personally by increasing their knowledge and understanding of health care and the community, they were uncertain as to if the project had an effect on the broader community.

> *"I am not sure if it impacted beyond the committee itself. I don't know". (Respondent 9)*

Several participants commented that had the self-help promotion piece been implemented more of an impact might have occurred. The disbandment of the steering committee also lessened the influence because of missed opportunities to work together on different health initiatives.

> *"And then there was some talk about well maybe we should be on the board of that [North Diagnostic and Treatment Centre] particular committee because there was some committee that was going to be looking at the building of that and again I have never heard anything since." (Respondent 5)*

4.2.7 Recommendations

While most participants commented that the process adopted by the Calgary Health Region was excellent and as one person suggested should be *"followed like a blueprint" (Respondent 10)*, participants did provide advice regarding what they thought could enhance future projects.

4.2.7.1 Community Health Councils

One suggestion participants had was for communities to form health councils or advisory boards that are focused on the health needs and concerns of a particular area. Participants felt that had the steering committee been maintained once the project had been completed, the Calgary Health Region could have interfaced with them on future projects thus addressing some of the issues around feedback and continuity.

> *"I mean things have been happening as a result of the project, it's just that it is so low profile that the average person would not know anything about it... plus there is no one to send the report back to because our phase one steering committee is finished and there was no advisory committee that grew out of that and maintained itself." (Respondent 1)*

Some also believed advisory boards may help with sustainability of community participation projects because it would provide a sense of purpose and direction for communities:

> *"Part of, I guess, the excuse is, with all the committees and everything else that I do and am on, like not to say they aren't a worthwhile group, but because there is no united project right now its not a priority" (Respondent 12)*

4.2.7.2 Resources

Although having resources in place to support community participation (i.e. administrative assistance) was identified as a major strength of the process, participants did have some concerns about this. By providing funds and personnel to facilitate a community participation process, health agencies run the risk of the project being viewed as "theirs" which can negatively affect sustainability.

> *"We had a group of people come together because really the Calgary Health Region directed them to come together. I thought it was really proactive for them to do that but once that part was done then who was going to lead the next part?" (Respondent 4)*

Participants were not sure how to resolve the tension between needing to provide financial and administrative support to community participation projects and the project being seen as a temporary health agency initiative but again suggested that having a community health council might help.

> *"... if the Health Region was to consider doing something like this again, I think I would be looking to put-I would be asking the community to create some kind of a body that the Health Region would interface with. So that it's not perceived as being our responsibility. Because I think the steering*

> *committee was driven by the Health Region and so when that ended, the project ended. And so there was no living body left with which to communicate." (Respondent 1)*

4.2.7.3 Feedback

Another significant learning was the importance of developing mechanisms for ongoing feedback. Much of the dissatisfaction expressed toward the project ending can be traced to participants feeling that no action was taken on the recommendations put forth by the committee.

> *"I keep saying to myself, 'I wonder what the hell ever happened with what we did?' Because for awhile there I was getting quite a few emails from the project manager keeping us informed with what was going on in other committees. There was always something at the table and you got your minutes. Somebody was taking notes from the Region. And we were always kept a little bit informed on what was going on." (Respondent 11)*

Although Calgary Health Region staff stated that there have been things occurring since phase I of the project concluded, they acknowledged that they struggled in communicating back to the community what impact their participation had on decision-making:

> *"I think that is one of the biggest problems for us is closing the loop. And I think one of the other issues is how, its very hard to do, but I think we need to work at showing how this contributed to our decision-making." (Respondent 2)*

Calgary Health Region staff also mentioned the need to find better ways of communicating within their own agency as to the results of community participation projects so that they can learn from each other's success and mistakes.

> *"Well I think-I always wondered how much of an understanding there was within the organization, of what this project had been. And not that it was a huge project, but I actually think it was fairly successful. The first phase of it. And I think we learnt a lot about engaging stakeholders and I think it ended up being quite a positive experience overall". (Respondent 6)*

4.3 Community Participation Assessment Tool

Upon completion of the interviews, participants were asked to fill out the Community Participation Assessment Tool. They were instructed to place an "x" on each of the five arms to represent the level of community participation they perceived in the areas of needs assessment, leadership, organization, management, and resource allocation. Scores of 5 represented high community participation while 1 and less are low levels. The results from the Community Participation Assessment Tool were used in two ways. First, participants' diagrams were compared to their transcripts to see if their visual representation were consistent with their verbal accounts. Second, the tool was used to see if there were any significant differences in perceptions of participation between community and health region participants, as well as provide a map of community participation.

