A Review of the Trends and Benefits of Community Engagement and Local Community Governance in Health Care

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non-profit   community-governed   multidisciplinary   primary health care

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Executive Summary

Background

In recent years, community engagement has emerged as an important dimension in health care planning and decision-making within regionalized health care systems across Canada. Understanding the value of community engagement and community governance in policy, planning and decision-making within local communities and the broader health system is of critical importance as health reforms continue to change and evolve. This review was commissioned by the Association of Ontario Health Centres (AOHC) to gather information and evidence on the concepts of community engagement and community governance within the context of regionalized health systems. The purpose of the review was to present evidence on the positive benefits of community engagement and the value added by inclusion of citizens in local organizational community governance.
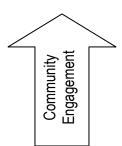
The review began with a brief examination of the concepts of community engagement and community governance. This was a necessary exercise given the variety of terms associated with community engagement (e.g. "participation", "consultation", "involvement", "empowerment") and the number of interpretations of community governance that exist. To better understand the concepts of community engagement and community governance it is helpful to ask two questions:

1. To what extent does a community participate in decision-making?
2. How much do governments and regional authorities support decision-making or empower communities to make decisions?

Community engagement is a spectrum of different levels of citizen participation and power sharing and has been depicted as a "ladder of participation" (Figure 1 *Levels of Engagement (adapted from Bruns, 2003)*. At the bottom of the ladder, communities receive information provided to them by governments and decision-makers in health care. As you move up the ladder, communities have a voice and are given greater influence in decision-making. At the top, citizens are empowered with decision-making on issues that affect the health of their own communities. At this level, decision-making power is transferred from politicians, government administrators and health professionals who have traditionally dominated health care decision making, to local community members.

Figure 1   Community Governance

Autonomy & Empowerment
Delegate Authority
Partner
Collaborate
Involve
Consult
Inform

Community Engagement

For the purposes of this paper, community engagement was defined as a process, involving citizens at various levels of participation based on interpersonal communication and trust, and a common understanding and purpose. Community governance was defined as a method of community engagement that ensures effective involvement and empowerment of local community representatives in the planning, direction setting and monitoring of health organizations to meet the health needs and priorities of the populations within local neighbourhood communities

As the Ontario government moves forward with the implementation of a regionalized health system through Local Health Integrated Networks (LHINs), highlighting the benefits of community governance and community engagement are of paramount importance to locally governed Community Health Centres (CHCs), Aboriginal Health Access Centres (AHACs), Community Family Health Teams (CFHTs) and other community health organizations and the communities they serve. A description of the current trends in community engagement and community governance was discussed to provide contextual relevance of this issue within Ontario.

Across Canada, there has been a general shift in how public participation in health care is being carried out. Community governance has been shifting away from direct democracy of locally elected community boards toward engagement through various other mechanisms such as information sharing and consultation, and by the establishment of community advisory committees, councils or groups. From the perspective of governments, devolved authority to regional structures and the encouragement of citizen participation in planning and priority setting through these various means is seen as moving health care closer to communities. But locally governed community health organizations and individual community members see these trends as a movement towards more remote and centralized governance. Although, community engagement is being promoted as a means to involve citizens in health care planning, empowerment of local citizens (including the most vulnerable populations) achieved through local community governance may be declining.

Despite a limited amount of empirical evidence directly relating community governance to health and health care outcomes and the evaluation challenges

associated with this work, numerous case studies, discussion papers and research reviews are suggesting that meaningful community engagement is key to improving health and health care. New, emerging research is exploring the value added to health and health care that community governed primary health care organizations can bring. New Zealand provides an international example of movement toward community governed primary health care.

In February 2006, the WHO Europe Health Evidence Review published a research report on the effectiveness of empowerment strategies. Based on their review of the research, "the most effective empowerment strategies are those that build on and reinforce authentic participation ensuring autonomy in decision-making, sense of community and local bonding, and psychological empowerment of the community members themselves". The most significant value added of community governance in health appears to be related to its ability to achieve better health outcomes for both individuals and communities by increasing empowerment and social capital. A research review undertaken by Health Canada (2003) indicated that "research associating social capital with health shows that the higher the level of social capital in a community, the better the health status and that strengthening the social capital of communities would consequently constitute a promising means of reducing inequality in the area of health". Recent studies of social capital also see it as a determinant of certain diseases.

