



CIHR IRSC



CIHR's
Citizen Engagement
in Health Casebook



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160 Elgin Street, 9th Floor
Address Locator 4809A
Ottawa, Ontario K1A 0W9 Canada
www.cihr-irsc.gc.ca

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Foreword

Citizen engagement, sometimes referred to as public involvement or participation, and societal or community engagement, is about meaningful involvement of individual citizens in policy or program development. It generally includes all of the activities organizations take to involve the communities they serve in directing policies and priorities or in their governance. It also frequently refers to processes where members of the general public, as opposed to representatives of stakeholder groups, are the main foci of the engagement, who are meaningfully involved in two-way interactions consisting of dialogue and deliberation with the health care organization or group. Ultimately citizen engagement is about sharing decision making power and responsibility for decisions.

There is a long history of governments and health care institutions in this country trying to engage citizens in decisions related to health care. Citizen engagement exercises have been conducted in all provinces, relating to most areas of care, and have used numerous methods of engagement. We have seen large national engagement exercises as part of Royal Commissions to individual hospitals engaging their local publics about the services they provide. However, while there have been many successful examples, citizen engagement is still not the norm within our health research or health care systems.

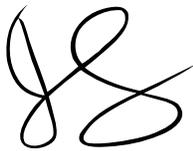
This Casebook was first conceived at a workshop I attended in Toronto, Ontario in November 2010, hosted by the CIHR funded Priority Setting in Health Care Research Group, based at the University of Toronto.¹ Participants at the workshop represented health care organizations from across Canada who convened citizen engagement processes, practitioners of citizen engagement, researchers on citizen engagement, other stakeholders and citizens who have participated in these processes. One of the main recommendations arising from this two-day meeting was the need to better document and share examples of citizen engagement in health care across Canada, so that others could learn from the experiences and processes of other organizations. I and other participants also felt that health care organizations and their stakeholders would benefit from descriptions of cases where members of the general public have been engaged.

At the Canadian Institutes of Health Research (CIHR), the Partnerships and Citizen Engagement (PCE) branch is responsible for a wide variety of tasks and projects which guide, facilitate, and manage partnerships and engagement activities. As part of these activities, the PCE branch has developed the CIHR Framework for Citizen Engagement and a Citizen Engagement Handbook to help support citizen engagement across the organization and for its stakeholders. Having previous experience in developing a Partnership Casebook and dedicated expertise in this area, the PCE took the lead for this project and invited members of the Priority Setting in Health Care Research Group to act as editors.

¹ The Toronto Health Policy Citizens' Council Website, 2011.
Available at: <http://www.healthydebate.ca/about-us/thpcc>, accessed on 20 Jan 2012.

It is my hope that the Casebook will be a useful reference for those wishing to know more about citizen engagement or wishing to facilitate citizen engagement. The cases illustrate some of the methods of citizen engagement which have been employed in the Canadian health care context. I expect that the Casebook will not only increase understanding of how to engage citizens but also increase understanding of the experiences of those undertaking citizen engagement activities. The publishing of this Casebook is an important step in promoting and facilitating citizen engagement by sharing promising citizen engagement practices.

I would like to thank the authors of the cases for their submissions, Karen Born, Roger Chafe, Andreas Laupacis and Wendy Levinson for collating and editing the Casebook and Rosa Venuta for managing the project and the production of the Casebook.



Ian D. Graham, PhD, FCAHS
Vice-President
Knowledge Translation and Public Outreach
Canadian Institutes of Health Research



Members of the Toronto Health Policy Citizen's Council and research team

Introduction

The primary purpose of this Casebook is to highlight and share some of the diverse citizen engagement activities that are occurring throughout Canada. There are many excellent examples; more than 40 outstanding cases of citizen engagement within the Canadian health care system were submitted for review for this Casebook alone. Those chosen for inclusion in this book represent a wide range of citizen engagement activities from across the health sector (including hospitals, non-profit organizations, and provincial, regional and local governments) and the different regions of Canada (such as urban, rural/remote, and First Nations communities). By presenting these unique cases, we hope to facilitate knowledge translation and exchange about citizen engagement in health, giving the diverse perspectives, approaches and groups within the Canadian health sector the opportunity to learn, share and discuss opportunities for further practice and policy.

While this Casebook focuses on Canadian organizations and experiences, in the spirit of learning from other jurisdictions, seven principles of successful citizen engagement originally developed by Dr. Carolyn J. Lukensmeyer, the Founder and President of *AmericaSpeaks*, can help frame themes from the fourteen cases. *AmericaSpeaks* has had over sixteen years of experience engaging citizens in the United States and across the globe on a broad variety of topics, including the reconstruction of the World Trade Center site after 9-11, disaster recovery in New Orleans after Hurricane Katrina, health care reform in the state of California, and confronting the federal deficit and debt of the United States. Dr. Lukensmeyer has described seven principles of successful citizen engagement. The process, she suggests, must:

- be linked to decision makers;
- include a demographically diverse group of participants;
- ensure that participants have neutral, accurate information about the question under discussion;
- ensure well-facilitated deliberations;
- help the participants aim to discover shared priorities;
- develop clear recommendations for action; and
- commit to sustaining an organization's citizen engagement activities.

Many of these key principles are reflected in the cases presented here.

Each case in this book is structured to allow the reader a quick overview of the purpose and rationale of citizen engagement processes, what methods were used for engaging citizens, the outcomes and impacts of the engagement, and the key lessons learned in each case. While each case offers a unique perspective, they do share a number of conclusions and lessons learned.

Citizen Engagement Impacts Policy Decisions

As the cases presented here illustrate, meaningful citizen engagement can benefit both the organizations and the citizens involved in the process. It can strengthen the relationships between the health care organization and the public or communities it serves. It lets people bring their own experience to the decision making process, which can lead to better decisions that can positively impact people's health. It can even help build a stronger civic society.

While there are many benefits to engaging citizens, including informing decision makers and providing opportunities to learn from the public, most health care organizations want to know if citizen engagement can also have a positive impact on policy discussions and outcomes. Accurately measuring the impact of citizen engagement on decision making is often difficult, but a number of the cases presented here show concrete impacts from engaging citizens. The Mental Health Commission of Canada's experience (Case 2) clearly illustrates how a framework for Canada's national mental health strategy was changed as the result of citizen and stakeholder engagement and input. The leadership of Northumberland Hills Hospital in Ontario (Case 6) was able to work with citizens from the local community to make difficult decisions about how to prioritize core medical services without losing the support of the communities it served. Of note is that 96% of the Northumberland Hills Hospital's citizen engagement participants felt that they had achieved something important through the process. Ontario's Citizens' Reference Panel on Health Technologies (Case 12) showed not only that citizens can meaningfully deliberate on complicated decisions about the funding of new health technologies, but that the Panel was successful in bringing social values and ethical considerations into the decision making around these technologies. In short, citizen engagement can positively impact policy decisions.

Citizen Engagement Can Bridge Divides

A number of the cases in this book report citizen engagement as a way of bridging divides across communities. Saskatoon Regional Intersectoral Committee (Case 5) focused on the need to provide citizens with easy access to local health data to allow for more evidence-focused discussions with stakeholders, helping to bridge the information divide. Vancouver Coastal Health (Case 1) found that while stigma can be a barrier to accessing health services for people living with HIV/AIDS, community involvement and participation in citizen engagement activities can help overcome these barriers. Eastern Health (Case 13) used a patient advisory panel to begin to heal the divisions between itself and cancer patients following a major adverse event. The Toronto Food Policy Council (Case 14) has over 20 years of experience using deliberation to bring people together from across sectors, disciplines, and political parties to work on the shared aim of improving food and public health issues for the city. Given that a key barrier to improved provision of services is often the divide some individuals or communities feel between themselves and the health care system, citizen engagement can be a powerful tool, positively affecting public health and bringing diverse groups of people together for meaningful collaboration and partnerships.

The Importance of Communication and Knowledge Translation

A theme running through most of the cases in this publication is the importance of effective communication throughout the engagement processes and the need to work at translating the findings into policy. The Manitoba Métis Federation–Health & Wellness Department (Case 8) uses Knowledge Networks to work with nine regional health authorities to better serve the Métis communities across the province. The Campobello Island Health and Well-Being Needs Assessment (Case 3) recognized the need for greater knowledge translation with their local community and realized that achieving this goal may require training members of the public as peer educators.

Other cases identify problems with their engagement processes as hampering the impact on policy. Gauvin and colleagues found that a lack of transparency about the process and its recommendations likely affected the influence of the Quebec Health and Welfare Commissioner's Consultation Forum (Case 4). They also observed that a lack of proximity to the actual decision making process can be detrimental to the impact of the citizen engagement processes. O'Doherty and co-authors report that, for Human and Tissue Biobanking deliberative processes (Case 10), having an unfocused question may allow for more in-depth consideration of issues, but that it also risks lessening the impact of the outcomes of those deliberations.

Employing Multiple Methods of Engagement

Employing multiple methods of engagement allows a more diverse group of citizens to participate in the process. For example, in a number of the cases in this book, online technologies were used to augment face-to-face discussions. Similarly, multiple and novel methods may be needed to engage marginalized communities. The New Brunswick Health Council (Case 7) found that employing a single process was not always appropriate for engaging a diverse group of participants and that it could actually harm recruitment. Based on this finding, the New Brunswick Health Council ultimately established a separate engagement exercise to ensure that young people were given sufficient opportunity to participate in the process. Canadian Blood Services (Case 9) found that when engaging on a specialized topic, it was important to reach a more "interested public" through numerous methods of engagement and outreach, such as social media. To overcome some of the barriers to engagement in northern communities, the North West Local Health Integration Network (LHIN) in Ontario (Case 11) used online tools, YouTube videos, and blogs, as well as community-led discussions and meetings, to engage over 800 people from this vast region. Tailoring the method of engagement to the preferences of the community was crucial to their success.

We would like to thank all of the groups who submitted abstracts and cases. Our hope is that this Casebook will allow others to learn from the citizen engagement practices and processes that are occurring across Canada, ultimately leading to more successful cases of citizen engagement in health care in the future.

Roger Chafe, Memorial University
Wendy Levinson, University of Toronto
Andreas Laupacis, St. Michael's Hospital

Karen Born, St. Michael's Hospital
Carolyn Lukensmeyer, America Speaks



The “Public Voice” Informs HIV Service Planning at Vancouver Coastal Health

Margreth Tolson Leader, Community Engagement
Vancouver Coastal Health

Introduction

1

Seek and Treat to Optimally Prevent (STOP) HIV/AIDS is a ground-breaking \$48 million, four-year pilot project (2009-2013) funded by the BC Ministry of Health to improve HIV testing, treatment and support services in BC, with the overall goal of reducing the incidence of HIV incidence. Project partner organizations include Vancouver Coastal Health, Northern Health, Provincial Health Services Authority, Providence Health Care and the BC Centre for Excellence in HIV/AIDS.

The STOP project focuses on individuals living with multiple barriers to care, including addiction, mental health issues, homelessness and other social or environmental factors. Launched in Vancouver's inner city and Prince George—two communities identified as priority sites for the project because they represent the majority of BC's HIV cases and have increasing rates of HIV/AIDS—the STOP project has identified community partnership as a critical success factor for an accountable, responsive and effective pilot project. To ensure community participation, the provincial STOP Leadership Committee recruited four community representatives (nominated by HIV organizations) from the outset of the project to ensure that diverse voices from local HIV communities informed the planning and implementation of the project.

Why Citizen Engagement?

From the beginning of the Vancouver portion of STOP HIV/AIDS, Vancouver Coastal Health (VCH) leadership expressed a strong commitment to community involvement so that the pilot project would be tailored not only to reflect the actual needs and conditions of marginalized communities, but also to increase project impact among hard-to-reach populations.¹ A crucial part of this focus was the role of the VCH Community Engagement (CE) department, which was invited to develop and enact mechanisms for ongoing community discussions. Working in partnership with the Vancouver-based community representative from the provincial STOP Leadership Committee, CE staff sought the experiences and recommendations of people living with HIV so that their perspectives would influence the health authority's decision making on project priorities throughout STOP's duration. While the VCH CE department facilitated these discussions with members of the public, the VCH STOP leadership facilitated equally important discussions with staff from community-based organizations (CBOs).²

¹ Through its 24,500 staff, Vancouver Coastal Health (VCH) is responsible for the delivery of health programs and services throughout Vancouver, Richmond, and the North Shore and Coast Garibaldi communities. With a direct Regional budget in excess of \$2.1 billion, it is the largest health organization in Canada in terms of funding allocations, serving a population of over one million people through 14 acute care facilities and over 556 clinical, community and residential locations. For more information, please visit <http://www.vch.ca/>.

² For the purpose of this case study, all references to “members of the public” indicate participants in VCH CE processes who are living with—or who are at risk for—HIV.

Methods: Phase One (May—September 2010)

Initial challenges

In May 2010, VCH CE staff contacted CBOs to explore how best to collaborate in forming the consultation groups. These initial discussions were often challenging because CBO staff were cautious of the intentions of the STOP project, and they were unsure of how (or even if) the VCH CE department would use the community discussion results in the decision making process. Furthermore, all stakeholders had strong concerns about a possible conflict of interest in this community engagement project. Many CBOs wondered how project funding would be allocated, how their involvement might influence distribution of funds, and how CBO feedback could be incorporated if they did not have members who could participate in public groups.

To navigate this complex, highly politicized, and very visible project, it was important for VCH CE staff to work in collaboration with the community representative, a person living with HIV who was a well-known member of the community. CE staff also wrote a detailed project charter, signed by VCH CE and VCH STOP leadership, that clearly stated the:

- scope of influence of this consultation;
- commitment of VCH CE and VCH STOP leadership to the public release of the consultation results;
- dedication of that same leadership to the development of sustainable mechanisms for ongoing and meaningful public involvement for the length of the VCH STOP HIV project;
- CE department's role in consulting with members of the public *only* (and not with CBO staff); and
- agreement that VCH leadership would consult with CBO staff.

It was hoped that by drawing this clear boundary between public and CBO staff consultation, the integrity of the CE department's consultation process would be protected from any perception of unfair bias in VCH's STOP funding and program decision making. Furthermore, to dispel concerns that some CBOs and populations may not have access to the CE public consultation, a half-day workshop was held with all CBO staff so that their experiences and recommendations could be incorporated into decision making.

Discussion groups: Preparation

CBO and VCH staff collaboratively identified key priority populations for the CE consultation. These populations included: Aboriginal peoples, youth, people with mental illness and/or addiction, immigrants and refugees, gay men and marginalized populations of men who have sex with men, homeless persons, and injection drug users. The community representative worked with CE staff to plan and conduct the engagement process. Discussion groups were identified as the most appropriate methodology for this phase of the pilot project so that people could share their experiences and build on each other's ideas for improved models of service.

The goal of these groups was to capture the experiences of both people living with—and at risk for— HIV, gathering information about gaps in HIV services and how best to meet the needs of highly marginalized

groups. It was recognized that, due to continuing and profound stigma, it would be potentially harmful to ask participants from some groups about their HIV status or to comment on services specific to HIV treatment. For that reason, two discussion guides were developed (one for only Testing Services, and one for Testing, Follow-up and Treatment Services), but both discussion guides asked the same two essential questions:

- 1) What is working or not working in these services?
- 2) How can we improve access to these services?

CE staff met with CBO representatives and co-facilitators before each focus group (several times in some cases) to discuss the goals of the work, to engender trust in the intention of the project, and to develop jointly an approach to the discussion group that would best meet the needs of their clients. Discussion group formats and guides were adapted in order to meet the unique needs of each specific group. For example:

- One large discussion group would not be effective for homeless clients living with severe mental illness, so several small discussion groups and one-to-one interviews were instead conducted during their regularly-scheduled breakfast at a clinic.
- Latin American youth living illegally in Vancouver cannot access health services, and they requested health testing and education in addition to the consultation. This service was facilitated by Spanish-speaking staff and arranged in partnership with street nurses during a Friday night "clinic and pizza" event.
- Aboriginal women from rural areas in BC often come to Vancouver for a range of services. A discussion group providing basic HIV information (something rarely available in remote areas) was co-facilitated with a First Nations HIV educator in a shelter for women who have experienced domestic violence.

Discussion groups: Process

All discussion groups were co-facilitated by CE staff and the STOP community representative and/or a representative of the partner CBO. Some discussion groups were scheduled to coincide with an already-existing event. Other groups were recruited via posters, phone calls, personal contact and online outreach. The 13 discussion groups were conducted during June and July 2010, including two groups in Spanish. The 113 participants reflected diverse age groups and Vancouver neighbourhoods, and the content of these discussions was summarized in a September 2010 report for VCH STOP leadership (see Table 1). In keeping with the VCH CE department's commitment to transparency and accountability, this report was mailed (and emailed) to all participants and CBOs. It was also published on the VCH website (www.vch.ca/ce/reports). VCH STOP leadership then combined the results of this work and a literature review with feedback on the meetings from clinicians, CBO staff and other service providers, in order to develop and prioritize pilot project strategies.

Table 1: Location and Demographics of Discussion Groups³

Group Name and Population	Number of attendees Phase One (Summer 2010)	Number of attendees Phase Two (Spring 2011)
Vancouver Native Health Society (HIV + Aboriginal street-involved people)	11 (7 male; 3 female; 1 two-spirited)	10 (9 male; 1 female)
Positive Women's Network--All members	8 (7 female; 1 transgendered)	9 female
Positive Women's Network--Aboriginal women	9 (8 female; 1 transgendered/two-spirited)	N/A
Downtown Community Health Clinic (HIV + with serious mental illness)	10 (4 male; 6 female)	8 (4 female; 4 male)
BC Persons with AIDS Society (HIV + support group)	11 male	6 male
Life Skills Centre (Street-involved people with addictions)	10 male	15 (13 male; 2 female)
WATARI Latin American families	18 (14 male; 4 female)	25 (18 male; 6 female; 1 transgendered/two-spirited)
Health Initiative for Men (Gay men)	3 male	3 male
Dr. Peter Centre (HIV + support centre)	3 male	N/A
Latin American youth group	16 (9 male; 7 female)	17 (7 male; 10 female)
Helping Spirit Lodge (Aboriginal women's shelter)	5 female	N/A
Youthco AIDS Society (Youth living with HIV)	5 male	5 (4 male; 1 transgendered)

Continued on next page

³ Anyone was welcome to attend the discussions, and there has been no attempt made to ensure that the attendees were consistent from phase to phase. Greater detail of the demographics in this table can be found in the original reports, which are available at www.vch.ca/ce/reports.

(Table 1 continued)

Group Name and Population	Number of attendees Phase One (Summer 2010)	Number of attendees Phase Two (Spring 2011)
BOYS R US (Male sex-trade workers)	N/A	7 (6 male; 1 transgendered/two-spirited)
Downtown Eastside HIV/IDU Consumer's Board (Injection Drug Users)	N/A	14 (10 male; 4 female)
Healing Our Spirit First Nations AIDS Society (Aboriginal people living with HIV)	N/A	11 (7 male; 2 female; 2 two-spirited)
Total	113 participants (69 male; 41 female; 3 two-spirited/transgendered)	130 participants (87 male; 38 female; 5 transgendered/two-spirited)

Methods: Phase Two (January—March 2011) and Phase Three (October—December 2011)

In December 2010, CE staff re-commenced meetings with VCH STOP leadership to plan the next phase of public consultation. Pilot project strategies had been tentatively determined (and in some cases already implemented), and VCH STOP Leadership identified key themes to be discussed by members of the public in order to inform the more detailed planning of health services that was to begin on April 1, 2011. CBO partners were again contacted to host these discussions, and they were once again extremely helpful: due to the careful partnership-building in Phase One, they were able to set up the second round of discussions very quickly.