Results from the Community Participation Assessment Tool were consistent with participants' verbal accounts of how they perceived the Airdrie/North Rocky View Health Needs project (see Table 1 for participants ranking of each factor and mean scores).

The *Resource Allocation* factor looked at how much control community participants have over the resources and outcomes of the project. Scores of community participation on this factor were very low (mean score = 1.67). Although participants had been actively involved in the generation of the four recommendations, the final decision as to which options would be carried out (if any) was left to the Calgary Health Region. This combined with the lack of funds to carry on with phase II of the project, which would have engaged the community in the planning and implementation of the recommendation(s), contributed to low scores on this factor.

The *Needs Assessment* factor addressed the degree to which the community was involved in the research and analysis of its needs. As the involvement of community members in the collection and analysis of evidence around urgent care needs was a central feature of this project and identified by participants as a real strength of the process, it is not surprising that scores on this factor were quite high (mean score = 4.29).

Similarly, the *Leadership* factor, which is concerned with how leaders represented the interests of the community, scored high as well (mean score = 4.08). This was consistent with respondents' comments that the steering committee and working groups had the interests of the community at heart and made every effort to include the community in the project.

Scores on the *Organizational* factor were also fairly high (mean score = 3.96). This reflects participants' feelings that a diverse group of people from a variety of organizations took part in the project as well as sat on the steering committee and working groups.

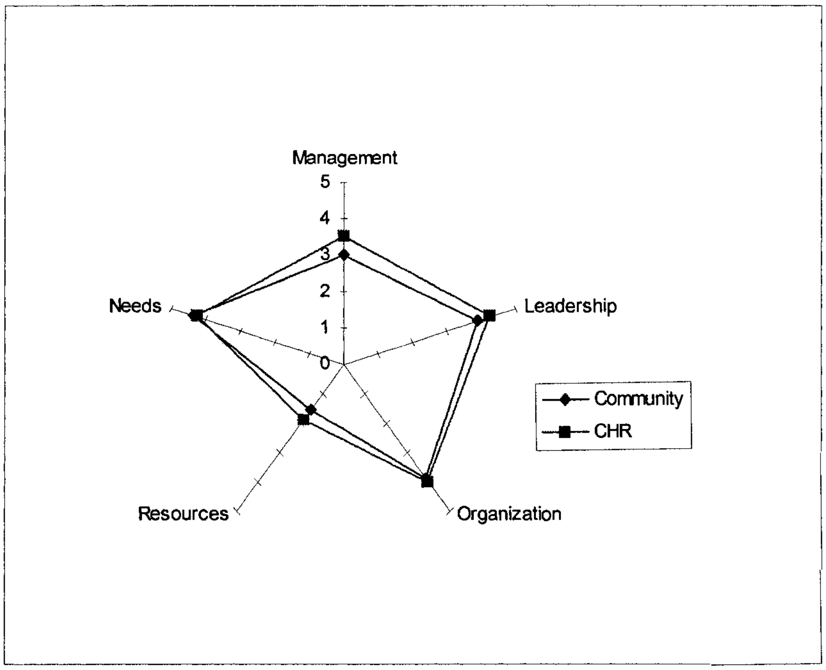
Table 1. Participants' individual rankings on the Community Participation Assessment Tool and the average score for each factor.

	Management	Leadership	Organization	Resources	Needs
Participant 1	3	4	4	2	4
Participant 2	4.5	4.5	4	2.5	4
Participant 3	1	3	3	1	4
Participant 4	3.5	3	4	1.5	4
Participant 5	1	5	5	2	5
Participant 6	3.5	3	4	2.5	4.5
Participant 7	3.5	3.5	3.5	1.5	4
Participant 8	5	5	4	1	4
Participant 9	3	5	3.5	1	4
Participant 10	2	4	4.5	2	5
Participant 11	5	5	5	2	5
Participant 12	4	4	3	1	4
Mean Score	**3.25**	**4.08**	**3.96**	**1.67**	**4.29**

Unlike the other factors, which had fairly consistent scores, *Management* had some mixed responses. The reasons for this seem to be how participants interpreted the scoring description provided for this factor. The *Management* factor is described as: *the extent to which the project was developed and managed by the community. Low participation is indicated if the project was induced and run by professionals. High participation therefore would be if the community induced and ran the project.* Several participants liked how the project was co-chaired by members from both the Calgary Health Region and community and did not feel that "health experts" were driving the process and thus gave the *Management* factor high scores. Others, although they too liked the project structure and who was involved, perceived the project as being initiated by the Calgary Health Region thus deserving of a lower score.