A Canadian study undertaken by Church and colleagues (2005) provides insights into the nature, extent and impact of citizen participation on policy and service outputs, in seventeen community health centres across the country. Findings from the study show some differences between locally governed CHCs and those CHCs accountable to larger regional governance structures. Community health centres with locally elected boards were more apt and able to take on advocacy roles and activities for their communities and were "an important source of developing and enhancing community capacity through leadership development". This research also found that citizen participation in community health centre decision making had led to improved programs and services and that the range of programs and services met the needs of the community. Community boards provided a strong link to larger local, provincial and national institutions and networks.

Other benefits of local community governance can include improved direct accountability to local communities, an ability to develop responsive and flexible programs and services to meet the needs of diverse populations, and a capacity to advocate for local health needs. Strong, representative community governance structures offer meaningful opportunities for citizens to become better informed of the complexities of health care decision making while enabling local community concerns to be heard and considered in program planning.

Finally, health programs designed through strong community engagement mechanisms have the potential to achieve efficiency in three ways.

1. When communities are empowered to influence health services within their own communities, more responsive and innovative programs will be developed by and for diverse populations most in need. This linking of citizen's values and preferences to outputs has been referred to as a form of allocative efficiency.

2. Research shows that because the health of individuals is rooted in the social determinants of health, programs that are defined by health professionals without community engagement will most likely not have sustained positive benefits. Local community engagement where issues are defined and managed by the community in a comprehensive approach will have a sustainable positive impact on health.

3. Cost savings achieved through community engagement and community governance has been realized through a decrease in health service utilization – healthier individuals use fewer services.

Newly formed LHINs in Ontario have a responsibility to its citizens to establish effective community engagement mechanisms inclusive of local populations. LHINs have an opportunity to build on emerging evidence that supports local community governance structures empowering individuals and communities for better health and health care. There is no doubt that more research in this area is needed. As the Canadian experiment with community engagement within regionalized systems of health care continues, opportunities for systematic, long term and comparative research abound. The existence of community governed primary health care organizations such as CHCs across Canada might just be the place to start.

Introduction

In recent years, community engagement has emerged as an important dimension in health care planning and decision-making within regionalized health care systems across Canada. Community engagement strategies that involve citizens in various capacities and processes are being recognized as necessary to improve the responsiveness and accountability of decision making in health systems previously dominated by government decision makers and health professionals. Community governance is a crucial means of engagement for local communities. Community governance enables a broad array of individuals within neighbourhood communities to work together to discuss, define and assess the health of their local community, identify and understand the nature of problems that affect community health, and design programs and services to meet the specific needs and priorities of the populations they serve. It also ensures accountability and contributes to making the best use of health resources. Community governance, in this context, has been the cornerstone of the success of Community Health Centres (CHCs) and Aboriginal Health Access Centres (AHACs) in Ontario

Understanding the value of community engagement and community governance in policy, planning and decision-making within local communities and the broader health system is of critical importance as health reforms continue to evolve. Emerging evidence is showing that *meaningful* participation of citizens in health, from governance to self-care management, is proving to be a key determinant of positive health outcomes for individuals and communities as a whole.

The benefits of community governance and community engagement in health will be presented in this report. A description of the current trends in community engagement will be discussed to provide contextual relevance of this issue within Ontario. As the Ontario government moves forward with the implementation of a regionalized health system, through Local Health Integrated Networks (LHINs), the importance of highlighting the benefits of community governance and community engagement are paramount.

Purpose of the Report

Citizen engagement and community governance is believed to have many important benefits for health and health care. Enhanced quality of health care, improved individual and community health outcomes, better accountability, and more efficient use of resources are key dimensions of health and health care where engagement of citizens can have a positive impact.

This review was commissioned by the Association of Ontario Health Centres (AOHC) to gather information and evidence on the concepts of community engagement and

community governance within the context of regionalized health systems. The purpose of this literature review was to present evidence on the positive benefits of citizen engagement and the value added by inclusion of citizens in local organizational community governance in health care planning and decision-making.

Approach to Information Gathering

The scope of the literature search conducted for this review was guided by the following parameters:

- Definitions of community governance and citizen engagement
- Citizen engagement related to quality health care
- Citizen engagement related to health outcomes at a systems, organizational and individual level
- Economic evaluation of community governance
- Accountability
- Examples of successful citizen engagement practices in primary health care

The methodology used to collect information was through Internet searches on Google search engine and www.scholar.google.com to obtain reports authored by government health ministries and agencies, policy networks and organizations as well as academic papers. Search terms used were: citizen engagement in health care, effect of community engagement on health, community governance in primary health care, patient centred health care, regionalization and community governance, and economic evaluation and community governance. Further searches were based on bibliographic references from identified articles.

Searches were also conducted through MD Consult – Medline on citizen engagement and patient participation in health care. Additional resources provided by the Association of Ontario Health Centres included reports, specific websites and key contacts within Canada.