A brief presentation was given at the beginning of each discussion group, reporting on the:

- themes and recommendations from Phase One;
- results of how public feedback from Phase One had been used and implemented; and
- questions for this second phase of consultation.

Participants were also asked for their recommendations on possible models for ongoing engagement that would allow the public to monitor the STOP project (until March 2013) as it is implemented.

Provisions were made to welcome experiences and ideas outside of the prescribed topics, and a commitment was made to present any additional concerns that arose as "Community Alerts" in the Phase Two report. The

12 discussion groups and 130 participants again reflected diverse age groups and neighbourhoods. As with Phase One, the report for Phase Two was sent to all stakeholders and published on the VCH website (www.vch.ca/ce/reports).

For future phases of public consultation, Phase Two participants agreed that the model of semi-annual feedback and discussion was effective, and that it was important for VCH STOP leadership and members of the public to maintain an ongoing dialogue throughout the project. Discussion groups were perceived to be an effective method of gathering input, but people also suggested that some discussion groups should include HIV education (on a variety of topics) and that online surveys should also be available for those who cannot participate in group discussions (or who do not wish to do so).

At the time of writing, Phase Three is currently in development with VCH STOP leadership, and it will reflect the recommendations that have arisen from the previous phases. In order to support VCH's planning for HIV services that will follow STOP after the project finishes in March 2013, community discussions will continue on a six-month rotation until Fall 2012.

Outcomes and Impact

Recommendations from public participants had the following direct influence on the VCH STOP HIV/AIDS pilot-project:

- *Peer involvement:* A large new network of community-based peer workers has been funded through CBOs to provide HIV tests and ongoing support to newly diagnosed patients. This network will also work with the STOP Clinical Team to provide HIV outreach services.
- *Provision of medical services in non-clinical locations:* The STOP HIV Clinical Team provides testing and treatment in partnership with many non-clinical locations, including shelters, drop-ins and community centres.
- *Services for immigrants and refugees:* A clinic for people who do not have medical insurance is now established, services for uninsured individuals with HIV are now available at all VCH clinics, and access to interpreters is now embedded in this work.
- *Public health messages:* Messages to encourage testing and treatment have been specifically tailored to meet community standards and norms (e.g. "What's Your Number" for the gay men's community: www.checkhimout.ca/testing).

For VCH STOP leadership, the ongoing multi-phase consultation with members of the public and CBO staff contributed to:

- building trust with partners, stakeholders and the public by showing that VCH STOP is committed to community involvement and partnership in this project;
- increasing trust with CBOs and reducing barriers to partnerships with those organizations, thereby improving services for clients; and
- strengthening existing partnerships with key communities, which results in population-specific engagement strategies being facilitated by CBOs themselves (and not mediated by the VCH CE department).

Lessons Learned

Four key lessons were learned during the planning of the STOP HIV/AIDS pilot project.

1. Collaborative community partnerships are key to successful public engagement and effective services.

A number of different partnerships have contributed to this project's success:

- The partnership between VCH CE and the community representative from the provincial STOP Leadership Committee is critical to the credibility of VCH CE's work;
- The partnership with CBO representatives is crucial to the success of VCH CE's work in bringing community feedback into leadership decision making; and
- The partnership between VCH STOP leadership and CBO partners is essential to creating services that are practical and accessible, thereby facilitating patient uptake of these health services.

It was gratifying to see these lessons reflected in VCH's prioritization of resources in the pilot projects, such as the greatly enhanced support for peer-based work and the partnering with CBOs to provide a comprehensive range of clinical services. It is hoped that these partnerships will also have an impact on the VCH STOP project's success in achieving reduced HIV incidence in our region.

2. The scope of influence of all public consultation must be acknowledged clearly and honestly.

Maintaining honesty with partners, stakeholders and the public about the scope of influence for their input is important. Given the complexity of relationships between provincial, regional and local stakeholders, in addition to the size and visibility of the project itself, it is not possible (or accurate) to attribute project decisions specifically to public input. Some priorities that were considered key at the community level are not priorities in the provincial plan (such as preventative education, ongoing disease management education, and communication skills training for health care providers), and they have therefore not been implemented.

While it is impossible to say "the public voice changed THIS," public recommendations were used to shape, support, or justify specific agendas, and in this, it was fortunate that VCH STOP leadership was largely formed of people who understand and support community priorities.

3. Careful and collaborative preparation of discussion topics contributes to the integrity of process.

Regular and ongoing communication between VCH CE staff and VCH STOP leadership ensured that the discussion topics in each phase of the consultation were carefully selected and phrased in a way that made the public feedback sought directly relevant to upcoming plans. Preparation included intensive discussions regarding the clarity and accuracy of questions, as well as VCH's ability to use the feedback. Similarly intensive discussions were also conducted with CBO partners in order to develop the question guides. This ensured that the discussions would be sensitive, relevant, and meaningful for their clients that chose to join the consultations.

4. Stigma continues to form a key barrier to health services, but community involvement can assist in building bridges.

Stigma still has a profound impact on people's willingness to be tested for HIV, acknowledge their HIV status, or engage with health care providers. HIV also disproportionately affects people who already experience strong societal judgment and encounter multiple barriers to accessing services from health care providers and other institutions. Public consultation and community involvement, however, can greatly assist in building trust with marginalized communities whose access to health services is compromised by stigma. This lesson is also applicable to many other areas of health service, such as mental illness, eating disorders, and addictions.

SUMMARY

Context: Consultation with members of the public who are living with—and at risk for—HIV; the goal was to inform planning of HIV services

Location: Vancouver, BC and Prince George, BC

Method of Engagement: Six-month rotating discussion groups and interviews between 2010–2012.

Who was Engaged:

- Phase One, Summer 2010: 113 members of the public;
- Phase Two, Spring 2011: 130 members of the public; and
- Future phases: in progress.

Topic on Engagement: HIV services for testing, diagnosis and treatment.

To Whom Were Results Reported:

- All participants and CBO partner agencies; and
- VCH and all stakeholders in STOP HIV leadership committees.

Methods of Dissemination:

- Mail, email, print and website: widely available;
- Results presented to VCH STOP leadership;
- Available on VCH public website and distributed through email networks; and
- Verbal and written summaries provided at all public consultations and meetings.

Lessons Learned: Community partnerships are critical to the credibility of the CE process in this highly contentious and politicized project, and they are also essential to the successful delivery of services in this pilot-project. The VCH CE department must continue to pay attention to the scope of public influence in this project and its commitments to the public on behalf of project leadership, thereby ensuring the integrity and honesty of the public consultation process.

Engaging Canadians in the Development of a Mental Health Strategy for Canada

The Mental Health Commission of Canada
Tristan Eclarin and Mary Pat Mackinnon, Ascentum

Introduction

2

The Mental Health Commission of Canada (MHCC) was established in 2007 to act as a catalyst for the development of Canada's first national mental health strategy.¹ In January 2009, the MHCC published a draft framework document, entitled *Towards Recovery and Well-Being—A Framework for a Mental Health Strategy for Canada*, for external review by the public and stakeholders.² This document set out eight high-level goals for a comprehensive approach to mental health and mental illness in Canada (see *Table 1*). In locations that spanned the breadth of Canada, the MHCC conducted 12 Regional Dialogues and three “focused consultations” on the proposed framework between February and April 2009.

Why Citizen Engagement?

The MHCC had two complementary objectives in conducting these engagement activities. First, it sought to draw on the rich experience and knowledge of the mental health community in revising the draft document, paying particular attention to diverse lived realities and previously ignored viewpoints. Second, the MHCC wanted to build support for the emerging orientation of a pan-Canadian mental health strategy.

Table 1: Draft Framework Goals for Towards Recovery and Well-Being—Pre-Engagement

Goals
1. The hope of recovery is available to all.
2. Action is taken to promote mental health and well-being, and to prevent mental health problems and illnesses.
3. The mental health system is culturally safe and responds to the diverse needs of Canadians.
4. The importance of families in promoting recovery and well-being is recognized and their needs are supported.
5. People of all ages have equitable access to a system of appropriate and effective programs, services and supports that is seamlessly integrated around their needs.
6. Actions are based on appropriate evidence, outcomes are measured, and research is advanced.
7. Discrimination against people living with mental health problems and illnesses is eliminated and stigma is not tolerated.
8. A broadly-based social movement keeps mental health issues out of the shadows—forever.

¹ Mental Health Commission of Canada, *Vision and Mission of the MHCC*, available from <http://www.mentalhealthcommission.ca/English/Pages/TheMHCC.aspx> (retrieved Oct 17, 2011).

² Mental Health Commission of Canada, *Toward Recovery & Well-Being: A Framework for a Mental Health Strategy for Canada* (Ottawa, 2009).

Methods

Prior to the public and stakeholder engagement process, the MHCC conducted an extensive internal review of the draft Framework by engaging the MHCC “family,” which includes the Consumers’ Council, Board of Directors, Advisory Committees, and federal, provincial and territorial (FPT) officials.³ This process helped gather detailed feedback on the draft Framework from these groups and build working relationships with stakeholders—an important part of the broader consensus-building process. Once completed, the input from the internal review process was integrated into a revised version of the draft Framework, which was published in January 2009 for public discussion. Immediately following the public release of this document, the public consultation process was launched. Ascentum, an Ottawa-based public and stakeholder engagement firm with experience in the mental health field, was hired by the MHCC to design, deliver and report on the consultation process.

The MHCC engaged a diverse range of individuals and organizations that represent the complex mental health community in Canada. This diversity includes people with the lived experience of mental health problems and illnesses, families and caregivers, advocates, service providers, researchers, policy experts, FPT governments, and Aboriginal organizations. The MHCC used a two-pronged engagement process that combined in-person and online methods. This distinctive design helped ensure robust representation in the engagement process by providing complementary opportunities for participation. The in-person Regional Dialogues enabled deeper deliberation and facilitated input from specific constituencies, while the online consultations not only fostered increased involvement from youth and people living with mental health problems, but also helped to alleviate the effects of stigma. This resulted in a greater willingness among members of the mental health community to participate in the engagement process.

The Regional Dialogues

Participation in the 12 Regional Dialogues was by invitation, with national, provincial, territorial and local stakeholders providing advice to the MHCC to ensure that the invitee list was well balanced. The Regional Dialogues were structured to maximize the opportunities for participants to make concrete recommendations to improve the Framework, to raise pertinent issues for their regions or sectors, and to provide the MHCC with comparable data across regions. In total, 450 individuals participated in the Regional Dialogues. The MHCC also hosted three “focused consultations” in Ottawa to explore the perspectives of three specific groups: representatives of First Nations, Inuit and Métis organizations; federal departments with responsibility for policies that have an impact on mental health and mental illness; and representatives of national organizations, including health professional associations.

All in-person dialogues were full-day events. Each dialogue began with “pre-test” keypad voting to assess participants’ initial “gut reactions” to each of the eight goals outlined in the draft Framework. This was followed by a focused presentation on the role and mandate of the MHCC, including a succinct overview of the Framework by the MHCC’s Director of Mental Health Strategy. Participants were assigned to small groups for facilitated dialogues. Each group was tasked with reviewing three or four of the eight goals, with a focus on

³ Ascentum Inc., *Setting the Goals of a Mental Health Strategy for Canada—Public Consultation Report* (Prepared for the Mental Health Commission of Canada, 2009)..

identifying what they liked about the formulation and description of the goals, what they felt were areas of concern, and what they would like to see changed, deleted or added. Each group shared its conclusions in plenary, which allowed for a broader discussion among participants on all the goals. The dialogues concluded with a round of “post-test” keypad voting to assess any shifts in participant attitudes on the Framework’s goals, followed by plenary discussion on the voting results. The agenda for these events is presented in *Table 2*.

Table 2: Sample Regional Dialogue Agenda

<p>Day: 8:45 am – 4:30 pm</p> <ol style="list-style-type: none">1. Objectives2. Initial Views on Eight Goals (Keypad Voting)3. Presentation & Discussion: “A Framework for a Mental Health Strategy for Canada”4. Small Group Work on Goals5. Report Back on Small Group Conclusions & Discussion6. Plenary Discussion7. Final Review of Eight Goals (Keypad Voting)8. Closing Comments & Evaluation
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Online participation

The MHCC also conducted a bilingual online consultation, which was open for just over two months, from February 11 to April 19, 2009. This was designed to complement and expand the reach of the Regional Dialogues, and the general public and stakeholder groups were encouraged to attend. Participants were recruited through a variety of methods, including a broad e-mail campaign, promotion during the Regional Dialogues, media coverage, word of mouth and networking within the mental health community. In total, 1700 members of the general public and 300 stakeholder groups shared their views with the MHCC through the online consultation process.

There were two options for online participation. In the first option, participants could complete an online workbook, which used a mix of close-ended and open-ended questions to elicit feedback on each of the Framework’s eight goals. The distinctive feature of the workbook was its focus on informed participation—it supplied participants with critical information that allowed them to learn about the issues and options under consideration before asking for their thoughts and perspectives. The workbook questions mirrored those asked in the Regional Dialogues, allowing for comparison of results.

The second option allowed participants to provide “free form” qualitative comments on the Framework. They were invited to share their personal stories and ideas relating to any of the eight goals and to comment on whether the goals described the direction and scope of change required to transform Canada’s mental health system. Participants could choose to have their submission published on the consultation website for others to read or to submit it privately for the MHCC’s final analysis. Stakeholders were provided with a similar

opportunity to provide comments and suggestions. Following analysis of dialogue and online results, the findings were presented to the MHCC “family” in May 2009 and a consultation report was made publicly available on the MHCC website.

Outcomes and Impact

Throughout the engagement process, the MHCC gathered an extensive amount of data: nearly 160,000 words of detailed notes were produced from the in-person Regional Dialogues, and over 465,000 words of comments were collected from the online consultations. There was a high degree of congruence that emerged across different individuals, groups, and organizations that participated in the consultation process. Given the volume and diversity of participants, this attests to an emerging consensus around both the desire to address mental health issues in Canada and the foundational pillars on which a strategy should be built.

The MHCC carefully reviewed the public and stakeholder contributions, including those from provincial and territorial officials, and this resulted in a number of significant changes to the draft Framework. First, the document was reframed to better integrate mental health promotion and prevention, as many participants felt that this required more attention. Second, a number of key concepts were more clearly explained and refined within the document. For example, many participants were concerned with the Framework’s repeated reference to an integrated “mental health system” in Canada. They suggested that this framing was misleading given that instead of an integrated system, Canada actually has a patchwork of multiple provincial/territorial systems with significant variation in policies, programs and services. The use of terms such as “cultural safety,” “recovery,” and “family,” in the draft Framework were also reassessed and clarified as a result of the concerns of participants. The Framework goals following the engagement process are presented in *Table 3*.

Table 3: Draft Framework Goals for Towards Recovery and Well-Being-Post-Engagement

Goals
1. People of all ages living with mental health problems and illnesses are empowered and supported in their journey of recovery and well-being.
2. Mental health is promoted, and mental health problems and illnesses are prevented wherever possible.
3. The mental health system responds to the diverse needs of all people in Canada.
4. The role of families in promoting well-being and providing care is recognized and their needs are supported.
5. People have equitable and timely access to appropriate and effective programs, services, treatments and supports that are seamlessly integrated around their needs.
6. Actions are informed by the best evidence based on multiple sources of knowledge, outcomes are measured, and research is advanced.
7. People living with mental health problems and illnesses are fully included as valued members of Canadian society.
8. <i>Goal dropped, replaced by: A call to action.</i>

The end result was that all eight of the Framework's goals were revised to varying degrees. In addition, the goal of "A Broadly-Based Social Movement Keeps Mental Health Issues Out of the Shadows–Forever" was turned into a "call to action," as participants saw it as a means to an end rather than a stand-alone goal.

The revised Framework document is now seen as a milestone for advancing mental health in Canada.⁴ It has been embraced by provincial and territorial governments, civil society organizations and people with the lived experience of mental health issues. The engagement process was central to the successful completion of the first phase of the development of a mental health strategy that was achieved with the release of the revised Framework. This set the stage for the second phase of the process—determining how to achieve the vision and goals identified in the Framework. The MHCC's engagement process also fostered productive, trusting relations that bode well for future collaboration on this issue over the long-term.

Lessons Learned

The MHCC's engagement process demonstrates that investing in respectful, meaningful public and stakeholder engagement can pay dividends on a number of fronts. First, it can lead to more inclusive, comprehensive and nuanced policy. Second, this initiative demonstrated that an effective engagement process can build greater trust and healthier relationships between (and among) diverse actors, which is needed to implement and sustain policy initiatives in areas such as mental health.

The experience also illustrates the importance of employing a range of methods in consulting with a complex stakeholder community. This engagement initiative shows that blending complementary online and in-person engagement processes using a common framing of key questions and objectives can help to achieve both breadth and depth of reach. It enabled participation from a fairly representative cross-section of Canadians, based on a number of key demographics such as region, gender, annual household income, rural/urban distribution, ethno-cultural background and Aboriginal heritage. It also allowed the MHCC to achieve higher levels of participation from those with lived experience of mental health problems and illnesses, as well as from the broad range of mental health stakeholders, such as health and social service workers, advocates, researchers/ academics, and government officials.

Two limitations of the process which the MHCC worked to address were: 1) online recruitment methods; and 2) Regional Dialogue time constraints. Due to budget considerations, the MHCC decided to not use random recruitment for its online participation, opting instead for self-selection through its website and extensive outreach to a diversity of organizations to encourage online participation. While a combination of random recruitment, outreach and self-selection is ideal, the process chosen by the MHCC nonetheless achieved high levels of participation from diverse groups across the country.

The second limitation stems from having Regional Dialogue participants working in small groups in focused discussion on a subset of the Framework goals rather than all of the goals. This was a conscious tradeoff given the reality of eight goals and time constraints. Following the small group work, a plenary session

⁴ Eclarin, T., *Creating a Framework for a Mental Health Strategy for Canada: Assessing the Engagement Process—A Case Study* (2010), available from <http://ascentum.com/wp-content/uploads/2010/10/Case-Study-MHC-FINAL-Sept-28.pdf> (retrieved Jan 13, 2012).

provided opportunity for all participants to engage on all goals. Having an extra half day to allow more time for participants to work through all the goals might be desirable, although the risk of a more substantial time commitment posing a barrier to the recruitment of participants would need to be carefully assessed.

Of a different order—and a subject for a separate case study—is the limitation or challenge that relates to the MHCC's unique position within the Canadian mental health domain. As a catalyst, it is neither a policy maker nor does it deliver services; instead, it must work through influence and persuasion. The longer term policy impact of participants' contributions to MHCC's work is intimately linked to the Commission's impact on the mental health system in Canada. This question would merit careful reflection in the next phase of the Commission's work.

SUMMARY

Context: National public and stakeholder engagement initiative on the development of a mental health strategy for Canada.