When the averages of community members' responses for each factor are plotted against Calgary Health Region participants, there does not seem to be a significant difference in these two groups' perceptions of the level of participation, although Calgary Health Region respondents did perceive greater levels of participation on all factors (see Figure 4). Overall, the project seemed to be perceived as fairly participatory with the exception of resource allocation.

Figure 4. Community vs Calgary Health Region respondents' views of the level of participation



4.4 Summary

For the most part those interviewed felt that the community participation process adopted by the Calgary Health Region was excellent. Participants identified the reliance on evidence, working together to collect evidence, and the project manger as real strengths of the process. The only real concern participants had towards the process was its length. While participants recognized that time was needed to collect all the information and data in order to get an accurate picture of the needs of the community, they did feel it limited who could actively take part in the project and wondered if all the right people had been around the table. Also, as time progressed, several key players had to leave the project due to changes in their jobs, which in turn impacted the momentum and flow of the project. Although participants felt the process implemented by the Calgary Health Region was a success, many expressed disappointment towards the outcomes generated and how the project ended. Several interrelated factors seemed to contribute to these feelings the first being the different expectations that participants had for the project. Community members had wanted to see more tangible outcomes while Calgary Health Region staff had wanted to build capacity within the community. When these expectations were not realized, motivation to remain engaged began to fade. Other factors, such as a lack of funds to carry on with subsequent phases of the Airdrie/North Rocky View project; life issues and priorities emerged that took precedence over health needs; and the announcement that a southern community located outside of Calgary was getting a urgent care facility, also contributed to feelings of dissatisfaction towards the project's outcomes and ending. Even though the results of the project did not exactly meet expectations, respondents did feel that the initiative achieved some larger benefits such as opening up a dialogue between the Calgary Health Region and the Community of Airdrie/North Rocky View, which increased understanding and awareness of each other's perspectives regarding health care provision. For community members there was also the sense that the information collected during the project legitimized their concerns about urgent care services and would be useful to illustrate the need for a facility in the future. As to the impact of the project, participants felt that it was mostly contained to the individuals involved in the initiative and took the form of personal learning.

Had some of the options been implemented right away there might have been more of an effect on the wider community. All respondents indicated that they would participate in another project like this, as they believed the two-way flow of information between community members and health providers generates invaluable learning and understanding. Participants in this study also had several suggestions as to how the Calgary Health Region could enhance similar projects. The first recommendation was for communities to form health councils or advisory groups in which the Calgary Health Region could work with on an ongoing basis to address health needs thus providing a forum for communication as well as potentially increasing sustainability of community participation projects. The other recommendations were around needing to appropriately resource community participation projects and establishing feedback mechanisms between the community and health region as well as within the region itself to ensure that best practices/learnings are being shared.

Results from the Community Participation Assessment Tool supported participant interviews, in that there was considerable community involvement in many aspects of the Airdrie/North Rocky View Health Needs project with the exception of resource allocation (i.e., control over decisions as to which options to implement and when). There also did not appear to be any significant differences between Calgary Health Region staff perceptions of participation and community members.

Chapter Five: Discussion

5.1 INTRODUCTION

The aim of this research was to address the need for evaluations of community participation in healthcare decision-making by assessing a project that took place between the Calgary Health Region and the community of Airdrie/North Rocky View. More specifically, this research sought to identify the community participation project's strengths, challenges, benefits and limitations, from the perspective of participants, in order to learn from and potentially inform future participation projects. In the previous chapter, the themes from participants' interviews were shared and results from the Community Participation Assessment Tool were presented. In this chapter, the implications of the information generated from the evaluation are discussed, the limitations of the research are acknowledged and future directions for research suggested.

5.2 IMPLICATION OF FINDINGS

The Airdrie/North Rocky View Health Needs Project provided an interesting study of community participation in health care decision-making in practice. Here was a situation in which a community and a health agency were at odds regarding the need for twenty-four hour medical services in the area. Unlike past attempts to address this issue, which had relied upon phone surveys of health service usage and letters from local physicians stating they provide adequate after-hour care services, the Airdrie/North Rocky View Health Needs Project sought to engage the community in identifying their urgent health care needs and service gaps in order to develop service delivery options that might address these needs. The aim of this research was to evaluate the Airdrie/North Rocky View Health Needs Project, *from the perspective of the participants*, to identify what worked, what did not and why in order to in order to learn from and potentially inform future participation projects.