Concepts in Community Engagement & Governance

A review of the benefits of community engagement and value of community governance in health care is difficult without a common understanding of the terminology. There are many definitions of community engagement presented and debated in the health care literature. Furthermore, the term, community governance has its own set of interpretations.

Community engagement is most often described as a process, involving citizens in various aspects of health care based on interpersonal communication and trust, and a common understanding and purpose. The International Association for Public

Participation, reported by the State of Minnesota Public Health, defines community engagement as follows:

Descriptions of community engagement from two jurisdictions in the United States and Canada are presented as examples of how definitions are modified and tailored to local health systems. The State of Minnesota defines community engagement as:

> *Citizen engagement is a process of involving community members and the reliance on a community's own resources and strengths as the foundation for designing, implementing, and evaluating solutions to problematic conditions that affect them. As such, community engagement involves interpersonal trust, communication, and collaboration.[1]*

Vancouver Coastal Health (VCH) Framework for Community Engagement offers the following definition (27).

> *Community Engagement is a term used to refer to a whole spectrum of activities that support the two-way interaction process between the VCH and its communities. 'Consultation', 'involvement', and 'participation' are all terms that are interchangeably used to describe community engagement activities. However, each term refers to intrinsically different forms of engagement, which are dependent on the overall objectives.*

To better understand the concepts of community engagement and community governance it is helpful to ask two questions:
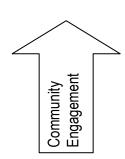
1. To what extent does a community participate in decision-making?

2. How much do governments support decision-making or empower communities to make decisions?

These questions imply that there are different levels of engagement. Indeed, community engagement as first described in 1969 by Abelstein, has been described as a "ladder of participation" (7, 10). In Figure 1 below, community engagement is a spectrum of different levels of citizen participation and power sharing. At the bottom of the ladder, communities receive information provided to them by governments and decision-makers in health care. As you move up the ladder, communities have a voice and are given greater influence on decision-making. At the top, citizens are empowered with decision-making on issues that affect the health of their own communities. At this level, decision-making power is transferred from politicians, government administrators and health professionals who have traditionally dominated health care decision making, to local community members. Locally governed health organizations are good examples of the highest level of community engagement.

Figure 1   Community Governance

| Autonomy & Empowerment |
| Delegate Authority |
| Partner |
| Collaborate |
| Involve |
| Consult |
| Inform |

Community Engagement

Community governance is one form of community engagement. It too has been defined in various ways, depending on how broadly the term is applied. Community governance can refer to governance of health care institutions or community organizations by elected representatives of local communities. CHCs and AHACs in Ontario are community governed primary health care organizations. Community governance has also been used in the context of single regional governance structures responsible for a number of health services/organizations in a given geographic area or region. Local Health and Social Service Networks in Quebec and Regional Health Authorities in most provinces are examples of this interpretation. Even more broadly, community governance can refer to *activities* at a local level where the organizing body may not assume a legal form and where there may not be a formally constituted governing board. For example,*Turning Point, Collaborating for A New Century in Public Health*, funded by the W. K. Kellogg Foundation and the Robert Wood Johnson Foundation in the United States has been referred to as "community health governance"

[1] The Association of Community Health Centre reference to community governance was taken from their Submission to the Legislative Assembly Standing Committee on Social Policy regarding Bill 36, the proposed *Local Health System Integration Act, 2005* in Ontario.

The Association of Ontario Health Centres (AOHC) strongly supports community engagement in health care at all levels and it asserts "community governance must respect and be guided by the dynamics of community at the neighbourhood level" and that "community governance must not be misunderstood or misrepresented as governance of all health services in a given local region by a single regional structure, as has been the recent case in the province of Quebec.

For the purposes of this paper, community engagement will refer to the broad definitions outlined above. Community governance will refer to a method of community engagement that ensures effective involvement and empowerment of local community representatives in the planning, direction setting and monitoring of health organizations to meet the health needs and priorities of the populations within local neighbourhood communities

Trends in Community Engagement & Governance

In recent years, shifts are occurring among the various players in the health care environment. Traditionally, governments and health professionals have dominated decision-making in the health care arena. In the last decade, all ten provincial governments in Canada have regionalized their health care systems, devolving authority of their health care delivery system to some form of regional health authority or network structure. In Ontario, regionalized bodies are referred to as Local Health Integrated Networks (LHINs). Within these new structures, governments are pushing responsibility for planning and delivery of health services closer to communities, and civil society and citizens are being asked to play a greater participatory role in these processes.