Location: Regional and Focused Dialogues (St. John's, Halifax, Montreal, Ottawa, Toronto, Thunder Bay, Winnipeg, Regina, Edmonton, Vancouver, Whitehorse, Yellowknife, Iqaluit).

Method of Engagement: Regional and Focused Dialogues and Online Consultations.

Who was Engaged: Regional and Focused Dialogues (450 stakeholder representatives), Online Consultations (1700 members of the general public, 300 stakeholder representatives).

Topic of Engagement: Goals outlined in the MHCC's Draft of Recovery and Well-Being.

To Whom Were the Results Reported: MHCC "family" (Consumers' Council, Board of Directors, Advisory Committees, and federal, provincial and territorial officials); participants and the public.

Methods of Dissemination: Public consultation report posted on MHCC website.

Lessons Learned: Investing in respectful, meaningful public and stakeholder engagement can lead to more inclusive comprehensive and nuanced policy. Employing a range of methods to engage a complex stakeholder community can help achieve both breadth and depth of reach.

Campobello Island Health and Well-being Needs Assessment (2008-2009)

Verlé Harrop, PhD
Province of New Brunswick,
Research Mentor, UNB Faculty of Education

Introduction

3

In 2008, St. Joseph's Community Health Centre (CHC), in Saint John, New Brunswick, partnered with the residents of Campobello Island (population 1,056, Census 2006) to carry out a collaborative, community-based health and well-being needs assessment (NA). The purpose of this assessment was to establish a determinants of health baseline and action plan. Little was known about the island's needs aside from those related to its unique geographic location. During the summer months, a privately owned ferry operates between Campobello Island and Deer Island, but during the winter, islanders must cross the bridge into Lubec, Maine and drive 84 kilometers before re-entering Canada, a round trip requires passing through customs four times. The island's isolation, compounded by heightened post 9/11 border security and a perceived escalation in the local drug trade, signaled a community in crisis. In response, the CHC invited the Regional Health Authority's (RHA) Senior Researcher in Applied Health Research to perform a NA.

Methods

The research team carried out a four-phase program of Participatory Action Research. Qualitative data from interviews and focus groups underscored well-being challenges, while survey data quantified the pervasiveness of emergent themes. The research, production of the report, and formation of the action plans were all structured around the Public Health Agency of Canada's (PHAC) "12 Determinants of Health Framework."¹

Preliminary activities

In February 2008, the CHC issued an open invitation to the community to attend an "Informational Session" where Dr. Harrop presented the "Bell Island Health and Well-Being Needs Assessment, Phase 1, 2006."² Forty-eight people attended. In March 2008, the CHC hosted a follow-up public meeting and facilitated the election of the Campobello Island Health and Wellness Advisory Committee (AC), which represents seniors, single moms, persons on social assistance, teachers, nurses, and business. There were 45 participants at this event. An agreement in principle was struck between the AC and the CHC to collaborate on the NA, and the AC and researchers started meeting bi-weekly.

¹ Taken from the Public Health Agency of Canada, *What Determines Health* (Ottawa, 2011), available from <http://www.phac-aspc.gc.ca/ph-sp/determinants/index-eng.php> (retrieved November 1st, 2011).

² Harrop, V., "The Bell Island Health and Well-Being Needs Assessment, Phase 1, 2006," available from <http://www.easternhealth.ca/OurCommunity.aspx?d=1&id=400&p=379> (retrieved November 1st, 2011).

Phase I: Interviews and focus groups (May 10–15, 2008)

The NA team held six days of key informant interviews and focus groups. Over 270 islanders and health professionals participated in 56 sessions. The AC took complete responsibility for developing a representative invitee list and scheduling the sessions using Google Calendar and Facebook.

Phase II: Survey (June 18–20, 2008)

An eight-page survey structured around the “Determinants of Health” framework was developed by the NA team and deployed by the AC. Of approximately 650 eligible residents (aged 19+), 483 (74.3%) completed the survey. Over the summer, AC members reported a growing number of inquiries from Islanders about the “All About Us” survey findings.¹

Phase III: “Building Bridges—Building Teams” (September 11–18, 2008)

Community- and systems-level interest in the survey findings was leveraged into a week of events structured around key concerns. At each event cited in Table 1, pertinent survey data were presented and augmented with the community’s narrative. Representatives from the following organizations and communities then participated on panels and in facilitated question and answer periods: social development, addictions and mental health; Canada Mortgage and Housing Corporation; alternative and co-op housing; the RCMP; the school district; public health; the New Brunswick Extra-Mural Program; and experts in rural governance, community schools, teen centres, community access centres and on-line adult education. These events enabled islanders to personally identify and connect with the representatives from government and non-profit agencies who would be best able to collaborate with the community on local solutions.

Table 1: Building Bridges–Building Teams: Schedule and Participation

Date	Event Participant	Total
09/11/08	Presentation: survey findings	150
09/13/08	Topic: Drugs	50-60
09/15/08	Topic: Community	125
09/16/08	Topic: Housing	50-60
09/17/08	Topic: Governance	75
09/18/08	Presentation: action plans	125

All week, the research team connected and networked islanders, professionals and experts into intersectoral “communities of interest.” The week concluded with special interest groups coming together and developing action plans, which they then shared with the community as a whole. Approximately 585 islanders, professionals and domain experts participated.

¹ Harrop, V., “All About Us”: *The Campobello Island Health and Well-Being Needs Assessment Survey Findings* (2008), available from <http://www.ahsc.health.nb.ca/AboutUs/OurFacilities/campobello/Campobello%20Island%20Survey%20Findings%20Sept%202011%202008%20PUBLIC%20FINAL.pdf> (retrieved November 1st, 2011).

Phase IV: Action plans & interventions—“Where the Rubber Meets the Road” (October 2, 2008)

Recognizing the community's limited capacity and the identification of self-governance as the top priority, the 52 islanders formed nine working groups that continued to meet independently. Each working group gave an update on its work at monthly meetings held by the AC. The working groups' accomplishments are presented in *Table 2*.

Table 2: Accomplishments of Working Groups

Working Group	Accomplishments 2008–2009
Governance	<ul style="list-style-type: none"> • Working with key contacts from “Building Bridges–Building Teams” (Rural and Small Town Program, Mount Alison University; Local Government Department) the Governance Working Group spearheaded a movement to evolve the Local Service District of Campobello Island into a Rural Community with an elected council* (*Achieved, May, 2010).⁴
Ferry	<ul style="list-style-type: none"> • Continues to work with the Governance Group, recognizing improved ferry service predicated on having elected council.
Housing - Youth	<ul style="list-style-type: none"> • Deployed housing survey; • Land donated for seniors/assisted living complex; and • Application submitted to Canadian Mortgage and Housing Corporation. • Island youth tour Saint John Teen Resource Centre; • Youth volunteers fundraise for Wii in nursing home; • “Girl’s Circle Training” offered; and • Church starts floor hockey and school starts activity club.
School	<ul style="list-style-type: none"> • Parent School Support Committee grows from three to 130 volunteers (RCMP security check required); • School previously pejoratively referred to as “lock down facility,” now fully accessible; • Family movie nights instituted; and • Health Centre’s Nurse Practitioner offers three information sessions: • Diabetic Management (16 attend); “<i>Everything you wanted to ask your teenager about sex but were afraid to ask</i>” (25, including 10 youth, attend); and Women’s Health (50 attend).

Continued on next page

⁴ Government of New Brunswick, *Campobello Island votes to Become a Rural Community (10/5/11)*, available from <http://www.gnb.ca/cnb/news/gl/2010e0710gl.htm> (retrieved November 1st, 2011).

(Table 2 continued)

Working Group	Accomplishments 2008–2009
“My Choices, My Health”	<ul style="list-style-type: none"> ● 11 of 12 graduate; two plan to become trainers.
Food Bank	<ul style="list-style-type: none"> ● Church and Health Centre start Food Bank; and ● Jan 2009: 1,604 lbs food collected and 705 lbs are delivered.
“Tidal Chatter”	<ul style="list-style-type: none"> ● Monthly newsletter includes “On the Fridge” inserts generated by Public Health, CHC, and Mental Health-Addictions, citing programs and services delivered (including where and by whom); and ● RCMP and working group apply for funding.
Drugs/Mental Health/Addictions	<ul style="list-style-type: none"> ● Methadone clinic established; and ● On-line, cognitive therapy program implemented.⁵

Outcomes and Impact

The NA process was foundational to Campobello Island becoming a self-governing Rural Community. Concerns around drugs faded as the community became more engaged with children and youth, and as community leaders came forward, health centre staff became more excited about their work and initiated outreach activities.

Lessons Learned

To better support transparency, accountability, and ultimately sustainability, training around bookkeeping and formal civic and administrative protocols should have been incorporated onto the NA process.

Despite that, structuring the NA around PHAC’s Determinants Framework:

- enabled citizens and agencies to understand the determinants and their interrelatedness;
- shifted expectations away from the health system and back to the community;
- created a gradient of entry points leading to action;
- enabled the community to identify, collect and leverage meaningful, comparative local data; and
- made the need for intersectoral cooperation and collaboration clear.

Finally, the NA process is incomplete without “knowledge translation,” the grass roots process that is undergone by the whole community.

⁵ Wiseman, Eve, *Computer-Assisted Therapy for Addictions* [PowerPoint Slides], available from [http://www.acdccamc.ca%2Fen%2Fdocs%2FPresentations%2FC%2520A%2520T%2520%2520\(2\).ppt&ei=y74QT_O7GOHq0gGQ7LnPAw&usg=AFQjCNFlsSdsxH85cRHkTd5tCnZKEieexQ](http://www.acdccamc.ca%2Fen%2Fdocs%2FPresentations%2FC%2520A%2520T%2520%2520(2).ppt&ei=y74QT_O7GOHq0gGQ7LnPAw&usg=AFQjCNFlsSdsxH85cRHkTd5tCnZKEieexQ) (retrieved November 1st, 2011).

SUMMARY

Context: Participatory Action Research

Location: Campobello Island, NB

Method of Engagement: Community-based, Health and Well-being Needs Assessment.

Who was Engaged: Island residents; health centre, CHC, RHA, public health, extramural, and family services; Departments of Health, Social Assistance, and Education; domain experts on governance, transportation, housing, youth, mental health and addictions; RCMP, and Canadian Customs and Border Agency.

Topic of Engagement: A determinants of health approach to health and well-being.

To Whom Were the Results Reported: Island residents; CHC and RHA, attendant health, education and justice professionals, and departments.

Methods of Dissemination: "All About Us" Survey Report; annotated on-line report; community meetings; community newsletter; newspapers.

Lessons Learned: PHAC's Determinants Framework is a powerful tool for community engagement, enablement and empowerment. Putting local data into the hands of the community is key. Training around civic processes needs to be incorporated into the needs assessment process.



Québec Health and Welfare Commissioner's Consultation Forum

François-Pierre Gauvin, Ph. D, Centre de collaboration nationale sur les politiques publiques et la santé, Institut national de santé publique du Québec

Élisabeth Martin, candidate au doctorat, département de médecine sociale et préventive, Université Laval

Julia Abelson, Ph. D, Centre for health economics and policy analysis, McMaster University

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Introduction

In 2005, the Government of Québec created the Health and Welfare Commissioner, whose mission is to shed light on public discussion and government decision making, thereby contributing to the improvement of the health and welfare of the people of Quebec.¹ To fulfil this mission, the Commissioner must assess the results achieved by Québec's health and social services system, examining the various factors that influence health and welfare.

Why Citizen Engagement?

In 2008, in accordance with section 24 of the *Act Respecting the Health and Welfare Commissioner (R.S.Q., chapter C-32.1.1)*, the Commissioner established a Consultation Forum composed of 18 citizens and nine experts. The mandate of this forum is to provide the Commissioner with its perspective on health care performance and to discuss select social and ethical dilemmas related to the health care system that have been submitted to it by the Commissioner. Since 2008, topics discussed by the Consultation forum have included prenatal screening for Down's syndrome, chronic diseases, perinatal health, mental health, and the rights and responsibilities relating to health and social services.

Methods

When making its plans for this Consultation Forum, the Government of Québec examined the experience of the Citizens Council of the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom at some length.² Ultimately, however, Québec decided to create a hybrid forum whose members would include not only ordinary citizens, but also persons with special expertise. The underlying objective was to develop a new perspective on the issues based on the combined knowledge of citizens and experts. The Forum met 13 times between March 2008 and March 2011.

Recruitment and selection of members

The Forum consists of 27 members who were appointed by the Commissioner for a period of three years. Of these 27 members, 18 are citizens drawn from all of Québec's administrative regions, while the nine others have special expertise in the field of health and social services.

¹ Assemblée nationale du Québec, *An Act Respecting the Health and Welfare Commissioner* (RSQ, c C-32.1.1.) (2005), available online at <http://www.canlii.org/en/qc/laws/stat/rsq-c-c-32.1.1/latest/rsq-c-c-32.1.1.html> (retrieved December 5, 2011).

² National Institute of Health and Clinical Excellence (UK), *Citizens Council of the National Institute for Health and Clinical Excellence*, available online at http://www.nice.org.uk/aboutnice/howwework/citizenscouncil/citizens_council.jsp (retrieved December 5, 2011).

Two different processes were used to recruit the members of the forum—one for the citizens, the other for the experts—but both processes were governed by the *Regulation Respecting the Procedure for Choosing Persons Qualified for Appointment to the Consultation Forum*.³ During the process of recruiting citizens, an invitation was issued through all the major media for interested persons to submit their applications. In the process for recruiting experts, the Commissioner invited various bodies to submit a list of no more than three potential candidates each; nine expert members were then selected from these lists.⁴ By the end of the recruitment campaign, the Commissioner had received 266 applications for the 18 seats that were reserved for citizens, while some 30 different bodies, including university departments, had suggested 51 different persons to hold the seats reserved for experts.

How the forum operates

The legislation appointing the Commissioner gives him a great deal of freedom to determine how the Forum operates. About four times per year, the Commissioner brings the members of the forum together for a two-day meeting where they discuss various topics in plenary sessions and smaller groups. These discussions are guided by specifically developed questions and the help of a professional moderator. In general, the members of the Forum are consulted two or three times on the same topic.

For each meeting, the members receive a set of briefing documents. These documents include a consultation guide that reviews literature on the topic to be discussed and provides information gathered through a targeted call for submissions, hearings, and the results of other consultations (as appropriate). Experts sometimes make presentations to the Forum's members in order to stimulate the discussions at their meetings. It should be noted that the Forum does not explicitly seek a consensus; instead, it simply tries to highlight issues that will be useful for the Commissioner to know.

The Forum's discussions are recorded in a set of minutes prepared after each meeting by a member of the Commissioner's office. These minutes are then validated by the Forum's members in discussions held via its extranet site before they are adopted in their final form at the following meeting. Only after the final version of the minutes has been adopted is their content used in the Commissioner's work. Thus the consultation process is iterative, allowing every topic to be discussed more than once, both in face-to-face meetings and in discussions via extranet. The Commissioner hopes that this process will enable the Forum to come to a position to which all of its members have contributed.

Outcomes and Impact

In the members' opinion, it is difficult to know whether the Forum has had a real influence on government decisions or public debates. The Forum has three major characteristics that may have reduced its ability to exert an influence.

³ Assemblée nationale du Québec, *Regulation Respecting the Procedure for Choosing Persons Qualified for Appointment to the Consultation Forum* (BRQ, c C-32.1.1, r 1) (2007), available online at <http://www.canlii.org/en/qc/laws/regu/rrq-c-c-32.1.1-r-1/latest/rrq-c-c-32.1.1-r-1.html> (retrieved December 5, 2011).

⁴ The Collège des médecins du Québec, the Ordre des infirmières et infirmiers du Québec, the Ordre professionnel des travailleurs sociaux du Québec, the Agence d'évaluation des technologies et des modes d'intervention en santé, the Conseil du médicament (respectively, the professional colleges/orders of physicians, nurses, and social workers in Quebec; the Québec agency for evaluation of health technologies and treatment methods, and the Québec agency that determines which medications will be funded by public health insurance), along with Québec universities, associations of health and social service institutions, and any other bodies that deal with health and welfare.

First, the Forum's meetings are not public and neither are their minutes. This may minimize the Forum's influence. The legislation does, however, require the Commissioner to provide an account of the Forum's deliberations, its conclusions and recommendations. These are therefore included in the reports published by the Commissioner, which are submitted to the Minister of Health and Social Services and then to the National Assembly. The Commissioner's reports are then made available on his web site.

Second, the Forum serves in a consultative capacity to the Commissioner, who himself serves in a consultative capacity to the government. For this reason, it is not possible for the Forum to influence the government directly.

Third, the Commissioner can use a variety of mechanisms to broaden the debate and examine topics in greater depth. He can conduct targeted consultations with experts, decision makers and groups that have an interest in a given topic. He can also conduct public consultations online. Thus, although the Forum is a highly valued source of information, its consultations are only one among a range of consultation options.

That said, the Forum has encouraged institutional learning within the Office of the Commissioner.⁵ The Forum has unquestionably made a key contribution to the Commissioner's methods of assessing the performance of the health and social services system—so much so that it would now be hard to imagine any rigorous assessment process that does not systematically apply citizens' knowledge.

Lessons Learned

On the whole, the members of the Forum and the Office of the Commissioner have found the experience with the Forum to be a positive one. This experience has also brought to light three main challenges associated with deliberative forums:

- 1) The Government of Québec and the Office of the Commissioner wanted to institutionalize and structure the Forum in order to ensure the integrity and smooth operation of its deliberations. It is important, however, that this structure is flexible enough to meet any needs and expectations of both the participants and the host organization that may emerge over time.
- 2) Summarizing hours of discussions in a document that is perceived as valid and legitimate by the participants—and useful by the host organization—is a complex, delicate task. Great care must be taken that the discussions are not framed too vaguely, that the members are not asked to consider too many questions, and that members are encouraged to develop collective statements at their meetings that can be reproduced in the minutes.
- 3) Hybrid forums such as this one may generate some confusion as to the respective roles of the citizen members and the expert members. The citizen members of this forum had some trouble determining what “voice” they represented and what original contribution they were making in discussions that were sometimes highly technical. At the same time, given their role as “citizens with special expertise,” the expert members had trouble defining the kind of special knowledge that they were supposed to bring to the discussions.

⁵ Jones, M. and Einsiedel, E., “Institutional Policy Learning and Public Consultation: The Canadian Xenotransplantation Experience,” *Social Science and Medicine* 73.5 (2011): 655-662.

SUMMARY

Context: Institutional

Location: Montreal and Québec City, Quebec

Participation method: Consultation forum

Who is involved: 18 citizens from each of Québec's administrative regions; nine experts.

Topics for participation: Multiple topics.

To whom the results were reported: The Forum's meetings and the minutes of these meetings are not public, but these minutes are used to prepare the Commissioner's reports, which are submitted first to Québec's Minister of Health and Social Services, then to Québec's National Assembly, and finally to the public.

Methods of disseminating the results: Only the Commissioner has access to the minutes of the Forum's meetings. The Commissioner can then incorporate some elements of these minutes into the reports that he submits to Québec's Minister of Health and Social Services, to Québec's National Assembly, and finally to the general public via his web site [<http://www.csbe.gouv.qc.ca>].