5.2.1 What worked?

For participants in this study the process adopted by the Calgary Health Region to address the need for after-hour medical was identified as the strength of the project. Several factors stood out for participants as contributing to its success. First, was the use of evidence to identify health care needs. For both the Calgary Health Region and community participants using evidence was identified as important as it was a way to figure out what was really going on in the community regarding after-hour medical needs. Seeing the low levels of actual demand compared to perceived need helped community members to begin considering alternatives to a hospital for Airdrie. For Calgary Health Region staff it identified that there were gaps in health services and provided directions for improving services. Community participants also felt the compilation and documentation of health usage data was beneficial as it gave a sense of authenticity to their health care concerns because there was now actual evidence to support their claims of service gaps rather than anecdotes. They felt the evidence generated from this project would assist in providing a solid case for more health services in the future.

A second strength identified by participants in this study was that the Calgary Health Region worked with and in the community. The Calgary Health

Region's willingness to work in and with the community, made many community members feel that for the first time the Calgary Health Region was genuinely interested in the needs of the Airdrie/North Rocky View area. Working together to collect and interpret health usage information also played a part in community participants feeling like their input mattered and that this was not just the Calgary Health Region attempting to rubber stamp a predetermined outcome. Working together also opened up a dialogue between the Calgary Health Region and the Airdrie/North Rocky View community, which facilitated a greater understanding and awareness of each other's needs and perceptions.

Lastly, the commitment of funds and human resources to carry out the process was considered a strength. By committing funds, community members felt that the Calgary Health Region was serious about addressing their concerns. The administrative support, such as organizing and facilitating meetings, taking minutes, compiling and circulating information, provided by the project manager was considered invaluable as community members felt that they would not have been able to do the work that was required to carry out this project on top of their day to day responsibilities. Along with the administrative piece, participants also felt that the project manager brought particular qualities to the role such as openness, fairness, passion and objectivity, which made community participants feel that the process was legitimate and truly participatory with no set agenda.

5.2.2 What did not work?

While participants were greatly satisfied with the process adopted by the Calgary Health Region to address the health care service needs of the community, reactions to the outcomes and ending of the project were less positive. The major reason for this was the lack of funds to carry out phases II and III of the project, which would have involved the steering committee in the implementation of some of the recommendations generated in phase I. The lack of action on the recommendations left many community members feeling like once again the Calgary Health Region had dismissed their concerns. It also resulted in community participants feeling lost as to where to go from here or what to do next as they knew they would not be getting a hospital and had no power to carry out the recommendations themselves.

5.2.3 Recommendations and Learnings

Drawing upon the findings from the interviews and Community Participation Assessment Tool this section presents some of the key learnings that emerged from the evaluation that the Calgary Health Region may wish to consider to improve future initiatives. Some of these findings may also have relevance to others who are designing their own community participation projects.

Probably one of the most significant learnings that arose from this evaluation was the need to clarify people's expectations for and understanding of participation before engaging in community participation projects. For community members in this study, the Airdrie North Rocky View project was seen as an opportunity to get more substantial health services in Airdrie. Calgary Health Region staff, on the other hand, envisioned the project differently and more as a capacity and relationship building exercise. These different expectations of participation resulted in feelings of frustration about the project's outcomes and how the project ended as people perceived that their goals had not been met.

Recognizing that not everyone who participates in a participation project have the same views of participation or goals, one recommendation that might enhance future community participation projects would be to invest time into identifying people's (both staff and community) understanding of and expectations for participation. This would allow different views to be addressed and ensure that realistic expectations about what can actually be achieved though participation are promoted early in the project. In addition, by clarifying purpose and setting reasonable objectives in advance, outcomes for participation can be more easily identified and agreed upon which according to Rowe and Frewer (2004) would make research into and integration of findings more possible.

Developing a logic model of the community participation exercise might also be a helpful in accomplishing this. A logic model is a picture of how a project should work. A logic model links outcomes (both short- and long-term) with program activities/processes and the theoretical assumptions/principles of the project in order to highlight how it is expected to work, what activities are needed, and how desired outcomes will be achieved (Dalton, Elias & Wandersman, 2001).

A second interesting learning from this research was that a successful community participation process does not necessarily guarantee that the results generated by the process will be perceived as positive. Participants in this study felt that the approach taken to engage the community in assessing its health care needs was excellent and even went so far as to suggest that it be used as a blue print for future endeavors. Reactions to the project outcomes, on the other hand, were filled with disappointment and frustration. Several factors contributed to these feelings including: unmet expectations; lack of funds to continue with the next phase of the project, other priorities taking precedence; and another community south of Calgary getting an urgent care centre. This finding has implications for planners and evaluators of community participation projects, as there seems to be an assumption that getting participation techniques right is the principle way of ensuring successful outcomes (Chess, 2000; Rowe & Frewer, 2004). This research suggests that numerous factors can have a significant impact on perceptions of a community participation project's effectiveness apart from how well an exercise was implemented. This supports several scholars observations that participation is heavily influenced by factors like culture, historical, social, economic and political environments which are not easily quantifiable or predictable and can interact in unexpected ways on processes and outcomes (Abelson & Gauvin, 2006; Rifkin, Lewando-Hundt & Draper, 2000; Rifkin, Muller & Bichmann, 1988). Further research is needed to determine how these different contexts can influence and impact community participation initiatives.