Theoretically, in a decentralized health system, more opportunities for community engagement are possible. In some jurisdictions with well-developed community engagement processes in place, the number of citizens participating in health care resulting from regionalization processes may well be increasing (17, 21). Even if the numbers of citizens participating in health care are increasing, and apart from individual engagement in personal care decisions, there is little evidence to show what level of decision-making, individuals or communities are willing and able to take on and what influence they have actually made on decision-making (10). Much more research is needed in this area.

From the perspective of locally governed health organizations and individual community members, regionalized structures can be seen as a move toward more

centralized and remote planning and priority setting. Broad governance structures responsible for many health sectors within an integrated system may be seen as not serving local health interests as well as locally governed health organizations. Additionally, they may not be able to effectively address local community issues if power differentials among the health players are not addressed and the political and administrative leadership committed to meeting local health needs are not in place.

Community governance has been shifting away from direct democracy of locally elected community boards toward engagement through various other mechanisms (17). In some jurisdictions, community governance of individual health care organizations is, in fact, declining. In Quebec's recent health reorganization, longstanding locally governed, centres locaux de services communautaires (CLSCs) have been merged and brought under a health and social service agency governance umbrella along with general hospitals, and residential and long-term care centres (14). In Ontario, within each LHIN, individual Community Care Access Centres (CCACs) are consolidating to form one CCAC that will be governed by one board of directors.[1] Also, traditional CHCs in British Columbia and Alberta have been allowed to retain local community boards, but new CHCs are under direct operational control of the regional health authorities. In Ontario, Part III, Section 16, of the *Local Health System Integration Act, 2006* [2] supports community engagement on an "ongoing basis" regarding integrated health service plans and for priority setting. The mechanisms by which communities will be engaged have been left up to the discretion of each individual LHIN.

The motives behind support for community engagement may vary. The belief system and values of the politicians and decision-makers of the day have a significant impact on the support for local community governance and community engagement activities. At one end of the spectrum, a governments' desire to increase public participation in health care decision- making may be to legitimize unpopular decisions (10). On a more encouraging note, there appears to be a growing awareness that strategic and deliberate community engagement mechanisms are a valuable component to improving quality health care and ultimately, achieving good health outcomes. Regardless of the motivation, interest in community involvement in health care has resulted in the establishment of many different community engagement mechanisms across the country. Mechanisms have taken many forms including community health councils, community advisory committees, formalized partnerships and networks, and the use of various consultation, information sharing and reporting mechanisms as well as national and provincial quality health councils. Several jurisdictions in Canada have developed community engagement frameworks, clearly outlining a commitment to community engagement through a variety of methods for citizen engagement (8,9, 27, 32, 33).

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[1] The CCAC in Niagra provides an example of the CCAC consolidation. It will come together with neighbouring CCACs to form a new organization serving the Hamilton, Niagara, Haldimand-Norfolk, Brant and Burlington area.

[2] *Local Health System Integration Act, 2006* http://www.e-laws.gov.on.ca/DBLaws/Statutes/English/06l04_e.htm

Citizens are playing a significant role in ensuring their involvement. Citizens want to participate at some level. This is occurring for several reasons. Some researchers indicate that citizens are becoming less willing to rely on elected officials as their sole advocates of their interests and realize that the complexities on today's society requires broader input on decision making (1). Although citizens may not necessarily want responsibility for decision-making, they do want an opportunity to express their views, to be heard and to ensure accountability and transparency when decisions are made (2,17).

Two other significant changes are influencing the trend toward community engagement: the Internet and the increasing cultural diversity in communities across Canada. The Internet and communications technology are relatively new methods to engage citizens in health. These technologies offer rapid transfer of information as well as create a vehicle for consumer input on questions of health care. For example, more than 30,000 Canadians participated in the Romanow Commission's on-line survey.[3] There is also a growing demand for on-line health resources and information. Individuals, with access to Internet, who traditionally sought out health information through a health professional or health care organization, are increasingly using websites, newsgroups and email as a means of seeking and exchanging information about health (16). Informed citizens are helping to redefine the care management relationships with their health providers. The movement toward client-centred care demonstrates this change of relationship.

Increasing cultural diversity is making it more important to develop effective community engagement strategies to accommodate differences at a local level (2). Emerging research on the influence of neighbourhoods on health is showing that local community characteristics play a role in health disparities (5, 24). The connection between neighbourhood and health, support the argument for local community governance, as a necessary vehicle to ensure the inclusion of diverse populations in identifying and addressing their specific health needs. Furthermore, effective community engagement structures such as local governance of Community Health Centres provide a voice for vulnerable populations who carry the greatest burden of health in our society (21).