Lessons learned The Government of Québec and the Office of the Commissioner wanted to institutionalize and structure the Forum so as to ensure the integrity and smooth operation of its deliberations. It is important, however, that this structure is flexible enough to meet the needs and expectations of the participants and of the host organization that may emerge during the discussions.

Also, summarizing hours of discussions in a document that the participants perceive as valid and legitimate, and that the host organization also considers to be useful, is a complex, delicate task.

Lastly, hybrid forums such as this one may generate some confusion as to the respective roles of the citizen members and the expert members.

The CommunityView Collaboration

Saskatoon Health Region
Amanda Clarke, M.H.Sc.
Public Health Officer - Policy Analyst
Office of Public Health Practice, Public Health Agency of Canada

Introduction

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What do you get when you combine a whole community, a cup of collaboration and a mixture of diverse perspectives? The CommunityView Collaboration (CVC). CVC (www.communityview.ca) is a web-based information system that houses local aggregate data, resources and emerging hot topics. CVC aims to: a) bring the community together to provide valuable insight into the determinants of health; and b) contribute to overall health and well-being in Saskatoon through supporting evidence-based decision making for program and service delivery, and policy making. This community project originated in 1999, when citizens expressed a need for the ability to easily access local data. Since then, the engagement process to this point has mostly included key stakeholders through a number of mechanisms such as dialogues, the formation of a Steering Committee, involvement of project champions, and “train the trainer” sessions. Moving forward, however, CVC will involve the general public more extensively in order to enhance uptake and the sustainability of the tool in the community. Through this collaboration, we are building evidence for action!

Methods

The planning stage

Over the years, the methods for CVC citizen engagement process have changed depending on the phase of the project. The project started in 1999 with discussions between community leaders, such as the Chief Medical Health Officer of Saskatoon Health Region, about evidence-based decision making and the need for local data to inform program and service delivery as well as policy. This was then brought to the attention of the Saskatoon Regional Intersectoral Committee (SRIC). The SRIC is one of ten standing committees located across Saskatchewan that coordinates linkages between human service leaders, community partners, and research support. One of their main objectives is to shape and influence program, policy, and resource allocation to meet the diverse needs and interests of Saskatoon citizens. The SRIC sponsored the CVC project.

Environmental scanning was conducted in CVC's planning stage, including literature reviews to determine best practices, similar models, and appropriate theories and principles to guide this work. Principles of citizen engagement such as capacity building, organization, coalitions and innovation were also considered. The foundation for the development of CVC was the view that “healthy communities are those that have well-integrated, interdependent sectors that share responsibility to resolve problems and enhance the well-being of the community.”¹

¹ Centre for Disease Control and Prevention, *Principles of Community Engagement* (Atlanta, Georgia, 1997), available online at <http://www.cdc.gov/phppo/pce/> (retrieved January 15, 2012).

Project champions from public and volunteer sectors began to approach organizations for their support and commitment to the project. A number of planning meetings were held, and the community response was very positive about moving forward. A CVC Steering Committee was developed to ensure representation from different sectors, and it currently includes the municipality, health region, police services, local school divisions, social services and the University of Saskatchewan. As a group, they were instrumental in voicing their needs to determine the scope and design of CVC.

During the development phase, the project was primarily spearheaded by the CVC Coordinator and tool developer, ProjectLine Solutions Inc. Putting together a highly technical resource in a simple, user-friendly format took time and resources. As a result, there was less engagement during this phase. Beginning in January 2010, when the tool was nearly complete, it was necessary to actively re-engage stakeholders. The CVC Coordinator organized one-on-one dialogue, regular updates, Steering Committee meetings, developed and piloted online training videos and held "train the trainer" sessions for the sector leaders.

The launch

In June 2011, CVC was officially launched in the community. The launch had close to 100 attendees and included an introduction to CVC's history, followed by presentations by the champions from various sectors, each of whom spoke about the applicability of CVC to their own work. In the audience were representatives from the community, provincial and federal governments, ProjectLine Solutions Inc., and other organizations and initiatives, such as the Saskatoon Poverty Reduction Partnership (SPRP), university students, media, and interested citizens. An interactive training session with approximately 40 participants followed the launch. Feedback was very positive, with one member of the SRIC stating that the CVC release was, "the best launch I have ever been to."

The Steering Committee is now forming a number of working groups (technical/data, training and communications) to maintain the fluidity and sustainability of the project. Feedback has strongly pointed to the desire for community interface with interactive forums, hot topics, and the promotion of community reports, articles and activities. SPRP has also expressed interest in this development.

There are many possibilities for CVC's use that have yet to be explored. Implementing CVC knowledge exchange mechanisms targeted to appropriate audiences will be an ongoing task to promote and encourage citizen engagement.² There will also be a shift to allow a further focus on the engagement and uptake of the tool by citizens other than the key stakeholders already on board.

² Canadian Institutes of Health Research, *Citizen Engagement* (Modified June 1, 2011), available online at: <http://www.cihr-irsc.gc.ca/e/41592.html> (retrieved January 15, 2012).

Table 1: Building Bridges–Building Teams: Schedule and Participation

Timeline	Method	Description
Initiated in 1999 and ongoing	Project Champions	To spearhead an effective strategy to promote change ³
Throughout early design phases	Community outreach initiatives (dialogues and consultations)	To determine the expressed needs of the community
Early design phase	Environmental scanning and developing a case	To engage potential partners
Early design phase	Steering Committee and ongoing meetings during planning phase	To represent intersectoral partners
Ongoing	Presentations and briefings to federal, provincial and regional governments	For example: Senate Sub-Committee on Population Health, 2008, and Provincial Ministries
2004 to Summer 2011	Dedicated Coordinator	To provide support for the project and bring stakeholders together
Ongoing	Email distribution lists	To keep stakeholders up to date
Winter 2011	Training web videos posted to CVC	To instruct on the function of CVC and ease uptake of the tool
Spring 2011 and ongoing	Train the trainer sessions	To develop CVC experts within each organization.
June 2011	Community website launch	To release access to website; attendance of close to 100
June 2011	Media coverage	Print, radio and television media on hand for the community launch
June 2011	Online user survey	To inform current status and next steps
October 2011	Working groups (technical/data, training and communications)	To respond to current needs; the Steering Committee is now developing specific working groups.
Ongoing	Presentations at conferences	Sample presentations in 2011: Housing Ideas that Matter Housing Tools that Work; Western Canada Medical Health Officers; and World Alliance for Risk Factor Surveillance
Ongoing	CVC training by University of Saskatchewan students	MPH students developed a training session to offer at the University on an ongoing basis
Ongoing	Innovative knowledge exchange mechanisms	To increase engagement and uptake of citizens

³ Howell, J.M., Shea, C.M., and Higgins, C.A., "Champions of Product Innovations–Defining, Developing, and Validating a Measure of Champion Behaviour," *Journal of Business Venturing* 20.5 (2005): 641-661.

Outcomes and Impact

Engagement has led to a more refined system that includes data requested by the community. When knowledge users are involved from the beginning, the chance of use is that much higher, and in the case of CVC, users also become knowledge producers and mobilizers.⁴ Knowledge users have already indicated how they will use CVC, including:

- The Saskatoon Police Service will use CVC as a tool for resource deployment and preventive program development and delivery.
- The United Way of Saskatoon and Area will monitor the changes in health status and quality of life of children living in Saskatoon's poorest neighbourhoods where targeted programs are taking place.

It is expected that a year after CVC's release (June 2012), a formal impact evaluation will be conducted to identify gaps and opportunities, as well as the uptake and use of evidence available on CVC. Data collection has already begun. One anecdotal impact is that community ties have strengthened amongst stakeholders representing different sectors. The impact of CVC, including its impact on citizen engagement, will be assessed with some of the following measures:

1. the number of user surveys, webpage hits, and "train the trainer" sessions;
2. the number of intersectoral projects, policies and practices that result from CVC data, resources and projects, along with examples of outcomes and actions taken by citizens using CVC;
3. the number of Steering Committee members who continue to be engaged and champion; and
4. the uptake of this model in other regions and provinces.

"Now we can quickly access local data to not only support our programs and services, but our intersectoral projects too. Using evidence to inform our work validates our decision making process."
- An Engaged Citizen

Lessons Learned

There are several lessons learned from the citizen engagement process. Engagement is ongoing and does not end with the launch of CVC. There were different levels of engagement in the CVC planning, development and implementation process. The key for us was to have a "swinging door" that allowed individuals/organizations to come and go. Wenger refers to this concept as "building benches on the sidelines."⁵ With the SRIC as a model for intersectoral human service work, we strongly encourage others to engage with different sectors in projects as it brings richer perspectives. We also need to continue to understand how the tool can be seamlessly incorporated into users' work, since there needs to be value added to improve uptake into the future.⁶ Finally, the influence of project champions from different sectors cannot go unmentioned. Project

⁴ We use the term "knowledge mobilization" here to mean an interactive "dialogue to deliver and receive a message," "engage an individual in a process," and "exchange a process or product." See the Canadian Interprofessional Health Collaborative, *Dissemination Strategy*, available online at http://www.cihc.ca/files/publications/CIHC_DS-May07.pdf (retrieved Jan. 15, 2012). For more on the increased chance of knowledge use when the users are involved in a process from the beginning, see Abelson, J, Montesanti, S, Li, K., Gauvin, F.P., Martin, E., *Effective Strategies for Interactive Public Engagement in the Development of Healthcare Policies and Programs* (Canadian Health Services Research Foundation, 2010), available online at http://www.chsrf.ca/Libraries/Commissioned_Research_Reports/Abelson_EN_FINAL.sflb.ashx (retrieved January 15, 2012).

⁵ Wenger, E., McDermott, R., and Snyder, W.M., *Cultivating Communities of Practice: A Guide to Managing Knowledge* (Boston: Harvard Business School Press, 2002), available from <http://hbswk.hbs.edu/archive/2855.html> (retrieved January 27th, 2012).

⁶ Liebowitz, J., A Schieber, B.A., and Andreadis, J., *Knowledge Management in Public Health* (Boca Raton, FL: CRC Press, 2009), p. 178.

“champions create and communicate strategic meaning around the innovation, persistently promote the innovation, sell the idea to top management in order to secure resources, and involve and motivate others to support the innovation.”⁷ While CVC was just recently released, it will always be a work in progress, but with ongoing citizen engagement, it will be around for a very long time.

SUMMARY

Context: Community Collaboration

Location: Saskatoon, Saskatchewan

Method of engagement: Steering Committee that includes intersectoral stakeholders, project champions; community outreach initiatives such as dialogues, consultations and “train the trainer” sessions; and a designated coordinator.

Who was, and remains engaged: Saskatoon Regional Intersectoral Committee composed of leaders from the human services sectors sponsored the project. Funding came from the Saskatoon Health Region, City of Saskatoon, Ministry of Social Services (Centre Service Area), Saskatoon Public School Division, and Greater Saskatoon Catholic Schools.

Topic of engagement: CommunityView Collaboration (www.communityview.ca) is a web-based information system that houses local aggregate data, resources and emerging hot topics. Citizens are able to share data and knowledge with each other and the greater community.

To whom were the results reported: Ongoing planning, development and implementation results are reported through the Steering Committee. There was a public launch in June 2011 that included close to 100 attendees from various organizations, and a hands-on training session was offered afterwards to approximately 40 participants.

Methods of dissemination: Steering Committee, community outreach initiatives, dedicated coordinator, “train the trainer” sessions, project champions, training web videos, email distribution lists, local/provincial/national presentations at meetings and conferences, public launch, media coverage, user online survey, and ongoing innovative knowledge exchange is planned to evolve with the needs of users.

Lessons learned: Engagement is ongoing and does not end with the launch of CVC. There are different levels of engagement, but the key is to have a “swinging door” that allows individuals and organizations to come and go. Search out ways to engage with different sectors to bring valuable perspectives to the table and ultimately to increase active uptake.

⁷ Howell, J.M., et al., “Champions,” p. 646.



Shared Challenge, Shared Solution: Northumberland Hills Hospital's Collaborative Budget Strategy

Robert Biron, President & CEO Northumberland Hills Hospital
Jennifer Gillard, Director, Communications and Community Engagement

Introduction

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Located in Cobourg, Ontario, 100 km east of Toronto, Northumberland Hills Hospital (NHH) faced difficult choices during the 2010 fiscal year. Although efficient by most key measures, the 110-bed hospital had run three years of operating deficits in order to maintain the 23 services that its community had come to expect. This was not sustainable, and the long-term viability of the hospital was at risk. Furthermore, Ontario's hospitals are required, by law, to balance their budgets.

Why Citizen Engagement?

Recognizing the fiscal realities and the tough choices they faced, the NHH Board embarked on a public consultation focused on the challenging—and potentially controversial—issue of service prioritization. It did so in the context of a small community that was heavily invested in—and supportive of—its hospital, both as a leading employer and the focus of considerable donor and volunteer commitment.

The objectives of NHH's engagement process were threefold:

- 1) to receive public input through a genuine process that would inform the NHH's Board of its options;
- 2) to maintain or enhance the trust felt towards NHH within the community; and
- 3) to achieve Local Health Integration Network Board approval for the ultimate choices made by the NHH Board regarding service adjustments that were necessary to balance the budget.

Conducted over a 10-month period, Northumberland Hills Hospitals collaborative budget strategy, *Shared Challenge, Shared Solution* (SCSS), offers a unique case study for effectively engaging the community served around a subject facing many hospitals in Canada.

Methods

NHH's community engagement initiative was partly triggered by a requirement in the *Local Health System Integration Act* of 2006, which requires that Ontario's health service providers “engage the community of diverse persons and entities in the area where it provides health services when developing plans and setting priorities for the delivery of health services.”

Regardless of the requirements of the Act, NHH strongly believed that there was significant value to engaging its community prior to making decisions relating to service changes. As such, the engagement initiative was anchored on three fundamental principles, namely that the hospital would be:

- **proactive:** NHH would seek public input at the beginning of the budget and service planning process rather than after decisions had been made.
- **transparent:** NHH would keep the community informed throughout the process and encourage open dialogue and discussion about options.
- **inclusive:** NHH would obtain as many perspectives as reasonably possible to reflect the diversity of the community served.

SCSS aimed to involve external stakeholders in the decision making process to help identify and prioritize the core services of the hospital while maintaining the community's expectations for quality patient care. The challenge was to deploy an engagement process that would be effective and viewed as legitimate by the broader public.

To support the design and process of public input, NHH followed a number of resources. A framework document published by Dalhousie University, entitled *A Framework for Involving the Public in Healthcare Coverage and Resource Allocation Decisions*, was used to map out the overall process.¹ NHH also followed the International Association of Public Participation's spectrum of participation while implementing the SCSS strategy, informing, consulting, involving and, finally, collaborating with the community served.

Inform and consult

The first stage of the plan—the “inform” portion—commenced in April 2009 with community presentations by the CEO being delivered to community groups, including municipal councils, service clubs, and other health service providers. Within each group was a distinct set of community thought leaders. The focus of the presentations was a financial update on NHH and context on the funding challenges facing NHH and hospitals throughout Ontario.

Running parallel to this outreach—which was designed to get community members thinking and talking about both the fiscal challenges faced by NHH and the prospect of change—was a telephone survey.

Conducted by an independent polling company on NHH's behalf, the survey was carried out in April 2009. The survey focused on whether the public wanted to be involved and, further, how they wanted to be involved in budget deliberations, preparing the way for the future public engagement exercise.

A total of 510 telephone interviews were completed. In line with NHH's “inclusive” promise, interviews were collected from a representative sample from across the community served. Phone interviews were also conducted with representatives from the First Nations of Alderville, ensuring that their representation in the survey was proportional to their percentage of the overall population. Results were weighted by region and gender (based on the most recent census data) to ensure representative results.

Following a recommendation from the Northumberland Poverty Reduction Action Committee (one of the many community groups visited by the CEO), face-to-face surveys were subsequently added to solicit input

¹ Chafe B., Neville D., Rathwell T., Deber B., et al., *A Framework for Involving the Public in Healthcare Coverage and Resource Allocation* (Halifax, N.S.: School of Health Services Administration–Dalhousie University, 2007).

from lower-income individuals who might not have been reached by the telephone survey. A total of 36 face-to-face surveys were completed, bringing the overall total of citizens polled to 546.

Close to half of the residents surveyed stated that they wanted to be more informed about hospital services (49%), as well as key decisions and plans related to the hospital's future and priorities (47%). One in five residents surveyed said that they wanted to be "much more informed."

The April 2009 survey also endorsed NHH's vision of establishing a mechanism through which it could engage residents to solicit input into changes to services, with 51% of respondents indicating that they wanted input into changes in hospital services.

Another objective of the surveys was to "identify the public's preferred methods for being engaged in budget discussions relating to service options." In this regard, the survey concluded that west Northumberland residents viewed community advisory panels and public meetings as the most effective methods for obtaining their input. In other words, this community preferred "face-to-face" meetings to deliberate and discuss these matters instead of other technologies, such as phone or web surveys. As a result, NHH had clear direction on how to structure its engagement process.

Consult and involve

Northumberland Hills Hospital's Citizens' Advisory Panel ("CAP") would eventually prove to be a new way for community members and NHH to work together to solve the difficult problem of service prioritization. It was essential to strike a Panel that was—and was perceived to be—independent of the Board.

To support the establishment of the CAP and the engagement process, NHH issued a request for proposals for consulting services. MASS LBP, a consulting firm based in Toronto, was selected to work with NHH. Their approach to community engagement and their unique selection process for selecting participants aligned with NHH's engagement principles and core values. MASS LBP deploys an innovative approach to establishing citizen reference panels using a civic lottery, a selection process similar to the way in which a jury is selected in the justice system.

The Hospital Board provided governance oversight of the process, while researchers with expertise in resource allocation decision making and program evaluation from The Monieson Centre at Queen's University's School of Business provided an independent evaluation of the engagement process.

In the fall of 2009, a letter inviting residents to participate in the CAP was sent to 5,000 random households within NHH's catchment area. One in twelve households received the letter, which served as a further communication tool for spreading information on NHH's financial challenges and the tough choices ahead. Signed by the Board Chair and CEO, the letter invited the household to nominate one member over the age of 18 to volunteer to serve on the CAP.

Working with approximately 100 eligible responses received, CAP members were then blindly selected by MASS LBP based on the prescribed attributes of gender, age and geographical location to match the profile of the region. In addition, a minimum of 50% of the CAP participants (or one of their immediate family members) had to have recently used the hospital's services. This was done to ensure that a patient's perspective was also included in the deliberations.

NHH and MASS LBP developed the extensive curriculum for all of the CAP sessions. Over the course of five full-day sessions held between October and December 2009, the CAP members went through an intensive process. They studied, deliberated and discussed the hospital's 23 patient services. They toured the hospital, heard from experts, stakeholders and service providers, carried input from their neighbours and colleagues back to the CAP through private conversations, and hosted a public roundtable meeting which extended the conversation to the broader community. Through a facilitated process, the CAP was not only able to apply a values-based framework that evaluated and prioritized NHH's core services, but also to prepare their recommendations for the NHH Board.

Collaborate and empower

In January 2010, the CAP delivered its report to the NHH Board. The report included, as requested: an outline of the participants' vision for the future of the hospital; a values-based assessment framework for ranking NHH's 23 services; and a ranking of NHH's services into core and non-core areas, in accordance with the CAP's vision for the future of the hospital, including their rationale and expected impact on NHH's budget.