A third relevant learning was the challenge of maintaining motivation. When discussing reactions to the project's outcomes and ending, community participants frequently mentioned feeling lost as to what to do next and how they struggled to stay together as a group once the project ended. This was frustrating for Calgary Health Region staff, as they had hoped the committee would carry on in some capacity and seemed surprised that this did not occur. For community members, several factors seemed to play a role in their loss of motivation. First, as many had joined the project with the goal of getting urgent care services for the community, once they realized this was not feasible they did not see a point of continuing. Second, once the project had ended, the committee had no one to report to, no funds for administrative help, no projects to work on or take forward, and no power or influence to implement changes. Lastly, community participants had other obligations such as family and work that limit their ability to engage in committees, especially if they are expected to lead, support and finance these groups. The implication of this finding is that bringing people together on a project or issue does not necessarily encourage long-term sustainability of participation once the project is completed. If health agencies are interested in sustaining participation, it is recommended that resources and support be provided to community groups. Unfortunately, this can be very challenging for the health sector as funding of projects is often one-time, short-term, and insecure (WHO, 2002).

A final learning from this evaluation is the importance and challenge of feeding back to communities the impact that their input had on decision-making. During the interviews several community members wondered what had become of the work that they did. The lack of immediate action on the recommendations put forth by the committee left many community members feeling that once again the Calgary Health Region had dismissed their concerns. Calgary Health Region staff interviewed suggested this was not the case. Work did continue on the recommendations submitted by the steering committee but this occurred a year later when funding was secured to conduct a pilot telehealth project with a local physician's office. Unfortunately they had not been able to involve the community in its implementation as planned in phase II of the Airdrie/North Rocky View Health Needs Project. Calgary Health Region staff indicated that they had wanted to communicate with the community as to this development but as the steering committee had not maintained itself there was no one to take the information to.

Although the need for reporting back to communities the impact their input and ideas had on the decision-making process has been identified in participation guides and frameworks as an important step (e.g. Health Canada, 2000, p. 19), little information is available as to how this should be achieved especially in situations where impact is not immediately apparent or action is not able to be taken at the time (Abelson & Gauvin, 2006). Therefore, a recommendation would be that research is needed to identify effective strategies for communicating back to communities both in the short and long term what happened to their input, what difference it made and if it was not used, why not. Failure to do so runs the risk of damaging the trust and relationships developed during these projects; fosters mistrust in the sponsoring organization and increases apathy towards community participation activities (Abelson et al., 2004; WHO, 2002).

5.3 RESEARCH LIMITATIONS

One potential limitation of this study was that the evaluation of the project occurred approximately two years after the Phase I concluded. This prevented the evaluator from observing the project in action, which may have elucidated other issues or concerns for exploration that were not identified in the final report or interviews. Second, as this evaluation occurred after the fact, participants may have forgotten aspects of the project that could have enriched understanding.

Another potential limitation of this study may have been the inexperience of the evaluator. According to Patton (1990, p. 472), "the researcher is the instrument in qualitative inquiry" and therefore the quality of the data collected is highly dependent on his/her skills. As this was the evaluator's first attempt at conducting an evaluation as well as engaging in qualitative interviewing, this may have affected the quality of the data and research.

5.4 CONCLUSION

Although extensive work has been undertaken by Canadian health agencies to develop guides and toolkits for engaging communities in health care decision-making (Calgary Health Region, 2002; Health Canada, 2000; Winnipeg Regional Health Authority, 2004; Vancouver Island Health Authority, 2003), very few evaluations of these initiatives have been reported in the literature. The lack of evaluation research in this area is concerning in that without these it is difficult to determine which community participation practices work (or not), under what conditions, and whether they are having the desired impact on participants, decision-makers and the larger community. While work is underway to develop frameworks for community participation evaluation and identify criteria by which to judge the effectiveness/success of participation exercises (Beierle, 1999; Rowe & Frewer, 2000) it is still in its infancy and does "little to provide decision-makers with the research evidence they need to inform subsequent processes" (Abelson et al., 2007, p. 2216). What is needed are in-depth analyses of community participation projects, at the local level, that share both positive and negative experiences in order to learn from past mistakes and enhance health agencies' ability to design more meaningful participation projects and programs in the future.