The Value of Local Community Governance

Effective local community governance at the neighbourhood level is crucial to achieving flexible, relevant and efficient health services to meet the unique characteristics of communities. Local community governance is increasingly regarded as a key ingredient in health care to:

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[3] Media release. 10 September 2003. www.hc.sc.gc.ca/english/care/romanow/hcc0122.html

- Improve health outcomes through building social capital and empowering individuals and communities
- Improve transparency and accountability
- Restore and strengthen trust in democratic processes
- Meet needs within a diverse, multicultural society through responsive, flexible programs and services
- Ensure better resource allocation and more appropriate health service utilization based on the values, strengths, resources and expectations of the community

How can we know that community governance is making a difference in the quality of health care or an impact on health? Empirical evidence linking citizen engagement to quality health care and its impact on decision making in public policy processes is limited (3, 10, 20, 34). Despite the dearth of rigorous evaluative research on citizen engagement and its impact on planning, decision-making and policy influence, there are a significant number of discussion papers and emerging research showing the value or benefits of empowerment strategies such as local community governance. Some of these studies are exploring the impact of local community governance and citizen engagement on health with the context of community health centres (10, 11), community governed primary health care organizations (6,13) and health co-operatives.[4]

In a recent paper by WHO Europe Health Evidence Review, research on the effectiveness of empowerment strategies was identified and several policy considerations were presented based on the review findings (30). There is also a generous amount of anecdotal evidence and "real life stories" that demonstrate the value of local community governance.

a) Healthy Communities - Empowerment & Social Capital

The links between strong communities and good health are becoming more and more evident. Recent evidence, based on multi-level research designs are showing that empowering initiatives can be used as an effective public health strategy and can lead to better health outcomes (28, 30). Empowering citizens, building social capital and creating connections among people in local neighbourhoods may be key elements to creating significant positive health impacts. The effectiveness of empowerment strategies has been examined from two different lenses: empowerment as a process and its effects in improving health and reducing health disparities.

As a process, the WHO Regional Office for Europe Health Evidence Network has identified a number of policy considerations related to health planning and

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[4] The Co-operatives Secretariat website, found at www.agr.gc.ca/rcs-src/coop/index offers a good summary of health co-ops across the country. The Centre for the Study of Cooperatives at the University of Saskatchewan is doing research on how these "social economy enterprises" are helping to build relationships within communities (www.usaskstudies.coop/).

empowerment strategies. Based on its findings, the following policy considerations are most relevant to this discussion:

- *"While participatory processes make up the base of empowerment, **participation alone is insufficient** if strategies do not also build capacity of community organizations and individuals in decision-making and advocacy.*
- ***Successful empowering interventions*** *can not be fully shared or "standardized" across multiple populations, but **must be created within or adapted to local contexts**.*
- *The **most effective empowerment strategies** are those that **build on and reinforce authentic participation** ensuring **autonomy in decision-making**, **sense of community and local bonding**, and **psychological empowerment of the community members themselves**.*
- *Structure barriers and facilitators to empowerment interventions need to be identified locally.*
- ***Effective empowerment strategies*** *are **needed for socially excluded populations**" (30).*

The WHO Health Evidence Network review cites the World Bank's four characteristics that will ensure participation is empowering: " people's access to information on public health issues, their inclusion in decision-making, local organizational capacity to make demands on institutions and governing structures and accountability of institutions to the public" (30).

In a recent Canadian study of CHCs, researchers found that citizens who were participants in decision making processes of the organizations, felt that their participation " led to improved programs and services, and that the range of programs and services met the needs of the community" (11). Furthermore, CHCs were seen as " organizations that increased community capacity through helping communities and individuals to raise awareness about health and social issues, identify community strengths and weaknesses, build shared community values, increase community and individual confidence to participate, and increase levels of trust within the community" (11). Individual capacity enhanced through board membership and volunteerism in turn flows back into the community.

Determining the direct link between empowerment strategies such as local community governance, on improving health and reducing health disparities is challenging, as many contextual factors influence the relationship. Nevertheless, there are some studies testing the hypothesis that community participation in decision-making will make positive benefits in health or health care. Much of this work emphasizes the benefits of social capital[5] on health.

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[5] There are many definitions of social capital described in the literature. A Health Canada Working Paper Series on Social Capital authored by van Kemenade (2003) offers a good description of the term (28). In the context of this report, social capital refers to social trust, mutual respect and group membership that people can draw on to solve common problems.

In a report published by Health Canada in 2003, the concepts and research on social capital is examined from the perspective of a determinant of health. With respect to social capital and health policy, the authors state that "research associating social capital with health shows that the higher the level of social capital in a community, the better the health status. Strengthening the social capital of communities (and countries) would consequently constitute a promising means of reducing inequality in the area of health" (28).