In keeping with the transparency promise, news that the Board had received the CAP's recommendations was released to the community, but the details of its proposals were not shared until the Board had completed its deliberations two months later. This decision posed considerable challenges from a media perspective, as speculation grew over what the CAP had proposed to excise. This delay, however, was essential to NHH maintaining its initial commitment to the CAP: that while the citizens would collaborate with the Board (i.e., provide recommendations) and inform outcomes, the final tough decisions would remain the responsibility of the hospital Board and, on its approval, the LHIN.

From January to March, the NHH Board deliberated over the CAP's recommendations, combining the input of the citizens with that of other stakeholders, namely the LHIN, hospital staff, physicians and community health service providers.

In March, 2010, the Board released its final plan, which accepted many of the CAP's recommendations. Most importantly, it reflected the CAP's insistence that the hospital should "focus its efforts on acute care services" and divest other, non-core services into the community, where such services could also be effectively delivered.

Outcomes and Impact

Shared Challenge, Shared Solution was designed to help develop a plan to place NHH's finances back on sound, long-term footing while retaining trust in the hospital as a valued public institution in west Northumberland that was worthy of ongoing and active donor and volunteer support. It did just that.

The CAP process brought together personal experience, expert knowledge, and public context to give Panel members the insights that they needed to translate their opinions and ideas into meaningful and credible recommendations for the hospital Board. It respected the hospital's commitments to be proactive, transparent and inclusive. The communication before, during and after the CAP kept the broader public informed and highlighted avenues where everyone could, if they desired, become involved.

The LHIN accepted the Board's proposed service changes without amendment. Implementation of that plan, which involved the closure of several programs, began immediately. As a result of these efforts, on March 31, 2011, NHH achieved its first balanced operating budget in years, and it is on track to sustain the same balance in 2011/2012. Donations, as measured by local participation in ongoing Foundation and Auxiliary fundraising events, have grown or held steady, indicating continued trust in the organization.

In April, 2010, the Hon. Deborah Matthews, Ontario's Minister of Health and Long-Term Care, praised the NHH project as "innovative" during a statement in the provincial legislature, and she encouraged other Ontario hospitals to consider NHH's approach when seeking ways to engage the public:

The Citizens' Advisory Panel [is] something that I think other hospitals may wish to explore because it does actually ask the people in the community what they need to protect and what could be done better outside the hospital.²

On Tuesday, March 1, 2011, The Globe and Mail featured an article highlighting NHH's "novel approach of creating a Citizens' Advisory Panel on Health Service Prioritization..."³

In NHH's 2010 accreditation report, Accreditation Canada acknowledged NHH's community engagement practices as an area of strength:

The NHH is embarking on a transformation journey. It has engaged the community in a meaningful manner with respect to service provision, given its financial imperatives. The community advisory panel, along with perspectives from other stakeholder groups, were considered in the organization's new draft strategic plan and submission of the 2010/2011 operating plan.⁴

² Hon. Deborah Matthews, Ontario Minister of Health and Long-Term Care, Provincial Legislature, April 27, 2010.

³ Galloway, Gloria and Lisa Priest, "Health Care Action Plan urged to avert 'looming crisis'," Globe and Mail, February 28, 2011, A4.

⁴ Accreditation Canada, "Accreditation Report: Prepared for Northumberland Hills Hospital" (2010), p. 2, available from <http://www.nhh.ca/LinkClick.aspx?fileticket=ZGe9SVb8Dh8%3d&tabid=790&language=en-US> (retrieved January 27, 2012)

Lessons Learned

The CAP process was audited and evaluated by researchers from The Monieson Centre at the Queen's University School of Business. As part of this process, panelists completed a total of eight surveys: one after each of the five sessions, a pre-survey, and two post-CAP surveys. This evaluation not only provided NHH with information for future community engagement processes, but it also enabled facilitators to modify sessions as they received Panel member feedback following each CAP meeting. Baseline, mid-stream and post-event evaluation tools are strongly recommended for organizations planning public engagement, regardless of the participation method selected.

Clear communication around the organization's expectations of participants at the beginning of the exercise is also recommended. In the early stages of planning for the CAP, a detailed Terms of Reference was prepared to outline the roles and responsibilities of the CAP, their reporting relationship, and most importantly, the scope of their mandate. This document, developed in consultation with the NHH Board and senior management team, was made available on the hospital's website at nhh.ca, and it was essential to the CAP's success.

The 185-page evaluation report delivered to the NHH Board from Queen's University concluded that NHH "went far above and beyond the minimum requirements for public consultation" and achieved its goal of engaging the community.⁵ Before the CAP, 43% of the panelists were satisfied with NHH's method of making decisions about services; this jumped to 83% in the post-CAP survey.

The members of the CAP recognized the significant commitment of the CEO and NHH's Senior Management Team, and they greatly appreciated the hospital's willingness to listen and share information. Survey comments praised NHH's overall facilitation of the CAP, saying the sessions were well organized, the overall curriculum and format were effective, and the facilitators were unbiased. Of particular interest is the fact that the panelists unanimously agreed that NHH should continue to use the CAP model to obtain public input. Given the chance, 92% of the members would participate in a similar process, and 96% felt they had accomplished something important.

⁵ The Monieson Centre, "Report on the Community Engagement Process" (2010), p. 30, available from <http://www.nhh.ca/SharedChallengeSharedSolution/MoniesonCentreReport.aspx> (retrieved January 27, 2012)

SUMMARY

Context: Collaborative budget strategy including public input for service prioritization.

Location: Northumberland County, Ontario

Method of Engagement: Citizens' Advisory Panel chosen at community's recommendation following a telephone survey that confirmed how the community wanted to be engaged; panel members selected by civic lottery and balanced for age, gender and geographical representation. Participants had to be 18 years of age or older, with some direct experience of the hospital (patient, relative of a patient) in the previous 12 months.

Who Was Engaged? Members of the public and hospital patients of the west Northumberland County community, including:

- 546 members who participated in a telephone and face-to-face survey;
- 24 members who served on a Citizens Advisory Panel; and
- 62 members participating in a public roundtable.

Topic of Engagement: Service prioritization for a public hospital.

To Whom Were the Results Reported?: NHH Board of Directors followed by the community at large.

Methods of Dissemination: Direct mail, hospital website/newsletter, paid ads, proactive media relations (news releases), and community presentations.

Lessons Learned: Engagement process effectively achieved its goals, as proven by the third-party report provided by researchers at Queen's University, Kingston.



Our Health. Our Perspectives. Our Solutions: ESTABLISHING A COMMON HEALTH VISION

New Brunswick Health Council
Nicole Pollack and Mary Pat Mackinnon, Ascentum

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Introduction

The New Brunswick Health Council (NBHC), an independent organization created by the New Brunswick Government in 2008, is mandated to measure, monitor and evaluate population health and health service delivery in the province, and to ultimately formulate recommendations on those topics for the Minister of Health. The creation of the NBHC was driven by the recognition that citizens are the health system's most important stakeholders.

Why Citizen Engagement?

In February 2010, the NBHC undertook a province-wide citizen engagement initiative entitled Our Health. Our Perspectives. Our Solutions to help inform its recommendations to health care partners on what citizens believe is required to achieve a citizen-centred health system. The three-phased approach was designed to involve New Brunswick citizens and health care stakeholders in a dialogue about the provincial health system, particularly on topics such as what people value most about the system, how it can be strengthened, and what can be done to improve provincial health outcomes (see *Table 1*).

Table 1: Topics of Discussion

PHASE I PERSPECTIVES	Values of an “ideal” health system
	Priority issues to improve the health system in New Brunswick
	Strengths and opportunities to create the kind of health system you want
PHASE II SOLUTIONS	“Image-ing” a citizen-centred health system
	Where and from whom health care, services and supports should be delivered
	What the health system should do more—and less
	Encouraging healthier choices and behaviours
PHASE III COMMON GROUND	Making tough choices: primary care priorities
	Making tough choices: acute/supportive care priorities
	Making tough choices: system-wide priorities
	Health care sustainability and funding models

Methods

Our Health. Our Perspectives. Our Solutions was the NBHC's first large-scale public engagement initiative. The NBHC contracted Ascentum, an Ottawa-based public engagement firm that specializes in public participation and stakeholder engagement, to provide strategic advice, collaborate on the engagement design and process, and provide documentation, analysis and reporting services.

The locations for Phase I and II (Moncton, Bathurst, Edmundston and Saint John) were chosen to ensure that New Brunswickers could attend a dialogue session without having to travel more than 200 kilometres. Phase III, the final phase of the approach, featured a provincial dialogue session in Fredericton, the provincial capital. In total, nine dialogue sessions took place across all three phases.

The initiative brought together a diverse mix of participants: half of them were randomly recruited citizens, while the remainder were targeted stakeholders, including representatives of various community and public interest groups, health and wellness managers, academics, health professionals, provincial government decision makers and elected municipal officials. At the outset, a target of 125 participants was set for each of the four Phase I dialogues (for 500 participants in total), but due to challenges randomly recruiting public participants, the final tally was 310.

For Phase II, all participants were invited to reconvene in the same locations for a second day of dialogue in order to continue their work together. More than two-thirds (223 participants total) returned for this phase. Phase III then brought together a random selection of participants—roughly one third (111) of the original Phase I participants—drawn from each of the four locations for a final dialogue. Inviting the same individuals to attend multiple dialogue sessions allowed them to deepen their understanding of the issues by reflecting on what they heard between phases, thus offering richer and more informed perspectives throughout the phases.

In Phase I, the NBHC provided participants with information to help them form a clear and accurate picture of New Brunswick's health care system challenges (see *Table 2*). The process encouraged participants to explore what they valued about the system. Phase II asked them to envision the kind of health care system desired by New Brunswickers and to identify solutions that would address the challenges faced by the system.

In Phase III, the NBHC validated the findings from the first two phases and helped participants to link their ideas to actual sectors in the health system and to prioritize potential action plans. This phase took a more deliberative approach; exercises such as "Imagine that You are the Health Minister" enabled participants to weigh distinct options that reflected different value propositions and to consider the difficult decisions with which policy makers must wrestle in allocating resources.

During each phase, participants were well supported with detailed Conversation Guides, which provided a wealth of accessible information on the New Brunswick health system (such as its structure, costs and services), as well as key findings from the previous phase.

Table 2: Sample of Phase I Agenda (8:30 AM - 4:00 PM)

Welcome and Opening Remarks
Keypad Voting (demographics)
Table Introductions: New Brunswick Health System Trivia Cards
Learning Session: Provincial Context and the NB Health Sector, Plenary Q&A
Table Discussion (personal reflection and sharing): What would you value most in an “ideal” health system?
LUNCH
Plenary: What would you value most in an “ideal” health system?
Learning Session: How are we doing?
Table Discussion (personal reflection, sharing and post-it note exercise for prioritization): Reflect on the health system—broadly defined—and collectively identify your “top 3” priority issues, based on what you believe to be most important for all of New Brunswick.
HEALTH BREAK
Plenary: Priority Issues
Table Discussion (paired interviews and sharing): Identify the strengths and opportunities that we can build upon to create the future health system you want.
Plenary: Strengths and opportunities to build on
Closing Remarks

Participants were assigned to tables based on language and perspective. Tables worked in either French or English, and they were composed of a balanced mix of citizens and stakeholders whenever possible. Simultaneous interpretation for the plenary presentations and discussions was available at all sites. The dialogue design for each of the phases featured a mix of learning sessions, facilitated small group work, the sharing of perspectives in plenary, and validation through keypad voting for critical questions. Trained table facilitators, assigned to each table, were responsible for both facilitating and recording the table conversations on template worksheets.

The NBHC stressed the importance of good dialogue practice throughout the initiative. The message that dialogue is all about people working together to explore and understand different points of view was reinforced across all three Phases. To that end, participants were frequently reminded that there are no “right” and “wrong” answers—only individual experiences and points of view, each of which would carry equal weight and legitimacy in the eyes of the NBHC. Participants’ written evaluations indicate a very positive reaction to the dialogue process.

Participants provided rich feedback to the New Brunswick Health Council (see *Table 3*). While diverse perspectives were heard, the degree of consistency in participants’ comments across dialogue sites and

across all three phases highlights a powerful province-wide consensus on key elements that, taken together, established the foundation for a common vision for health care in New Brunswick.

Table 3: Key Findings

<ul style="list-style-type: none"> ● A firm belief in the importance of addressing barriers relating to distance, language, socio-economic status and cost, to ensure equitable access to health care services province-wide.
<ul style="list-style-type: none"> ● A strong endorsement of community health centres, clinics, home-based care (such as the Extra-Mural Program), Tele-Care and tele-health as strategies for bringing health care closer to citizens, and for ensuring that hospitals remain focused on their primary purpose: acute and supportive care.
<ul style="list-style-type: none"> ● A call for a fundamental paradigm shift towards wellness, health promotion, health literacy, and illness prevention (“health care” versus “sick care”), with a particular focus on reducing the incidence of chronic diseases and fostering a “culture of health” early on in childhood.
<ul style="list-style-type: none"> ● The belief that more must be done to optimize the roles and responsibilities of health care professionals, to ensure that all available health human resources are used to their full capacity, within the framework of the province’s public health system.
<ul style="list-style-type: none"> ● Recognition that the rising costs of health care must be better communicated to citizens and controlled through a variety of different methods, including: improved systems and processes; promotion and prevention; more creative use of available public infrastructure; and reducing the costs of drugs.
<ul style="list-style-type: none"> ● A strong sentiment that health care is a valued public good in which not only citizens but also communities have a strong stake.
<ul style="list-style-type: none"> ● Strong support for strategies that encourage and empower citizens to take responsibility for their own health.
<ul style="list-style-type: none"> ● A deep appreciation for the commitment and generosity for front line health care workers, the people who make the health system work.

Outcomes and Impact

The three-phased engagement initiative was designed to iteratively “build up to establish a common health vision” for a citizen-centred health system. This was done strategically to be in alignment with the *Provincial Health Plan (2008-2012)*, which affirms that the province’s health system needs to become citizen-centred in all aspects. The rationale for aligning with the Provincial Health Plan was to increase the relevance of the results to health system planners in order to increase the potential impact.

The results of *Our Health. Our Perspectives. Our Solutions* became the cornerstone for the NBHC’s 2011 recommendations to the Minister of Health for improving the system. Participants’ primary health care priorities were extrapolated from the final report and highlighted in an accessible one-page document. Prior to the Minister’s Primary Health Care Summit (October 20-21, 2011), the NBHC used the one-page document to brief the Minister and ensure that she was well prepared to incorporate key messages about citizens’

primary health care priorities in the Summit proceedings. The Assistant Deputy Minister of Health has stated that the engagement report has been positively referenced around the board table of the Department of Health on several occasions.

The key findings of the initiative have been presented to various decision makers, including the health system senior management teams (from organizations such as the Department of Health, Horizon Health Network, Vitalité Health Network, Ambulance New Brunswick, and FacilicorpNB) and the associations of municipalities in New Brunswick (Union of Municipalities of NB and the Association francophone des municipalités du N.-B.). Furthermore, the key findings were so well received by the associations of municipalities that the NBHC was invited to make a presentation to the municipal zones. These dissemination activities have brought the key findings of the engagement initiative and the resulting recommendations to the attention of important government decision makers. Senior government officials, including the Minister of Health, refer to the *Our Health. Our Perspectives. Our Solutions* report in their day-to-day work and their public addresses.

Lessons Learned

Important lessons emerged from the challenges of recruitment. The NBHC hired a third party recruitment firm who made over 39,000 calls to New Brunswickers with a goal of recruiting 500 participants for Phases I and II. In total, 479 participants confirmed their participation for the Phase I dialogues, with 310 actually attending. Attendance dropped to 223 in Phase II. The high attrition rate may have been partially a result of not offering a stipend or honorarium to participants. The sessions were held on Saturdays to accommodate those working regular business hours, but both stakeholders and the younger population reported that this was a deterrent to participation. The NBHC learned that more intensive advance networking is critical to ensuring good stakeholder turn out. Involving marginalized groups was also a challenge, as was designing a process to suit varying literacy levels. The NBHC realized that a single process may not be effective for all target audiences, and as a result, it undertook a secondary stream of engagement with younger adults.

Another lesson learned relates to the importance of having not only clear and measurable objectives at the outset, but also careful, transparent management of participant expectations about how the results of the engagement will be used. The credibility of the process was heightened by the presence of the NBHC CEO, who moderated all of the sessions and conveyed a strong message at every dialogue that the outcome of the work would be the cornerstone of the NBHC's recommendations to the Minister of Health. Articulating how participants' contributions would be used was critical for participant buy-in and commitment. Senior decision makers in attendance benefited from hearing citizens' perspectives, and in turn, participants were reassured that their voices were being heard. The process also demonstrated that citizens were able and willing to have tough discussions on cost-effective health care strategies when provided with credible health system information, well-framed questions and a process that allowed for meaningful engagement.

Finally, the NBHC learned the importance of ongoing communication strategies with its various audiences (the public, stakeholders, media, and government), and maintaining contact with past participants. The link

to the NBHC 2011 "Recommendations to the Minister of Health" document was sent to all dialogue participants, and stakeholders were invited to the press conference at which the Minister of Health was officially presented with the NBHC's recommendations.

SUMMARY

Context: Provincial citizen engagement initiative on health care transformation.

Location: Moncton, Bathurst, Edmundston, Saint John and Fredericton, New Brunswick.

Method of Engagement: Iterative, generative and deliberative dialogues; mix of table work, plenary discussions, and keypad voting.

Who was Engaged: 310 randomly recruited citizens and targeted stakeholders.

Topic of Engagement: What people value most with regard to the provincial health system, how the system can be strengthened, and what can be done to improve provincial health outcomes.

To Whom Were the Results Reported: Final report sent to: 310 participants; NBHC board members; Senior officials at the Department of Health; all 55 MLA's; Deputy Ministers of Health, Wellness & Social Development; both provincial Health Networks (Horizon Health Network, Vitalité Health Network); Ambulance New Brunswick; FacilicorpNB; New Brunswick Nurses Association; all allied professional health associations in NB; Health Councils across Canada; and various community partners.

Methods of Dissemination: The final report was sent to the above recipients either as a hard copy in the mail or as an electronic link in an email. The final report was also posted on the NBHC website (www.nbhc.ca).

Lessons Learned: Lessons learned include: recruitment challenges (getting a representative mix of the general population and high attrition rates); the importance of having clear objectives and managing expectations; and, ongoing communications strategies/staying in contact with past participants is critical to sustaining impact.

The Use of a Holistic Wellness Framework & Knowledge Networks in Métis Health Planning

Manitoba Metis Federation Health & Wellness Department
Judith G. Bartlett; Sheila Carter; Julianne Sanguins; Brenda Garner

Introduction

8

Métis are a distinct People, descended from 17th century strategic economic, social, and political relationships between North American Indians and Europeans.¹ The Manitoba Métis Federation (MMF) was founded in 1967 to represent Métis citizens in Manitoba. The organization has 200 employees governed by an elected Board (consisting of a president and 21 board members) that is accountable for programs delivered from the MMF Winnipeg Home Office and seven MMF Regions.² MMF Regions include approximately 150 MMF Locals spread across the province, each of which has three representatives that provide direction to Regions and the MMF Annual General Assembly. The MMF-Health & Wellness Department was created in July 2005 to enable MMF Regions, affiliated Regional Health Authorities, and Local Métis citizens to engage for health planning.