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APPENDIX A: INFORMATION NOTICE BY PROJECT MANAGER

Exploring Community Participation in Healthcare Decision-Making:
The Airdrie/North Rocky View Health Needs Project

A graduate student in Community Psychology from Wilfrid Laurier University is investigating community participation in healthcare decision-making and would like to use the Airdrie/North Rocky View Health Needs Project as a case study. She would like to talk to members of the steering committee and working groups about their experiences of participating in the project.

Her name is Aleisha Harrington and she will be in contact with you shortly to provide more information about her research and invite you to participate in her study.

Although we would greatly appreciate any feedback, you are under no obligation to the Calgary Health Region to participate in this study. The choice to participate (or not) in this study will in no way affect your relationship with the Region.

Thank you.

Sincerely,

Janet Gavinchuk, Project Manager

APPENDIX B: EVALUATOR'S INVITATION TO PARTICIPATE

My name is Aleisha Harrington and I am a graduate student from Wilfrid Laurier University working towards my Masters in Community Psychology. For my thesis I have chosen to explore community participation in health care decision-making and I believe the Airdrie/North Rocky View Health Needs Project is an excellent example of this process in practice.

The purpose of my study is twofold. First, this study seeks to describe peoples' lived experiences of participating in a community health project in order to understand and asses the process of community participation in health care decision-making in practice. Second, this research will compare people's lived experiences to the literature on community participation in health care decision-making to identify similarities as well as differences.

Your involvement in this study would consist of participating in a tape-recorded interview conducted by myself and filling out a community participation assessment tool. The estimated time to complete these procedures is an hour and 45 minutes.

At the end of the data collection process, you will be offered the opportunity to read and comment on the preliminary findings of this study. If it is of interest to you, a copy of my final report will also be made available.

I hope that you will consider participating in this study. I will be contacting you by telephone to invite you to participate and arrange an interview time and place that is suitable to you.

Sincerely,

Aleisha Harrington

APPENDIX C: INTERVIEW SCHEDULE

1. Involvement
    a. What was your reaction to hearing that a Needs Assessment was going to be done in Airdrie/North Rocky View regarding after-hour medical services.
    b. How did you come to be involved in the Airdrie/North Rocky View Health Needs Project?
    c. What were your initial expectations regarding this project?

2. Process of the Project
    a. What would you say was the purpose/goals of the project?
    b. Can you describe for me what it was like to be part of this project?
        - How did you participate?
    c. Do you feel like the project achieved its goals?
    d. Did it meet your expectations?

3. Effect/Impact of Participation
    a. How has participating in this project impacted you? The larger community?
    b. What would you say were the benefits of participating in this project? What were some of the drawbacks?
    c. What did you learn from participating in this project?
    d. What advice would you give the Calgary Health Region to improve future community projects?
    e. Would you participate in another project like this one? Why or why not?

4. Community Participation
    a. In your own words, what is your understanding of community participation?
    b. What are the advantages to having communities participate in health care decision-making?
    c. What are the disadvantages?

APPENDIX D: QUESTIONS TO HELP DETERMINE THE PLOTTING OF PARTICIPATION INDICATORS ON THE COMMUNITY PARTICIPATION ASSESSMENT TOOLS

Note: The following is a description of the broad framework of each of the five participation indicators. After explaining the two extreme points, a list of relevant questions is presented. These questions are not given as a checklist for finding the position of the indicators. Rather they are given as guidelines for evaluators to enable them to develop their own questions for each specific project.

1. Needs Assessment: This factor reflects judgments about the needs of people living in a certain area and decisions to act upon those needs. Needs assessment can be made by professionals using their training and past experience either to project possible problems or carry out surveys in order to plan actions. Professional assessment alone places the indicator at the narrow end of the spectrum. It moves towards broader participation with actions that involve community members in research and analysis of needs.
    - How were needs identified?
    - Did the identification include only health service needs or other health needs?
    - What role, if any, did community people participate in analyzing health needs?
2. Leadership: This factor examines who the existing leadership represents, how does the leadership act on the interest of various community groups, especially the poor and how responsive are the leaders to change. Narrow participation is present if the leadership represents only the small and wealthy minority and continues to act only in their interest. The indicator moves toward the wider end if leadership represents the variety of interests present in its constituencies
    - Which groups does the leadership represent and how does it represent these groups?
    - How was the leadership selected?
3. Organization: This factor looks at the involvement of community based organizations in the project. If planners and professionals do not include community organizations this indicates that narrow participation is present. The indicator moves to the wider end if a variety of community organizations take part.
    - How many community-based organizations were represented?
4. Management: This factor looks at the extent to which the project was developed and managed by the community. Narrow participation is indicated if professionals ran the project. Wide participation therefore would be if the community induced and ran the project
    - How did the project come about?