The Benefits of Community Engagement: a Review of the Evidence (2004) cites work by Robert Putnam and other researchers on social capital stating that:

> **"Over the last twenty years, more than a dozen large studies have been carried out in the USA, Scandinavia and Japan which show that 'people who are socially disconnected are between two and five times more likely to die from all causes, compared with matched individuals who have close ties with family, friends, and the community' " (26).**

Further more, since the late 1990s, social capital has been considered as a determinant of certain diseases (28). This type of research is becoming more and more frequent. For example, researchers from the University of Chicago recently published a study in the Journal of Psychology and Aging making a direct correlation between increased loneliness and significant increases in systolic blood pressure, doubling the risk of heart attack and stroke.   The researchers concluded that one strategy for treating blood pressure might be to get people more involved in the community (23).

Social power is also a component of social capital, though not often referred to in public health research. The importance of this aspect of social capital is seen in poor communities where strong social networks and connections may be present but a lack of political power and influence make it difficult for positive changes to be made. Community capacity building through local community organizations is one way to address this issue (19). A recent report published by PolicyLink [6] in the U.S. highlights community engagement strategies aimed at reducing health disparities in low-income communities and communities segregated by race and colour. This report states that, "local ownership and meaningful community participation are key to developing, implementing and sustaining community change" and that community capacity is built by connecting citizens, service providers, and community leaders around a "unifying agenda and benchmarks for change" (25).

Health services planning and priority setting that is carried out close to individuals who will use the services, and that includes people interested and willing to

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[6] PolicyLink is a U. S. national non-profit research, communications, capacity building, and advocacy organization working to advance policies to achieve economic and social equity. http://www.policylink.org/

participate, are essential to building healthier communities. Health disparities and health issues of concern to citizens appear to be much better addressed on a local neighbourhood level through the highest level of community engagement and empowerment mechanisms. A single regional governance structure, struggling to address many competing priorities and interests, has the potential be too remote, inflexible and less able to empower individuals and create the social capital needed to improve health.

b) Improving Accountability

Accountability is a big issue in health care. It was highlighted in all major health care reviews that have taken place in Canada in recent years. One of the solutions to the perceived lack of accountability of health care decision makers has been for governments to decentralize decision making to regional structures. On the surface, this seems like a good solution. However, these new governing structures still remain accountable to provincial governments for implementing provincial health policy and standards, continue to be reliant on the province for revenues, and remain largely made up of selected middle class representatives who are often health professionals and representatives of health organizations (10).

Accountability means being held responsible (17). It encompasses the concept of transparency or the ability to give explanations for the discharge of responsibilities by individuals and organizations in the health system. Evaluation of individual or organization actions against performance objectives and a process for correction if expectations are not met are also elements of accountability (17). From the citizen's perspective, accountability is linked to three key main concepts: transparency, trust, and citizen engagement (2). Accountability is based on a relationship between those people who make decisions and those who are affected by those decisions.

Local community governance can be an effective way to improve direct accountability in health care. Representative community governance structures offer meaningful opportunities for citizens to become better informed of the complexities of health care decision making while enabling local community concerns and issues to be heard and considered. The most appropriate and effective governance structures within an integrated health system should be characterized by the distinctness of each community, and should operate under the principles of good governance[7]. These principles are exemplified in the community health centre model of primary health care.

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[7] The Institute On Governance is a non-profit organization, established to explore, share and promote the concept of good governance in Canada and abroad, and to help governments, the voluntary sector, communities and the private sector put it into practice for the well-being of citizens and society. It defines five principles of good governance as: legitimacy and voice, direction or strategic vision, performance with respect to responsiveness, effectiveness and efficiency, accountability and transparency and fairness.

If the goal of citizen engagement is to improve the quality of governance decisions by ensuring that citizen values, needs and interests are adequately considered and reflected in decisions making, then citizen engagement " will require greater emphasis on information, power sharing, and reciprocity between citizens and their governors" (4).   Public involvement in accountability mechanisms will be two-way interactions and "its pay-off is a greater level of trust between citizens and decision makers" (4). Church and colleagues, in their recent study of citizen participation in community health centres states that " the recent move in Quebec to eliminate the governance role of their CHCs and fully integrate them into regional structures represents what existing CHCs have most feared about regionalization – the loss of autonomy and direct accountability to local communities" (11).