Initially, the Health & Wellness Department set out to develop a process for ongoing health planning engagement but found little information with which to proceed. In February 2006, the Health & Wellness Department approached the University of Manitoba to partner in publishing the *Profile of Métis Health Status and Health Care Utilization in Manitoba: a Population-Based Study*, also called the *Métis Atlas*.³ From 2008-2010, the Health & Wellness Department had sole use of preliminary *Métis Atlas* data, which was interpreted at Knowledge Network discussion tables using a specific Knowledge Translation model. The Knowledge Network discussion tables, the Knowledge Translation model and a holistic framework approach were essential for using “what we know” from research to influence “what gets done” in health services.

In this case, the holistic “Life Promotion Framework” methodology was adapted for use with the Métis population.⁴ Its use was to ensure the MMF-Regions and their affiliated Regional Health Authority had a basis for jointly developing a positive and holistic vision of the future, which makes it much easier to discuss more difficult current issues. Importantly, the “Life Promotion Framework” is a holistic tool that is not culturally-specific to the Métis population; it may be adapted for use by any group or organization.

¹ Sprague D.N., Frye R.P., *The Genealogy of the First Métis Nation: The Development and Dispersal of the Red River Settlement* (Winnipeg, MB: Pemmican Publications, 1983).

² For more information on the Manitoba Métis Federation, please visit www.mmf.mb.ca

³ Martens, P., Bartlett, J.G., Burland, E., Prior, H., Burchill, C., Huq, S., Romphf, L., Sanguins, J., Carter, S., Bailly, A., *Profile of Métis Health Status and Healthcare Utilization In Manitoba: A Population-Based Study* (Published by the Manitoba Centre for Health Policy in collaboration with the Manitoba Métis Federation, 2010).

⁴ Bartlett, J.G., *Theory, Reality, Hope: Proceedings, Proceedings of the Third International Conference on Diabetes and Indigenous Peoples* (Winnipeg, MB, 1995), pp. 44-48. Copyright for Métis Life Promotion Framework®, associated tools, and methods, is retained by Dr. Judith G. Bartlett for protection of Indigenous knowledge.

Methods

Knowledge translation

This Knowledge Translation model (*Table 1*) ensures that Métis research is used to maximize benefit for the Métis population. The model, based on the five levels of public participation articulated by the International Association of Public Participation, functions as a participatory method for “understanding and negotiating influence and action.”⁵ It facilitates negotiation between partners where they might inform, consult, involve, collaborate and empower one another during health planning.

Table 1: Understanding and Negotiating Influence & Action

Influence → We promise to: Action ↓	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
	keep one another informed.	obtain feedback and acknowledge concerns.	reflect concerns and provide feedback.	incorporate advice as much as possible.	make joint decisions.
Manitoba Métis Federation	informs Regional Health Authority on...	consults Regional Health Authority on...	involves Regional Health Authority in...	collaborates with Regional Health Authority on...	is empowered to...
Regional Health Authority	informs MMF on...	consults MMF on...	involves MMF in...	collaborates with MMF on...	is empowered to...

Clear understanding of each partner and what they can or cannot commit to at the beginning of discussion avoids frustrations and misunderstandings. Having been extensively evaluated in the “Métis Need to Know Too” Knowledge Translation research project in two MMF-Region Knowledge Networks, the Knowledge Translation model is highly supported and has already been implemented in a number of additional MMF-Region Knowledge Networks.

Knowledge networks

A Knowledge Network is a discussion table of six to ten individuals drawn from the MMF-Region offices and their affiliated Regional Health Authorities. To establish a Knowledge Network, the MMF-Region Vice-President requests participation from the Regional Health Authority Chief Executive Officer (CEO). To date, most Regional Health Authority participants are either the CEO and/or Senior Health Planners.

The MMF-Region participants are the Vice-President (or designate) and two or three program staff, plus an HWD-Knowledge Network Coordinator. Selection of Métis citizen participants is determined by the MMF-Region staff that has regular contact with citizens at the Métis Local level. Knowledge Networks receive all activities mapped out in the meeting schematic (*Table 2*) and described below, with focus on their own geographic area.

⁵ International Association of Public Participation (IAP2) (2003 and 2007), available online at http://www.iap2.org/associations/4748/files/IAP2%20Spectrum_vertical.pdf (retrieved Dec 9, 2011).

Table 2: Knowledge Network Activities to Interpret Métis Health Research

Two-Day Session (1)	Two-Day Session (2)	One-Day Session for Each Chronic Disease	Final Two-Day Session
<ul style="list-style-type: none"> ● study overview & informed consent ● orientation to holistic lens and approach ● develop 10-year vision for Métis health ● produce high level scan of Métis health perceptions ● train on reading graphs/ understanding chronic diseases ● overview of <i>Métis Atlas</i> content ● examine prevalence of Chronic Diseases ● select three priority Chronic Diseases for interpretation 	<ul style="list-style-type: none"> ● orient to adaptation initiative ● review Knowledge Network expectations ● orient to Knowledge Translation model ● negotiate Knowledge Network relationship ● review additional Chronic Disease priority-related graphs from <i>Métis Atlas</i> 	<ul style="list-style-type: none"> ● add Métis citizen stories/ experience with Chronic Diseases & health system ● add Chronic Disease protective & risk factors (based on literature & Métis citizen stories /experience) ● review additional <i>Métis Atlas</i> graphs ● add MMF Region social/economic program/services & Regional Health Authority health programs/services ● add general Métis health consumer experience as known by MMF or Regional Health Authority 	<ul style="list-style-type: none"> ● all information transferred to 3x5 cards; mapped on wall around holistic framework ● walls photographed for later use ● holistic view shows health information & policy gaps ● identify new research needs ● process cards in thematic analysis workshop ● use themes to develop a Knowledge Network plan to adapt Regional Health Authority programs/services ● produce evaluation plan for adaptation activities ● MMF Regions also use Knowledge Network outcomes for planning
<div style="display: flex; align-items: center; justify-content: space-between;"> <div style="text-align: center;">  </div> <div style="text-align: center;">  </div> <div style="text-align: center;"> <p>research needs sent back to HWD</p> </div> <div style="text-align: center;">  </div> </div>			

An initial two-day Knowledge Network session orients and trains participants on the holistic approach. The holistic methodology is then used to develop a ten-year vision for Métis health and wellness, followed by a high level scan of current perceptions of Métis health. Training modules on reading graphs and understanding chronic diseases are provided. An overview of the *Métis Atlas* is provided to prepare the Knowledge Network for receiving a first full set of health graphs. A graph with seven major chronic diseases is shown and the Knowledge Network *selects three priority chronic diseases* to examine in greater detail. Priority selection may be based on a high rate or severe consequences of a particular chronic disease, but it may also be based on other reasons, such as selecting a chronic disease where there is a program in place.

The next two-day Knowledge Network session begins with relevant training on the MMF Adaptation Initiative that is intended to adapt health services to meet Métis needs, Knowledge Network expectations, and the Knowledge Translation negotiation model. At this point, the Knowledge Network negotiates its relationship by completing and documenting the statements in the Knowledge Translation model (found in *Table 1*). This model focuses on both understanding and negotiating influence and action by mapping how partners in the process inform, consult, involve, collaborate and empower the various stakeholders.

The Knowledge Network then views additional *Métis Atlas* graphs related to each of the three selected chronic diseases priorities. Outside of the Knowledge Network meeting times, the HWD Knowledge Network Coordinator, supported by MMF Region staff, implements multiple focus groups with Métis citizens from MMF Locals in their Knowledge Network geographic area. This ensures that the voices of Métis citizens are included in the Knowledge Network health planning process.

Next, three one-day Knowledge Network sessions build on health information by adding:

- Métis citizen experience with chronic diseases and the health system;
- protective and risk factors of chronic diseases from literature reviews;
- priority chronic disease-related *Métis Atlas* graphs not yet seen;
- information about MMF Region and Regional Health Authority chronic diseases-related social and health programs/services; and
- additional Métis health consumer experience known by Regional Health Authority and MMF participants.

The final two-day Knowledge Network session reviews all information (which at that point has been transferred to 3x5 inch cards) mapped on a wall around the holistic framework. This view is photographed so that the layout of the holistically articulated ideas can be recalled at a later date. More importantly, the holistic view clearly identifies information gaps that require new research and provincial policy issues that require resolution. Finally, the cards are removed from the wall and processed through a group-based thematic analysis workshop.⁶ Resulting themes are used to inform a plan that advises the Regional Health Authority on potential service adaptations and an evaluation plan for adaptation activities.

Outcomes and Impact

Since 2008, nine of 11 Regional Health Authorities (six of seven MMF Regions) have engaged in MMF Region Knowledge Networks and are at various stages of completion in their first Knowledge Network cycle. Several have completed their first cycle of chronic diseases interpretation and now are moving to the next cycle to examine *Métis Atlas* child health and education results. Knowledge Network-determined research is underway or completed for five quantitative age and sex-specific studies and two community-based qualitative projects (involving eight Métis communities).

Ongoing provincial funding for the MMF-Health & Wellness Department central management of Knowledge Networks has been achieved, and a five-year Chronic Diseases surveillance program has been funded by the

⁶ Bartlett J.G., Iwasaki Y., Gotlieb B., Mannell, R., Forcythe, S., Hall, D., "Framework for Aboriginal-Guided Decolonizing Research involving Métis and First Nations Persons with Diabetes," *Social Science & Medicine* 65 (2007): 2371-2382.

Public Health Agency of Canada. A Provincial Métis Health Policy-Knowledge Network, which will use the same process, is planned to start early next year. Although not yet fully evaluated, the “Métis Need to Know Too” Knowledge Translation model has shown significant promise as a method of creating strong and sustainable health planning engagement between MMF Regions and their affiliated Regional Health Authorities.

Although Knowledge Networks were developed to influence Regional Health Authority services, MMF Regions are finding outcomes useful in their own social and economic program planning. Both MMF Regions and Regional Health Authorities are committed to continuing the process.

Lessons Learned

Knowledge Networks are geared toward the needs of Regional Health Authorities. Some of these are straightforward, while others are very complex. For example, the Winnipeg Regional Health Authority plans services centrally but organizes its work into 13 Winnipeg Community Areas, each with a Community Area Coordinator. The MMF Winnipeg Region-Knowledge Network logically began its activity in a Community Area with poorer Métis health. After getting to the point of needing to create an adaptation plan, it became apparent that there was no mechanism to transfer the Métis-specific knowledge to central planners. The solution is a two-pronged approach: first is the creation of a Winnipeg-wide MMF Winnipeg Region's “Community Area Coordinators” Knowledge Network, followed by Community Area-based Knowledge Networks. While the Community Area Coordinators Knowledge Network is able to influence central planners, the Community Area Knowledge Networks allows Métis citizens belonging to Winnipeg-Region Métis Locals and local community area health service providers to engage in planning to adapt existing service.

SUMMARY

Context: Research and Knowledge Translation

Location: Manitoba, Canada

Method of Engagement: Nine MMF-Region Knowledge Networks (six to ten members).

Who was Engaged: ~150 Métis citizens in six of seven MMF-Regions, nine of 11 Regional Health Authorities.

Topic: Interpretation of Chronic Diseases Research and the Adaptation of Programs and Services.

To Whom Were the Results Reported: MMF Regions; MMF Annual General Assembly and Provincial Regional Health Authorities; and Métis citizens.

Methods of Dissemination: Knowledge Networks discussion tables.

Lessons Learned: Holistic framework and Knowledge Translation model useful in moving research information to action. Winnipeg-Region Knowledge Network approached in a two-pronged manner due to Winnipeg-Regional Health Authority complexity.



Canadian Blood Services' Stakeholder Engagement for Organ and Tissue Donation

Canadian Blood Services

Chris Brennan, Manager, Stakeholder Relations and Communications - Organs and Tissues

Introduction

9

Despite numerous reviews in the past and some areas of excellence across the country, Canadian organ and tissue donation and transplantation (OTDT) performance nation-wide has remained unacceptably low and essentially unchanged for more than a decade. Almost 4,000 Canadians are currently waiting for an organ transplant that will save their life, while thousands more are waiting for cornea transplants to restore their sight.

In 2008, recognizing an opportunity to improve both system efficiencies and patient outcomes, the Federal, Provincial and Territorial (FPT) Ministries of Health asked Canadian Blood Services to take on a new mandate related to OTDT. Included in this mandate was responsibility for developing a plan for an integrated OTDT system that would improve donation and transplantation performance in Canada.

Given the wide stakeholder group, the independent nature of existing organizations and functions, the lack of comprehensive information about OTDT in Canada, and the diverse opinions in the OTDT communities, Canadian Blood Services decided to build extensive stakeholder engagement into its planning process.

Methods

From its inception, the stakeholder plan was three-pronged, using a parallel process to focus on three groups: OTDT health professionals, patients and the public. The information and perspective gleaned from these groups helped Canadian Blood Services identify the system design elements that have the potential to achieve breakthrough performance. This case will focus primarily on the public engagement aspects of the plan.

Health professionals

Three external committees were struck to guide the overall design work for a new system. One was a Steering Committee comprised of distinguished academics, medical administrators, and health policy experts. The other two were committees of experts—one focused on organs, the other on tissues—comprised of physicians, surgeons, representatives from organ procurement organizations and tissue banks, and other experts. These committees also helped navigate the broader health policy aspects of designing the new system.

Patient groups

Canadian Blood Services conducted extensive outreach to patient groups to ensure that their perspective was reflected in the conclusions and solutions being developed.

This process included developing strategic partnerships with national and regional organizations that collectively represent millions of Canadians. These organizations were engaged throughout the process via one-on-one sessions, group roundtable meetings, teleconferences and newsletters. Along with organ and tissue recipients, these organizations validated and challenged the observations and opinions expressed by those working in the system, providing strong input into the principles that should guide and underpin ODTD system reform.

Public involvement

Canadian Blood Services has always valued public involvement in the operation of the blood system. Since its inception, the organization has ensured that interested publics have an opportunity to contribute to decision making on issues related to the blood system through its national and regional liaison committee structure and open board process.

Building on this practice, Canadian Blood Services reached out to the Canadian public to gather input on the strategy and system design being developed to improve ODTD performance in Canada.

A series of nine public dialogues were held in key locations across the country. During sessions in London, Vancouver, Edmonton, Halifax, Winnipeg, Regina, St. John's, Moncton and Toronto, hundreds of Canadians representing diverse viewpoints and experiences provided candid feedback on their expectations of an effective ODTD system.

Dialogues were publicized through local advertising and media outreach. Local patient groups and networks were tapped to ensure their members were aware of the opportunity, while national patient groups assisted with communicating the information to their chapters and branches. Service organizations, health networks, religious institutions, colleges and universities, community centres, libraries, and other local resources were also contacted.

The dialogues included recipient and donor family speakers, as well as interactive learning sessions where the current state of the system was discussed. Participants then broke into breakout groups to discuss specific aspects in greater depth before presenting the results of those discussions back in plenary for further consideration.

In support of the public dialogue process, Canadian Blood Services launched a multi-media campaign to invite even broader opinions and insights. A "Kitchen Table Conversation Kit" was developed and published online to allow interested individuals and community groups to convene their own ODTD discussions. Participants were then invited to send their results to Canadian Blood Services.

An information website was also launched to help the public keep up-to-date on developments and to share information with their communities and Canadian Blood Services. All the information from that site, including summary reports from all the public dialogues, is available at organsandtissues.ca.

In many cases, members of the public validated the opinions and impressions brought forward by the expert community, but their contributions also helped to emphasize particular areas of concern or those that needed further consideration. As a result, the public brought a unique and necessary perspective to the work, and its importance cannot be understated.

Outcomes and Impact

Broad engagement yielded a number of benefits. It:

- gave the Canadian public (the ultimate beneficiary of this system) an opportunity to influence healthcare development;
- brought together a disparate community and achieved remarkable consensus about a vital component of the healthcare system;
- helped facilitate a collaborative relationship between OTDT-related patient groups;
- provided an opportunity to educate Canadians about the realities, challenges and disparity of the current state of the OTDT system;
- allowed Canadian Blood Services to learn from the experiences of the Canadian public;
- identified a group of extremely committed public champions; and
- resulted in a strategic plan (currently under assessment by Canadian governments) that is acknowledged to have overwhelming support and momentum from the community.

In addition to these benefits, broad engagement also created expectations and obligations of all stakeholders in the system. In particular, it:

- **raised** the expectation of the community for ongoing collaboration and engagement; and
- **created** high expectations of Canadian Blood Services and its commitment to transparency.

Lessons Learned

With regards to its public engagement efforts, Canadian Blood Services quickly learned that the focus ought not to be on the “general” public but rather the “informed” public—those with a personal connection to the issue who bring to the dialogue process experience, passion and a constant reminder of whom the system must serve.

A multi-media approach was necessary to take advantage of the many grassroots inroads that could be taken with this community. Unlike its experience with the blood system—where a quarter of a million people actively participate—Canadian Blood Services realized that its mandate in OTDT required new thinking and strategies for engagement. Social media mechanisms that leverage “word-of-mouth” and “who-you-know” methodologies will no doubt become a staple going forward.

Throughout the engagement process the “interested” public demonstrated a remarkable ability to absorb complicated scientific and ethical issues, and in turn, generate thoughtful and well-informed opinions. Perhaps this is the key lesson from this process and evidence of why the public ought to be engaged in health system consultation. Canadians have strong and passionate expectations about their healthcare system and welcome a rich dialogue about its future.

SUMMARY

Context: Health system consultation

Location: Across Canada

Methods of Engagement: Face-to-face consultations (conferences, teleconferences and one-on-one), public dialogues, roundtable discussions, newsletters, webinars, websites, and discussion tools (kitchen table discussion kit).

Topic of Engagement: Improving organ and tissue donation and transplantation performance in Canada

To Whom Were the Results Reported: Federal, provincial, and territorial ministries of health.

Lessons Learned: Relationship building is essential and it takes a substantial amount of time; it is not necessarily the number of people that are engaged that matters, but the interest and passion of the participants; it is not necessarily easier to engage a smaller group—in fact, it may require different methods of engagement; do not underestimate the public's ability to provide valuable input into health system consultation.

Human Tissue Biobanking in B.C

Michael Burgess (UBC); Kieran O'Doherty (University of Guelph);
David Secko (Concordia U)

Introduction

10

Biobanks are large collections of human biological tissue that are used for research, but they may also contain varying amounts of other health-related data, including clinical, medical and personal health histories. Due to the sensitive nature of this material, there are ethical complications to the use of Biobanks for research. Researchers at the W. Maurice Young Centre for Applied Ethics, University of British Columbia, have conducted two deliberative forums on the topic of human tissue biobanking: *The BC Biobank Deliberation* (2007) and the *BC BioLibrary Deliberation* (2009). The events were funded by Genome Canada/BC, CIHR, the PROOF (Prevention of Organ Failure) Centre of Excellence, and the BC BioLibrary. In both cases, members of the public from across British Columbia were invited to participate in two weekends of deliberation that would inform policy and practice on biobanks. The task of the participants in these forums was to consider the ethical and social implications of biobanking and to formulate recommendations for policy makers

Methods

Both deliberations were conducted using several core design elements and principles from deliberative democracy. Twenty-five demographically stratified participants from across British Columbia were randomly invited to the forums for four days of deliberation.¹ The first day of deliberation was primarily dedicated to informing participants about the topic and introducing them to the practice of deliberation. Information on the topic was provided through an information booklet written specifically for the event, along with additional key readings from the academic literature, presentations from speakers who were either experts or represented key stakeholder groups, and teaching aids such as a physical model representing biobanking processes.² Efforts were made to present a balanced and complete range of the available perspectives on the subject. Deliberation was conducted in small (7-9 individuals) and large (all participants) groups. While deliberation aimed at consensus, facilitators were instructed not to gloss over any disagreements. Rather, if disagreements persisted in spite of deliberation, they were to be clearly articulated and documented.