5. Resource Allocation: This factor looks at how much control community participants have over the resources and outcomes of the project. Low control indicates narrow participation. High control indicates wider participation.
    - How much control does the community have on the decision-making process?
    - Who benefited from this project the most?

(Adapted from Rifkin, Muller, Bichmann, 1988)

APPENDIX E: WILFRID LAURIER CONSENT FORM

INFORMED CONSENT STATEMENT

Research Project Title: Community Participation in Health care Decision-Making: The Case of the Airdrie/North Rocky View Health Needs Project.

Investigator: Aleisha Harrington
Advisor: Juanne Clarke

You are invited to participate in a research study. The purpose of this study is to explore the experience of participating in health care decision-making from the perspective of participants (community as well as Health Region) and connect these experiences to the theoretical literature in this area. This study is part of the researcher's Masters requirement for Wilfrid Laurier University.

INFORMATION

This study involves participating in a tape-recorded interview that will consist of a variety of questions about your understanding and experience of participating in the Airdrie/North Rocky View Health Needs Project. After the interview you will be asked to assess the level of participation using a community participation assessment tool. You will be asked to assess on a scale from 1 to 5 (with 1 being low and 5 being high) the level of participation on five factors: management, leadership, organization, resource allocation, needs assessment. Your responses will produce a map of participation. Completing the assessment tool should take approximately 15 minutes.

A transcriptionist will transcribe interviews in order to produce a text version of the interview. The transcriptionists name is Jacquie Stutt. She has signed and confidentiality agreement which prohibits her from discussing or sharing information about this project with anyone other than the principle researcher. If you know this person or do not feel comfortable having another person review the tape please let the researcher know immediately.

You will have the option to review your transcript to make any changes or deletions. The time required for this portion of the study will vary depending upon your needs. The investigator will then analyze the transcripts for themes. Once themes are generated they will be compared with themes acquired through other interviews to develop overarching themes, which will then be compared to the community participation in health care decision-making literature. Also, individual maps generated from the community participation assessment tool will be used to make comparisons with the results of other respondents and the literature as well as grouped together to form one large map.

This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Bill Marr, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-0710, extension 2468.

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty. You also have the right to pass on any question(s) or procedure(s) you choose. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed.

FEEDBACK AND PUBLICATION

Prior to disseminating any research findings you will be provided with the opportunity to review any quotes to be used in the final report to make any comments or ask for deletions. The findings will be reported in a thesis paper that will be submitted to the investigator's advisor and committee as well as in a report to the Calgary Health Region. You will also receive a summary of the final research findings via e-mail. You can request a copy of the thesis or report to the Calgary Health Region from the investigator. Results should be made available to you by May 31, 2004.

CONSENT

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature: ____________________________ Date:___________

Investigator's signature: ____________________________ Date: ___________

APPENDIX F: CALGARY HEALTH REGION INFORMED CONSENT

CONSENT FORM

TITLE: Community Participation in Health care Decision-Making: The Case of the Airdrie/North Rocky View Health Needs Project.
SPONSOR: Wilfrid Laurier University
INVESTIGATOR: Aleisha Harrington
ADVISORS: Jeanne Besner, Juanne Clarke

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

Despite widespread interest in the topic of community participation in health care decision-making, its practical application to real life settings has not received a lot of attention in the literature and minimal data has been collected which helps to define its potentials and problems. In the instances that it has been reported it is usually from the perspective of the project manager and involves "documenting how a particular method was used, what results were obtained with at best, a short discussion of 'lessons learned' or 'future recommendations' appended to the study. The neglect of the lived experience and perceptual realities of community participants combined with the paucity of quality studies on community participation in health care decision-making has created a need for in-depth analyses and rigorous evaluations of community participation endeavors that report the positive and negative experiences of community participation from more than one perspective (Meleis, 1992; Rifkin, 1986). Using qualitative methods this study seeks to explores community participation in health care decision-making by using the Airdrie/North Rocky View Health Need Project as a case study.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to explore the experience of participating in health care decision-making from the perspective of participants (community as well as Health Region) and connect these experiences to the theoretical literature in this area.

WHAT WOULD I HAVE TO DO?

This study involves participating in a tape-recorded interview that will consist of a variety of questions about your understanding and experience of participating in the Airdrie/North Rocky View Health Needs Project. After the interview you will be asked to assess the level of participation using a community participation assessment tool. You will be asked to assess on a scale from 1 to 5 (with 1 being low and 5 being high) the level of participation on five factors: management, leadership, organization, resource allocation, needs assessment. Your responses will produce a map of participation. Completing the assessment tool should take approximately 15 minutes.