c) Better Health Planning & Decision Making in Service Delivery

In 2003, Health Canada published a review and analysis of current literature on the evidence linking citizen engagement to quality health care including the dimension of health planning and decision-making (34). Findings show that the public is involved to varying degrees in planning and development of health care services across a range of service areas and levels.   This is occurring in local, national and international settings. What isn't known is what impact the contribution of citizens is having on the quality and effectiveness of the service plans, policy and decisions. Unfortunately, little empirical evidence is available on evaluating this aspect of community engagement.   Case studies and reviews reported in the Health Canada report show citizen involvement at the local level has led to:

- o *Changes in the provision of services – making services more accessible, providing more information, or new services resulting because of the involvement*
- o *Changes in attitudes of the organizations involving patients – staff attitudes towards patients became more favourable, organizations were more open to involving patients, and organizations developed more initiatives to involve patients*
- o *Effects on users of services – patients welcomed the opportunity to participate and self-esteem was increased, attention to process was important to participants* (5)

A Canadian study undertaken by Church and colleagues provides insights into the nature, extent and impact of citizen participation on policy and service outputs, in seventeen community health centres across the country. Findings from the study show some differences between locally governed CHCs and those CHCs accountable to larger regional governance structures. Community health centres with locally elected boards were more apt and able to take on advocacy roles and activities for their communities and were "an important source of developing and enhancing community capacity through leadership development" (11).   This research also found that citizen participation in community health centre decision making had led to improved

programs and services and that the range of programs and services met the needs of the community. Community boards provided a strong link to larger local, provincial and national institutions and networks.

A study conducted in New Zealand compared community-governed non-profit and for-profit primary care practices. Differences found between these two types of primary health care organizations were likely associated with their ownership and governance arrangements (13). Community governed non-profits were more likely to have quality management policies and to carry out local service planning and community needs assessments. They also had policies and practices in place that reduced financial and cultural barriers to access of services.

Numerous examples exist across the country where locally governed community health centres have created innovative health programs and services based on citizen input and participation matched to their specific health needs. The Ontario Health Quality Council recently made special mention of seven Community Health Centres and Aboriginal Health Access Centres in Ontario who have built innovative, responsive primary health care services. Some examples are:

- The Regent Park Community Health Centre (Toronto) which identified education as a major factor determining health in their community and has launched an outreach program cutting school absenteeism by 50 % and the drop-out rate by at least two thirds.
- Access Alliance Multicultural Community Health Centre (Toronto) provides interpretation in 60 languages for its clients and health and social service providers.
- Eight sites run by the Mamweswen North Shore Tribal Council Aboriginal Health Access Centre has made great strides serving Aboriginal clients in remote and rural settings.
- Woolwich Community Health Centre (Woolwich), whose Gesundheit fur Kinder program offers a comprehensive set of maternal and infant health services for German speaking Mennonites near St. Jacobs in southern Ontario.

d) Making Better Use of Resources

One of the main reasons that governments have transferred authority for health care to regions and rationalized services is to achieve cost efficiencies and better align limited health resources to population health needs. Fragmented health systems did not make it easy for resources to be allocated to meet established priorities. The hope for regionalized health systems is that health services will be more flexible, responsive and enable movement of resources to better meet the needs of the populations served. However, in order for regionalization to have an impact on resource allocation and health care costs a number of changes must occur, specifically: significant cultural shifts, changes in power relationships among health players and citizens, improved knowledge transfer among participants as well as a

stronger commitment to reallocating resources by government and decision makers in regional health authorities (or LHINs) (20).

Health programs designed through strong community engagement mechanisms have the potential to achieve efficiency in three ways. When communities are empowered to influence health services within their own communities, more responsive and innovative programs will be developed by and for diverse populations in most need (22). This linking of citizen's values and preferences to outputs is a form of *allocative efficiency* (1). Secondly, because the health of individuals is rooted in the social determinants of health, programs that are defined by health professionals without community engagement will most likely not have sustained positive benefits. Local community engagement where issues are defined and managed by the community in a comprehensive approach will have a *sustainable* positive impact on health (31). Finally, cost savings through community governance has been realized through a *decrease in health service utilization*. Engaging individuals in the governing of health services keeps people healthier, builds capacity and social capital, and increases skills and knowledge. These benefits all lesson the need for people to use costly health services (6, 26).

Community Governance as a Building Block of Primary Health Care

Health care systems in Canada are made up of a complex array of different services: acute care, home care, long term care, rehabilitative care, pharmaceuticals, mental health, addictions, primary health care. The foundation of the entire health care system is primary health care (29) and community engagement and the context within which health is achieved are cornerstones of that foundation (11, 29). Reported in a paper by Barnett and Barnett, Barbara Starfield, a well-known expert in the field of primary health care has shown "that countries with a stronger primary health care infrastructure have better health outcomes than countries that do not".