Beyond this, the two events differed in structure and outcomes. Whereas the 2007 Biobank Deliberation aimed to document underlying public values that could guide biobanking policy, the 2009 BioLibrary Deliberation intended to provide more detailed public advice that was targeted towards the ethical protocols and governance structures of the BC BioLibrary (a publicly funded organisation acting as an umbrella across

¹ Longstaff, H., & Burgess, M. M., "Recruiting for Representation in Public Deliberation on the Ethics of Biobanks," *Public Understanding of Science* 19.2 (2010): 212-224.

² MacLean, S., & Burgess, M. M., "In the Public Interest: Assessing Expert and Stakeholder Influence in Public Deliberation about Biobanks," *Public Understanding of Science* 19.4 (2010): 486-496; and Wilcox, E., "A Lego Model to Help Inform Participants at the British Columbia Biobank Deliberation," *Health Law Review* 16.4 (2008): 9-11.

several biobanks).³ In the 2007 BC Biobank Deliberation, participants' first deliberative task was to discuss their hopes and concerns about biobanking. Their second and more substantive task was to develop a conceptual design for a hypothetical biobank in BC. In the 2009 BC BioLibrary Deliberation, participants discussed five specific pre-determined topics: the collection of biospecimens; initial contact/ introducing the Biobank; linking samples to personal information; consent; and the governance of biospecimens and associated data.⁴ The five topics were chosen based on the particular needs of the BC BioLibrary for establishing ethically sustainable protocols, standard operating procedures, and governance structures.

In line with the different structures of the two deliberations, the results took different forms. The outcomes of the 2007 BC Biobank Deliberation were broad recommendations from the group across a large range of issues with different levels of agreement and disagreement.⁵ The 2009 BioLibrary Deliberation achieved more specific recommendations on the particular topics presented for deliberation.⁶ In both deliberations, the final outcomes (whether reflective of consensus or some degree of disagreement) were fed back to deliberants for ratification.

Outcomes and Impact

The results, methods, and analyses of various aspects of the deliberations have been published in several peer-reviewed papers.⁷ Beyond the peer-reviewed literature, the most immediate effect of the deliberations was on the practices of the BC BioLibrary, which had made an *a priori* commitment to public engagement in establishing its organisation. Since the BioLibrary is a coordinating body for many biobanks in British Columbia, it is anticipated that its adopted practices will influence individual biobanks. Moreover, several senior members of the BC BioLibrary are involved in other biobanks across Canada, leaving open the possibility that effective governance mechanisms used in BC will be transferred to other parts of Canada. In addition, members of the research team sit on various ethics or advisory boards and incorporate the findings through their role in the regulation of biobanking practice.

An unexpected outcome of the deliberations was that participants of the forums have since been recruited to act as community members on biobank boards or advisories (a member of the 2007 Deliberation was invited to sit on the BioLibrary governance oversight committee, and one of the 2009 Deliberation participants now serves on a national ethics advisory committee). Since forum participants have been exposed to a diversity of

³ For more on the BC BioLibrary, please see <http://www.bcbiolibrary.ca/>

⁴ O'Doherty, K. C., & Hawkins, A., "Structuring Public Engagement for Effective Input in Policy Development on Human Tissue Biobanking," *Public Health Genomics* 13.4 (2010): 197-206.

⁵ Burgess, M., O'Doherty, K., & Secko, D., "Biobanking in British Columbia: Discussions of the Future of Personalized Medicine through Deliberative Public Engagement," *Personalized Medicine* 5.3 (2008): 285-296; and O'Doherty, K., & Burgess, M., "Engaging the Public on Biobanks: Outcomes of the BC Biobank Deliberation," *Public Health Genomics* 12.4 (2009): 203-215.

⁶ O'Doherty, K. C., Ibrahim, T., Hawkins, A. K., Burgess, M. M., & Watson, P. H., "Managing the Introduction of Biobanks to Potential Participants: Lessons from a Deliberative Public Forum," *Biopreservation and Biobanking* (Forthcoming).

⁷ See Longstaff, H., & Secko, D., "Media Influence on Biobank Deliberations," *Journal of Health & Mass Communication* 2 (2010): 73; O'Doherty, K. C., & Davidson, H. J., "Subject Positioning and Deliberative Democracy: Understanding Social Processes Underlying Deliberation," *Journal for the Theory of Social Behaviour* 40.1 (2010): 224-245; Secko, D.M., Preto, N.S., Niemeyer, S., & Burgess, M.M., "Informed Consent in Biobank Research: A Deliberative Approach to the Debate," *Social Science and Medicine* 68.4 (2009): 781-789; Walmsley, H.L., "Mad Scientists Bend the 'Frame' of Biobanking Governance in British Columbia," *Journal of Public Deliberation* 5.1 (2009): Article 6; and Walmsley, H. L., "Stock Options, Tax Credits or Employment Contracts Please! The Value of Deliberative Public Disagreement about Human Tissue Donation," *Social Science & Medicine* 73.2 (2011): 209-221.

views and perspectives on biobanking and its potential effects on the community, they have the unique quality of being able to represent a range of viewpoints on an issue about which there is relatively little public awareness.

The main influence of the deliberations to date, however, seems to be the uptake of the methods of public engagement. This makes sense, since the BC deliberations explicitly sought to give voice to the values of the citizens and residents of British Columbia. Achieving similar political legitimacy in other jurisdictions thus required the implementation of similar forums involving local participants. The design of the BC Biobank Deliberation was subsequently applied in two other contexts with only minor differences. The Mayo Clinic (Rochester, Minnesota) used the design to conduct a deliberative forum in late 2007 involving citizens of Olmstead County to inform the ethical protocols and governance of a Mayo Biobank. In Western Australia, the Office of Population Health Genomics (Department of Health) was tasked with developing a position statement on biobanking. The Office involved several stakeholder groups in the development of this document and also used the design of the BC Biobank Deliberation with minor amendments in 2008 to consult citizens of Western Australia to inform their policy.⁸

Lessons Learned

One of the characteristics of the deliberation structure of the 2007 BC Biobank Deliberation was that discussion was relatively unstructured. This was a conscious decision in response to criticisms of public engagements conducted in the context of UK Biobank, which had argued that narrow framing of issues did not allow for meaningful consideration of public concerns. The BC Biobank Deliberation was designed to allow for in-depth consideration of issues that emerged from participants' discussions.

As a consequence, however, the results of these deliberations were very broad, making translation into policy difficult. For example, a recommendation of the forum focused on the importance of protecting donors' privacy while not making these restrictions so strict that they excessively impede research. The tension between privacy protection and research facilitation is well-recognised in the academic literature on biobanking, but beyond the observations that a public forum also recognised this dilemma, the recommendation does not provide specific input on how to navigate this issue. The design of the BC BioLibrary Deliberation conducted in April 2009 included changes to address these and other challenges.

A further problem identified in the 2007 Biobank Deliberation pertained to the concluding session of the deliberation. The deliberative event was structured in such a way that the participants were divided into three small groups, each of which came up with its own recommendations on issues they felt were most important. The purpose of the final session was to integrate the recommendations of the three separate groups into one coherent set of results. This was only partially successful because only a small proportion of the issues that were discussed in the small groups over the course of the event could be covered in this final discussion. This failure was a result of more than insufficient time. Many participants expressed frustration at having to

⁸ Molster, C., Maxwell, S., Youngs, L., Potts, A., Kyne, G., Hope, F., et al., "An Australian Approach to the Policy Translation of Deliberated Citizen Perspectives on Biobanking," *Public Health Genomics* (forthcoming).

revisit arguments that they had already covered in detail in their small groups. In many instances, deliberation in the final large group discussion faltered over misunderstandings, and confusion and disagreement arose regarding different meanings attached to terminology.⁹

The design of the 2009 BioLibrary Deliberation included refinements to successfully overcome this problem. In particular, discussions in the small groups were limited to an exchange of views only, without facilitators guiding deliberations towards group consensus. The small group discussions thus served to help people explore and articulate their own views on a particular aspect of biobanking, while also exposing them to the views of others in the group. The goal of reaching agreement on particular recommendations on biobanking policy was reserved exclusively for discussion in the large group. This strategy proved to be effective in that the considerations of the full complement of deliberants was brought to bear on all issues, and none of the participants expressed frustration at having to revisit particular arguments or discussions.

SUMMARY

Context: Research

Location: Vancouver, British Columbia

Method of Engagement: Deliberative forum

Who was Engaged: 25 members of the general public (random selection; demographically stratified).

Topic of Engagement: Human tissue biobanks.

To Whom Were the Results Reported: biobank community members; academic audiences; and policy makers.

Methods of Dissemination: Posted on website, directly e-mailed to a small number of stakeholders, and academic publications.

Lessons Learned: The events illustrate a theoretically informed methodology that includes diverse participants in well-informed and deliberative health policy discussions.

⁹ Walmsley, H. L., "Biobanking, Public Consultation, and the Discursive Logics of Deliberation: Five Lessons from British Columbia," *Public Understanding of Science* 19.4 (2010): 452-468.

Share your Story, Shape your Care—Engaging Northwestern Ontario

North West Local Health Integration Network, Thunder Bay, ON
Kristin Shields
Senior Consultant, Planning and Community Engagement

Introduction

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Mandated to plan, fund and integrate local health services, the North West Local Health Integration Network (LHIN) is one of 14 LHINs in Ontario. The North West LHIN covers 47% of Ontario's landmass, and with a dispersed population of only 235,000 residents, innovation in the use of local networks and communications channels is required.

To identify the priorities for the LHIN's *Integrated Health Services Plan (IHSP) 2010-2013* and inform local decision making, extensive community engagement was undertaken.¹ This was accomplished through the *Share your Story, Shape your Care* initiative by:

- stimulating community dialogue and deliberation on health issues;
- providing an interactive learning experience about key health challenges for participants;
- gathering information on values, priorities and informed choices; and
- identifying local innovations and community “success stories.”

Stakeholders included health service providers, general public, community leaders, academics and many others identified in the *North West LHIN's Community Engagement Strategy*.² Given the large geography, dispersed population, travel challenges (particularly in winter), and the need to reach as broad a group as possible, the North West LHIN embarked upon its *Share your Story, Shape your Care* initiative. This engagement project combined online deliberation, grassroots communications and face-to-face meetings in order to maximize participation and input.

Methods

To develop these products, key informant interviews were completed to ensure overall quality, relevance, clarity, and ease of navigation of the tools. A number of advisory teams were also involved in these reviews. Interview and advisory team participants proved to be excellent champions in encouraging their colleagues, clients and friends/family to participate.

¹ *The Integrated Health Services Plan* identifies local priorities for health system improvements and sets out plans to address these priority health care issues. A copy of the plan is available at: http://www.northwestlhin.on.ca/integratedhealthserviceplan.aspx?ekmensele2f22c9a_72_204_btnlink

² Health Services Providers included regulated and unregulated health professionals and workers who provide care in both LHIN-funded and non-LHIN funded agencies. More on the LHIN's Community Engagement Strategy (which is reviewed and updated annually as required), can be found at: http://www.northwestlhin.on.ca/Page.aspx?id=146&ekmensele2f22c9a_72_184_146_3

Communications planning occurred in the six weeks preceding the launch of Share your Story, Shape your Care. This allowed for the identification of local communications channels and preferences, as well as champions in communities and sectors, across Northwestern Ontario. Contact within geographic and cultural communities was widespread, with all local school boards, seniors' centres, faith-based organizations, municipal councils, First Nations Chiefs, Health Directors, professional colleges and associations, and libraries being contacted to identify how best to inform potential participants of this opportunity. A multimedia communications strategy—from a Facebook campaign to posters in local coffee shops—encouraged individuals to have their say. Close monitoring allowed targeted marketing to have participation reflect key demographics.

The primary engagement tool of the *Share your Story, Shape your Care* project was an online Choicebook™ and a suite of online tools that were co-developed and supported by Ascentum.³ Participants received information about local health care needs and priorities, and they were encouraged to express their views on these topics through an online discussion board. A YouTube video, blog, and online resource section were also made available, and participants could choose to receive paper copies of the Choicebook™. Finally, a conversation guide was developed to support community-led discussions.

Outcomes and Impact

Over 800 individuals participated in the *Share your Story, Shape your Care* initiative between January and April 2009. An additional 100 participants submitted paper copies between April and June of the same year. Through the collection of online and paper Choicebooks™, over 190,000 words were submitted, providing extensive qualitative information for planning and identifying priorities for the North West LHIN.

The priorities highlighted in the *North West LHIN's Integrated Health Services Plan* directly reflect those identified through this engagement process. Although some of the priorities included were outside of the direct mandate of the LHIN (such as primary care, with the exception of Community Health Centres), they remained local priorities due to strong support by local residents.

Results of the *Share your Story, Shape your Care* initiative were shared directly with participants and broadly with those living in Northwestern Ontario. Participants were able to request personalized reports comparing their responses with district and regional results. Summary and full reports were made available to LHIN advisory team members, contacts in the LHIN's database, and all participants who requested them. Results were also posted online.⁴

In 2009, the *Share your Story, Shape your Care* project was awarded the International Association for Public Participation's (IAP2) Core Values Award of the Year for "Innovative Use of Technology."

³ Ascentum is a consulting firm that specializes in in-person, online and social media engagement tools. For more information, see www.ascentum.ca.

⁴ All resources are available at http://www.northwestlhin.on.ca/publicationandreports.aspx?ekmense=e2f22c9a_72_206_btnlink

Lessons Learned

There were many lessons learned during this project, including the value of human contact and personal messaging to support online engagement, the use of technology to overcome many barriers (such as geography, weather, dispersed population, and participants' desire for anonymity) and the importance of recognizing the unique needs and strengths of local groups and communities.

Providing face-to-face support and in-person messaging was essential to the success of this project. The two primary reasons that people participated in *Share your Story, Shape your Care* were because the issue was important to them and/or they were encouraged to participate by someone whom they respect. Providing formal and informal leaders with both education about the project and messaging to communicate with their contacts enabled them to be the true champions of this work.

There is a belief among some that online technologies are not effective means of communication in rural and remote settings, but this was not our experience. Providing an opportunity for people to participate online gave everyone an equal chance to be involved, regardless of their location, age or socioeconomic status. This allowed us to reach those who—due to access issues (such as geography, timing, intimidation with a group setting, or the desire to remain anonymous)—would otherwise be unable or unwilling to attend a traditional meeting. It was, however, important to overcome challenges in accessing technology by:

- providing paper copies to those who required them;
- developing conversation guides for those who felt more comfortable participating in a session hosted by a trusted contact;
- encouraging health service providers to support the participation of clients/residents/patients by providing internet access, paper copies or completing the Choicebook™ with them; and
- asking local libraries and other organizations to change their homepage to the *Share your Story, Shape your Care* platform and/or advertising in those locations where the public accesses the internet.

Each community had preferences for communicating about this project. Working with representatives of these groups enabled the creation of tailor-made communications and identified the best means to advertise. Inclusion in local newsletters, church bulletins, community newspaper articles and community-wide mail drops supported broad awareness, and ensured that communications reached a wider range of participants.

SUMMARY

Context: Engagement to support priority-setting

Location: Northwestern Ontario

Method of Engagement: Online and paper Choicebook™, conversation guide and face-to-face.

Who was Engaged: Over 900 health service providers and members of the general public.

To Whom Were the Results Reported: Participants, general public, all individuals in contact database.

Methods of Dissemination: Personalized and reports (summary and full versions), broad direct email, posted on website, and academic publications.

Lessons Learned: The value of human contact and personal messaging to support online engagement, the use of technology to overcome many barriers, and the importance of recognizing the unique needs and strengths of local groups and communities.

Consulting Ontario Citizens to Inform the Evaluation of Health Technologies: The Citizens' Reference Panel on Health Technologies

Health Quality Ontario (HQO)

Julia Abelson, Ph. D, McMaster University, F. Wagner, MHSc, University of Toronto, L. Levin, MD, Ministry of Health and Long-Term Care, Head, Medical Advisory Secretariat, Y. Bombard, PhD, Yale University and Memorial Sloan Kettering Cancer Center, F-P. Gauvin, PhD, National Collaborating Centre for Healthy Public Policy, D. Simeonov, MSc, Institute for Clinical Evaluative Sciences, S. Boesveld, MSc, Doctoral student, McMaster University

Introduction

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In December 2008, a 14-member Citizens' Reference Panel on Health Technologies (CRPHT) was established to inform the work of the Medical Advisory Secretariat (MAS) and the Ontario Health Technology Advisory Committee (OHTAC), which produces evidence-based recommendations regarding the use of health technologies throughout Ontario's health system. One of the panel's specific goals was to elicit the societal and ethical values that should guide OHTAC in developing its recommendations. The creation of the CRPHT represents an early experimentation with a deliberative engagement method in order to incorporate public values and citizen perspectives into the expert-driven health technology assessment processes.

Methods

Participant recruitment

A civic lottery methodology was used to recruit the panel.¹ Thirty-five hundred Ontario residents were mailed an invitation letter, information sheet and postage-paid response form. From this sample, 163 expressions of interest in panel membership were received, from which 14 panel members—selected by geographic region and stratified by gender and age, with one participant coming from each of Ontario's 14 Local Health Integration Network regions—were selected blindly from the respondent pool. All travel expenses associated with meeting attendance were covered and each panel member received a \$65 honorarium after attending each meeting.

Deliberative discussions

The 14-member panel was convened for five one-day meetings at McMaster University in Hamilton, Ontario, between February 2009 and May 2010. At each meeting, panel members participated in structured dialogues covering two broad topic areas:

- 1) the core values that should guide the evaluation of health technologies—when and by whom should this be done?; and

¹ Dowlen, O., Sorted: *Civic Lotteries and the Future of Public Participation* (Toronto: MASS LBP, 2008).

- 2) reviews of selected health technologies (e.g., screening for colorectal and breast cancer, serological testing for celiac disease, and personalized medicine) to provide ethics and social values input to OHTAC deliberations.

The technologies selected for discussion at each meeting were jointly agreed upon by the research team, Medical Advisory Secretariat staff and OHTAC members.

Background material about each deliberation topic—including research summary and media articles, a workbook with topic summaries, and a set of discussion questions—was circulated one week before each meeting. Meetings began with an introduction to each topic, a brief summary presentation by the meeting facilitator or invited guest expert, and a question and answer session. Following the presentation, large and small groups held either externally- or self-facilitated discussions of questions that had been circulated prior to the meeting. Representatives from MAS and OHTAC attended two of the five meetings to describe the MAS-OHTAC process, to explain the rationale for the creation of the Citizens' Panel, and to answer questions from panel members.