WHAT ARE THE RISKS?

As the Airdrie/North Rocky View Health Needs project was quite small and the number of participants in this study smaller, there is a chance that you could be identified. Every precaution will be made to ensure this does not occur but it is a possibility. See confidentiality section.

WILL I BENEFIT IF I TAKE PART?

By participating in this study you will be helping to construct a practical understanding of community participation in health care decision-making and possibly challenge or support existing theoretical assumptions. There is also the possibility that your participation in this project will inform the Calgary Health Region about this process so they can modify or strengthen future projects.

DO I HAVE TO PARTICIPATE?

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty. You also have the right to pass on any question(s) or procedure(s) you choose. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed.

WHAT ELSE DOES MY PARTICIPATION INVOLVE?

You will have the option to review your transcript to make any changes or deletions. The time required for this portion of the study will vary depending upon your needs.

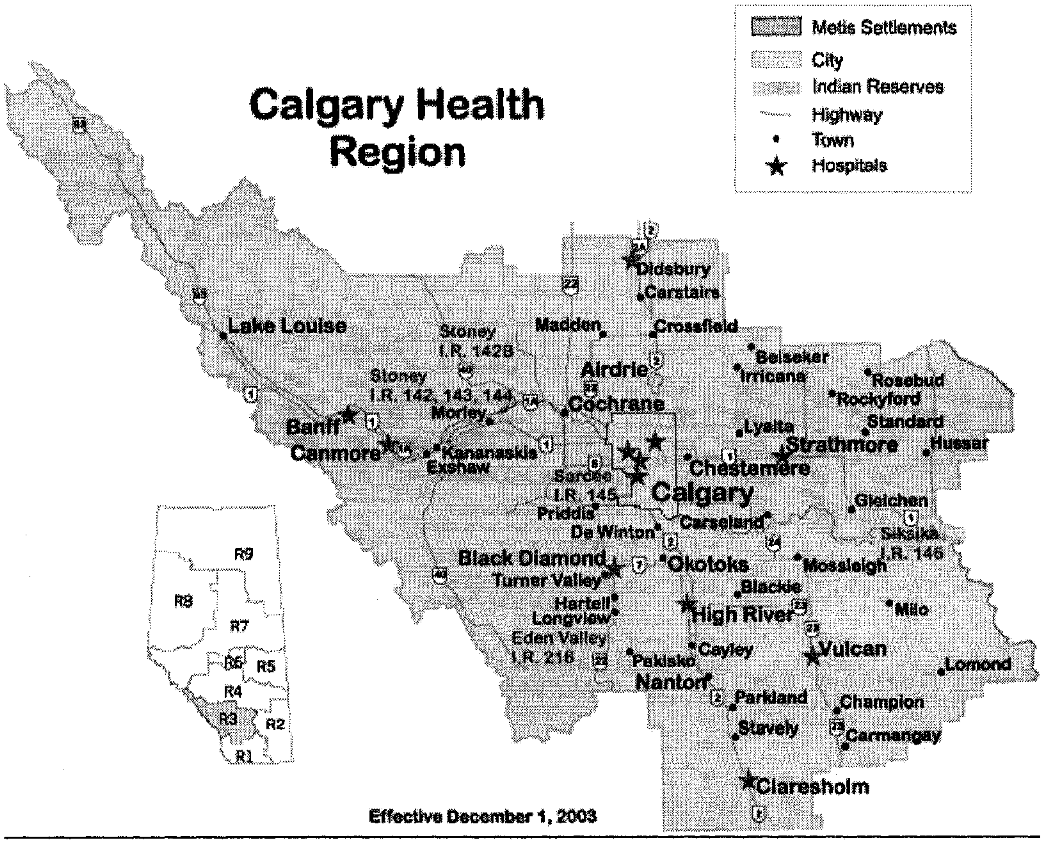
WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

There are no financial rewards for participating in this study nor will you have to pay for anything.

WILL MY RECORDS BE KEPT PRIVATE?

- Several precautions have been made to ensure confidentiality and anonymity:
- Research will be conducted by a person external to the airdrie/north rocky view health needs project.
- Participants will be encouraged to use general terms rather than making references to particular people or specific instances.

APPENDIX G: MAP OF CALGARY HEALTH REGION SERVICE BOUNDARIES AS OF 2003



APPENDIX H: MAP OF COMMUNITIES INVOLVED IN THE AIRDRIE/NORTH ROCKY VIEW HEALTH NEEDS PROJECT