Primary health care is usually the first contact of care that individuals have with the health system. It is a term that is not yet well known outside of health circles and is often confused with a narrower definition of primary care focused on medical aspects of care. The Declaration on Primary Health Care produced at the International Conference on Primary Health Care in Alma Ata 1978, defined primary health care as follows:

> *Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology **made universally accessible to individuals and families in the community through their full participation** and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and the community with the national*

health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process. [8]

This definition of primary health care has been interpreted and applied differently around the world depending on the realities of each country. Primary health care, built on social determinants of health will play a more dominant role in the health status of individuals and communities than by focusing solely on health care itself (15). In Canada, community health centres have been built on these concepts. The success of community governance in community health centres, the most mature primary health care organizations in the country, is evidenced by the creation of innovative programs, grounded in the social determinants of health, responsive to the populations served. Church and his colleagues attribute much of the success of community health centres to the "unique mix of organizational culture, leadership, structures and processes that favour a participative approach to decision making" (11).

Why then is community governance so important in primary health care? Simply put, every community is unique. Not only are the needs of an urban, multicultural neighbourhood different than those of a sparsely populated, rural community, there can be significant differences in population health needs within geographic areas defined by regional health authority boundaries. Local community-governed organizations that serve a defined neighbourhood community(s) or specific populations within those communities, effectively take these differences into account in health planning and decision-making.

The Primary Health Care Strategy in New Zealand provides an international example of a recent movement toward the development of community-governed Primary Health Organizations (PHOs). These new organizations, supported by equity objectives in primary health care delivery, are intended to achieve results in three main areas: improvement in population health, reductions in hospital use and greater empowerment for providers and consumers of health care services.

Barnett and Barnett state "the development of PHOs with greater community emphasis has the potential to increase social empowerment among disadvantaged populations. This is significant because cultural as well as economic barriers influence the use of services" and "it is expected that PHO development will lower rates of hospital admission" (6).

Empirical evidence currently available has not yet supported the claims that regional health structures, covering large geographic scope and responsible for broad mandates, can effectively involve citizens in decision-making (3, 10, 20). Furthermore, as most primary care practices in Canada are outside the scope of regional structures and operate without community governance or engagement

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[8] The Declaration of Alma Ata International Conference on Primary Health Care took place in Alma Ata, USSR in September 1978 in which 134 countries (including Canada) and 67 international organizations took part. The declaration can be found at www.who.int/hpr/NPH/docs/declaration_almaata.pdf

mechanisms, responsive services and empowered communities are unlikely to be realized. In Ontario, preserving and promoting community governance of CHCs, AHACs and CFHTs will be a critical element to maintaining effective and efficient quality primary health care for local communities.

Conclusion

This review was commissioned to explore the current literature and published reports available on the benefits of community engagement in health and health care, with a specific focus on community governance. Two factors acted as impediments in this review: the lack of conceptual clarity of community engagement and community governance; and the limited amount of empirical evidence directly relating community governance to health and health care outcomes. Trends and research on community governance and community engagement were presented to stimulate thinking about the future of community governance within a changing and evolving health system.

Across Canada, there has been a general shift in how public participation in health care is being carried out. Community governance has been moving away from direct democracy of locally elected community boards toward engagement through various other mechanisms. The trend has been to encourage community engagement through information sharing, consultation and reporting mechanisms as well as by the establishment of community advisory committees or groups. From the perspective of governments, devolved authority to regional structures and the encouragement of citizen participation in planning and priority setting is seen as moving health care closer to communities. But community health organizations and individual community members tend to see these trends as a movement towards more remote, centralized governance.

Numerous discussion papers and research reviews suggest community engagement is key to improving health and health care. New, emerging research in the area is starting to show the value added for community governed primary health care organizations. As the highest level of community engagement and participation, local organizational community governance empowers individuals and communities, builds social capital, ensures accountability, enables programs and services to be matched with local community values and needs, may improve and sustain better health, makes better use of resources and can contribute to reducing health care utilization.

Newly formed LHINs in Ontario have a responsibility to its citizens to establish effective community engagement mechanisms inclusive of local populations. LHINs have an opportunity to build on emerging evidence that supports local community governance structures empowering individuals and communities for better health and health care.

There is no doubt that more research in this area is needed. As the Canadian experiment with regionalization of health care and community engagement continues, opportunities for systematic, long term and comparative research abound. CHCs are well positioned for research in this area. They are the most experienced community governed primary health care organizations in the country and their organizational leadership, culture, structures and processes have been shown to support a participatory approach to decision making. The existence of these community governed primary health care organizations across Canada might just be the place to start.

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