Each of the five CRPHT meetings generated two types of outputs to inform MAS-OHTAC deliberations regarding the evaluation of selected technologies:

1. Qualitative reflections on a set of pre-circulated questions designed to elicit societal and ethical values related to the technology under review.
2. Pre- and post-meeting survey results of panel member rankings of the societal and ethical values central to the technology under review.

Examples of the "moral" questions reflected on by panel members for each technology included (but were not restricted to) considering how (or does) the technology:

- demonstrate respect for religious, social or cultural convictions?
- affect the distribution of health care?
- challenge patient autonomy?
- ensure that human dignity is respected?²

Despite slight variances across technologies, "universal access," "choice," and "quality care" were identified as core values that should be considered in both the evaluation of health technologies and the ensuing recommendations.³

A thematic summary of panel discussions was prepared in either report or presentation format following each panel meeting. It was then shared with OHTAC members for discussion at monthly OHTAC meetings.

² The list of moral questions for health technology assessment was adapted from Hofmann, B., "Toward a Procedure for Integrating Moral Issues in Health Technology Assessment," *International Journal of Technology Assessment in Health Care* 21.3 (2005): 312-318.

³ Bombard, Y., Abelson, J., Simeonov, D., Gauvin, F-P., "Eliciting Ethical and Social Values in Health Technology Assessment: A Participatory Approach," *Social Science and Medicine* 73.1 (2011): 135-144.

Outcomes and Impact

While tangible policy impacts are rarely observed in time-limited studies of this kind, there were some impacts observed over the course of this two-year project. Since it used social values and ethics data to inform its work, the CRPHT provided new insights in these areas to MAS and OHTAC. Panel input was also used explicitly in OHTAC deliberations for three of the five technologies reviewed.

Based on direct reports back to the CRPHT about how participant input was used, most panel members felt that their input was valued by OHTAC. Attendance of senior MAS/OHTAC officials at two CRPHT meetings, combined with the open invitation for CRPHT members to attend an OHTAC meeting so that they could provide their input on the value of the panel model, instilled further confidence among participants about the panel's perceived value to the two organizations. Other panel members believed the CRPHT's work had minimal influence but felt it was an crucial step to increasing the awareness of MAS and OHTAC about the importance of incorporating public values into these types of decisions.

Lessons Learned

Panel members rated the citizens' panel structure and organization very highly in all post-meeting evaluations. The adequacy of time provided for appropriately detailed discussion around certain topics was viewed slightly less favourably than other panel features.

A debriefing session was held at the final CRPHT meeting, followed by telephone interviews to allow panel members to reflect more deeply on their experiences (summarized in *Table 1*). Panel members unanimously called for the panel to continue and felt that it was just beginning to hit its stride.

Table 1: Assessment of strengths and challenges (source: CRPHT members)

Strengths	Challenges
<ul style="list-style-type: none"> ● Integration of input from a wide range of perspectives (citizen included) to contribute to provincial policy making ● Meeting its objective to provide citizen input on societal and ethical issues ● Facilitation of meetings kept the group on track and encouraged participation from all members ● Use of small groups to provide a platform for all members' input ● Arm's length relationship between CRPHT and MAS/OHTAC ● Sponsor's attendance at CRPHT meetings (re-affirmed panel role and contributions) ● Raising awareness of the importance of incorporating public input into the HTA process ● Creating a model for public involvement in HTA that can be improved upon in the future 	<ul style="list-style-type: none"> ● Informational requirements: "going into it cold" and the large quantity of information to take in during the session ● Discussions "meandered" or were "monopolized" at times ● Challenging to feel part of the panel again at each meeting given the time between them ● Size and representativeness of panel ● Role confusion ● Communication between citizen's panel and sponsor

Several specific suggestions were made to improve the panel's structure, processes and impact:

1. Increase the frequency of meetings, and consider alternative (and additional) communication vehicles.

A shorter gap between meetings (no more than 2 months) was recommended to make it easier for panel members to re-immense themselves in the material and to improve how the CRPHT's functioned. Face-to-face meetings could continue to be used as the dominant interaction medium, but additional media such as the internet, teleconferences and video conferencing also should be explored as a way of complementing face-to-face meetings

2. Ensure adequate attendance at each meeting, and expand the size and reach of the panel.

Panel members expressed concerns about ensuring both a critical mass of participants and balanced representation across age and gender (minimum) at each meeting. Ultimately, this yielded several suggestions:

- Alternates for each of the 14 panel members should be selected, or the panel's size should be expanded.
- The work and reach of the panel should be complemented by surveys, mini-panels or focus groups on selected topics.

3. Improve the clarity of roles and activities for CRPHT.

A clearly articulated purpose for these types of panels is essential, and it needs to be re-affirmed and revised periodically. This ensures that the panel reflects the thoughts of panel members and sponsors about how best to use it, but it also clarifies the panel's role relative to the sponsors, ensuring that it contributes meaningfully to their deliberations.

4. Clarify and strengthen the supporting infrastructure of CRPHT and the interface between CRPHT and sponsoring organizations.

An adequate infrastructure for the panel was viewed as critical to sustaining it over time. More specifically, a number of roles need to be formalized and nurtured to establish an effective and efficient interface, including:

- content expertise to inform the preparation of materials for CRPHT meetings and relevant technology-specific discussions; and
- a strong liaison function to ensure that potential topics for CRPHT meetings are identified in a timely manner and that input from the citizens' panel is effectively integrated into MAS and OHTAC deliberations.

SUMMARY

Context: Social values elicitation to guide health technology advisory decisions.

Location: Ontario (McMaster University)

Method of Engagement: Citizens' Reference Panel (five structured deliberations)

Who was Engaged: 14 Ontario citizens (one from each Local Health Integration Network region)

Topic of Engagement: social and ethical values guiding health technology assessment and related policy decisions.

Collaborating/sponsor organizations: Ontario Ministry of Health and Long-Term Care (Medical Advisory Secretariat); and Ontario Health Technology Advisory Committee (OHTAC).

Impacts: Informed evidence-based recommendations; regular reporting to MOHLTC and OHTAC; and academic publications.

Lessons Learned: A carefully designed citizens' reference panel with a clear purpose and coordinated linkages to an expert advisory body can usefully inform health technology advisory decisions.



The Eastern Health Patient Advisory Council for Cancer Care

Province of Newfoundland

Lisa Adams, RN, BN, BSc, MSc, PhD ©, CHE, CPMHN

Project Leader- Cameron Inquiry

Introduction

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In the summer of 2005, Eastern Health in Newfoundland and Labrador identified a potential problem in the accuracy of hormone receptor tests conducted for breast cancer patients. A review was undertaken to identify all breast cancer patients with negative estrogen receptor (ER) results who had been tested between 1997 and 2005. This review included breast cancer specimens from living and deceased patients. Specimens were sent to the Laboratory in Mount Sinai Hospital in Toronto, Ontario, for re-testing.

The Commission of Inquiry (COI) on Hormone Receptor Testing was created to facilitate this process, and in 2009, its report—authored by Justice Margaret Cameron—was released. This report outlined many recommendations to address issues with estrogen and progesterone hormone receptor (PR) testing and adverse health event management within the Newfoundland and Labrador health care system. Although not included in the report, the need for a patient advisory council to help oversee the implementation of the report's recommendations was identified by the Eastern Regional Health Authority. This volunteer patient advisory council included the patients, families, surviving spouses, breast cancer support and advocacy groups, and other significant stakeholders who had experienced and/or were involved in the hormone receptor testing events.

Methods

A systematic literature review was undertaken to determine how best to establish a patient advisory council and identify best practices for the council to follow. As the topic of ER/PR hormone receptor testing and the subsequent medical errors had such a wide-reaching effect, it was felt that provincial representation was needed so that all patients and families involved could have a voice in determining how to prevent a similar event from happening again. The formation of a patient advisory council also intended to help restore trust and confidence in the health care system.¹

As this was the first patient advisory council formally developed by Eastern Health, an outside model (developed by Aurora Health) was used as a reference.² In addition to this model, the principles outlined by the Citizens Council of the National Institute of Health and Clinical Excellence in the United Kingdom were

¹ Tharp, B. & Hollar, D., "Engaging Community Members in Health Policy Processes: a Mississippi Example," *Journal of Health and Human Services Administration* 24.4 (2002): 388-400.

² Leonhardt, K., Bonin, D. & Pagel, P., "How to Develop a Community-based Patient Advisory Council" (2008), available from <http://www.ahrq.gov/qual/advisorycouncil/advisorycouncil.pdf> (retrieved February 10, 2010).

also adapted to help guide the institution of this council.³ A draft Terms of Reference was developed—and later modified and approved—based on input from the council members. The membership and objectives of the council also evolved and were refined as the initial meetings took place and the roles and responsibilities of the participants were clarified.

This council was set up as a voluntary group interested in the delivery of cancer care in the province of Newfoundland and Labrador. It was chaired by the Chief Executive Officer of Eastern Health, the Vice President of Quality, Planning and Patient Safety, or the Vice President of the Cancer Care Program for Eastern Health.

Council members were selected using convenience sampling. A core group of health care clinicians and administrators from Eastern Health identified key stakeholders related to the mandate of this council. The events of the COI received a great deal of media coverage, and the identification of key players was not difficult. Stakeholders included cancer support members/leaders, a Canadian Cancer Society representative, patient care advocates, breast cancer survivors, a pastoral care individual, and health care administrators. To ensure provincial representation, all other regional health authorities were invited to identify someone from their geographical area that could participate.

Each patient advisory council meeting included an open discussion of the recommendations being addressed. A total of 5 meetings have occurred to date. The council has also discussed the Memorandum of Settlement between legal counsel and Eastern Health, as well as issues such as and the establishment of academic awards related to cancer research and erecting a monument in memory of those who died because of the hormone receptor testing errors. At each meeting, all council members are provided with an overview of the status of all recommendations, including those that have been completed, those nearing completion, and those not yet started. Barriers and challenges encountered during the process of implementing the recommendations are also mentioned.

The patient advisory council meetings are meant to be highly interactive forums where all members have the opportunity to contribute. A draft report of the minutes and agenda are circulated to all council members for their review prior to the next meeting. Once approved, minutes are posted on the Eastern Health website for public viewing. The council is mandated to meet four times per year, with meetings lasting between two and four hours.

Outcomes and Impact

The 2005 review posed an unforgettable and potentially unprecedented task for Eastern Health, one that challenged the very core of health care delivery for cancer care patients of Newfoundland and Labrador. The loss of public confidence in the province's health care system and the questions regarding its accountability permeated every corner of our society. For some of the patients and their families and loved ones, this

³ National Institute for Health and Clinical Excellence (UK), Citizens Council, available from http://www.nice.org.uk/aboutnice/howwework/citizenscouncil/citizens_council.jsp (retrieved February 10, 2010).

adverse event was a life-changing one. Helping to form the Patient Advisory council was part of the healing experience for some of them, providing the opportunity to help oversee the implementation of the recommendations in Justice Cameron's report and to transform cancer care delivery in the province.

The patient advisory council was initially intended to ensure and oversee Justice Cameron's recommendations, but as the council was refined and strengthened, it became apparent that the council could play a role in overseeing the delivery of cancer care in Newfoundland and Labrador.⁴

To date a total of nine meetings have taken place. Issues of transparency, accountability and communication are key themes that emerged from the COI on Hormone Receptor Testing report, but the very existence of the patient advisory council was just one way that these principles have been entrenched.

To help ensure and increase transparency of the topics and discussions of the patient advisory council, a website for the public was developed that provided information on the council's activities.

Lessons Learned

The biggest challenge faced by this council was overcoming the broad geographical layout of the province of Newfoundland and Labrador. Face-to-face meetings provide a sense of authenticity and presence that facilitates strong working relationships and a productive environment. As a result, while the technology of teleconferencing has helped to establish methods of communication and contact, members of the council are also funded to travel to St. John's on a yearly basis to meet in person. The logistics and costs of this travel have been a challenge.

A partnership between patients, families and health care organization has led to many changes, including the development of physician champions, numerous clinical quality safety leaders, patient navigators, lab audit schedules, clinician rounds, leadership education and, most importantly, a Patient Advisory Council to help ensure these measures were completed. For many, the Council has represented a welcome change, offering increased accountability, close adherence to patient and professional standards of practice, and a venue for open communication. These efforts have aimed to redress the pain and unanswered questions from the past, while strengthening the core of the provincial health care system and embodying Eastern Health's vision of "Healthy Patients, Healthy Communities."

⁴ Johnson, B., Developing and Sustaining Patient Safety and Family Involvement in Safety, available from <http://www.mihealthandsafety.org/2004conference/BevJohnson.pdf> (retrieved February 20, 2010).

SUMMARY

Context: Clinical

Location: St. John's, Newfoundland & Labrador

Method of Engagement: Eastern Health's Patient Advisory Council for Cancer Care.

Who was Engaged: 14 members in total (comprised of five Eastern Health executives and nine members of the general public).

Topic of Engagement: Justice Cameron's recommendations from the Commission of Inquiry on Hormone Receptor testing.

To Whom Were the Results Reported: Quarterly reports to be submitted to both the Canadian Cancer Society Board of Directors (Newfoundland & Labrador) and Eastern Health's Board of Trustees. Various stakeholders and their affiliated organizations and council members also received reports.

Methods of Dissemination: Agendas and minutes were emailed to all members. In addition, they were posted on Eastern Health's website, www.easternhealth.ca.

Lessons Learned: Regaining public trust after a major scandal requires demonstrating that governments are committed to collaboration, open communication, teamwork, and community involvement. Developing groups, such as patients advisory councils where consumer input helps guide the health care system, is one way to restore public confidence in the health care system.

The Toronto Food Policy Council: Twenty Years of Citizen Leadership for a Healthy, Equitable, and Sustainable Food System

Catherine L. Mah, Scientist, Centre for Addiction and Mental Health, and Member,
Toronto Food Policy Council
Lauren Baker, Coordinator, Toronto Food Policy Council

Introduction

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In 2011, the Toronto Food Policy Council (TFPC) celebrated 20 years of citizen leadership in municipal food policy.¹ The TFPC is a useful mature case study and model of citizen engagement in cross-sectoral collaboration for improved population health. Food policy councils are known worldwide as an innovative way to engage citizens in policy making related to the food system, including issues of agricultural production, public health, economic development, community wellbeing, social justice, and environmental sustainability. Over 100 food policy councils, established to identify opportunities for improving the food system, are documented across North America.² Despite food councils being so widespread, however, we have only begun to evaluate their impact, deliberative processes, and capacity from a health perspective.³

Why Citizen Engagement?

Food policy councils were founded in the North American context about three decades ago, but their applicability and popularity has since spread worldwide. They generally operate at the sub-national (local, regional, or province/state) level and include citizen members from diverse perspectives across the food system, from “grow it” (production) to “throw it” (waste management).

Food policy councils have embodied and promoted ideas about the benefits of participatory democracy, namely that citizens can play a meaningful role in policy deliberation on large and complex issues, even when much of the expertise, power, and authority in food systems are all concentrated in higher levels of government and the private sector.

Unlike other broad forms of citizen participation, such as one-time consultation processes, consensus conferences, and other ad-hoc juries or task groups, food policy councils have often sought to establish a

¹ Toronto Public Health, Toronto Food Policy Council (2011), available from http://www.toronto.ca/health/tfpc_index.htm (retrieved July 12, 2011); and Toronto Board of Health, *Minutes: Item HL4.3 from Toronto Food Policy Council 2010-2011 Report and Membership Update*, available online from <http://app.toronto.ca/tmmis/viewAgendaItemHistory.do?item=2011.HL4.3> (retrieved July 12, 2011).

² Community Food Security Coalition, *North American Food Policy Council Webpage*, available from <http://www.foodsecurity.org/FPC/> (retrieved October 31, 2011).

³ See Centres for Disease Control and Prevention (US), *Food Policy Councils* (2010), available from <http://www.cdc.gov/healthyplaces/healthtopics/healthyfood/foodpolicy.htm> (retrieved June 28, 2011); Centres for Disease Control and Prevention (US), *Food Policy Councils Make Healthier Places* (2010), available from <http://www.cdc.gov/Features/Fruits&Veggies/> (retrieved June 28, 2011); and Harper, A., Shattuck, A., Holt-Gimenez, E., Alkon, A., and Lambrick, F., *Food Policy Councils: Lessons Learned* (Oakland, CA: Food First/Institute for Food and Development Policy, 2009).

long-term role in advising decision makers on food issues and advocating for food system reform. That said, the form and functions of food policy councils vary. For example, some are formally embedded in government structures, while others operate outside government.

Methods

History

The TFPC was the first food policy council in Canada. Founded in 1991, the establishment of the TFPC was largely based upon the idea that food and health are intimately intertwined. The gestation of the TFPC began during the 1960s and carried on through the mid 1980s; the impetus to form a food policy council for Toronto was drawn from the Healthy Cities movement (also related to the launch of the Health in All Policies movement), the 1976 UN Convention on Social, Economic and Cultural Rights, and the 1986 Ottawa Charter for Health Promotion.⁴ The founding of the TFPC was influenced by public health advocates such as Trevor Hancock, inspired by key food system thinkers including Tim Lang (at the time with the London Food Commission), and initiated with political support from individuals such as Jack Layton, who was a Toronto city councillor and the Chair of the Toronto Board of Health at the time.

The early work of the TFPC was focused on issues of food security, social justice, and hunger. For example, the TFPC was influential in identifying key food and health issues requiring program and policy attention. In the early 1990s, the TFPC was instrumental in creating FoodShare's Good Food Box program to deliver healthy and affordable local food across Toronto. Through the work of the Food and Hunger Action Committee and a related series of policy papers, municipal grants became available for implementing community food projects. In 2001, as a result of this policy work, the Toronto Food Charter was endorsed by City Council. The TFPC currently works on policy initiatives beyond the municipal jurisdiction, and it undertook considerable research and advocacy related to preventing the use of rBGH in the Canadian dairy industry.

Current structure and role

The TFPC, which operates as a subcommittee of the Toronto Board of Health, is staffed by a full-time coordinator who is an employee of Toronto Public Health. At any one time, the TFPC includes up to 30 members, including city councillors and citizen volunteers drawn from diverse organizational and community backgrounds. These members embody a broad array of thinking about food and health. Current members, for example, come from academia, farming, foodservices and hospitality, dietetics, health promotion, food retail, and marketing, as well as various community, advocacy, and youth organizations. Members apply to participate in the TFPC, with new members approved by the Board of Health once a year. TFPC members are charged with bringing their experience and strategic perspective on food policy issues, and they do not represent their organization or sector.

⁴ Blay-Palmer, Alison, "The Canadian Pioneer: The Genesis of Urban Food Policy in Toronto", *International Planning Studies* 14.4 (2010): 401-16.

Outcomes and Impact

While the TFPC has no formal legislative authority and a modest budget, it has nonetheless had a major influence on food policy in Toronto and beyond, playing a key role in food issue identification, community animation, and advocacy. It is a resource for Toronto City Council when food issues are brought to City committees and council meetings, and it is the community reference group for the new Toronto Public Health-led Toronto Food Strategy. The TFPC also has enabled the formation of the provincial food advocacy network Sustain Ontario, supported the establishment of the world's first Youth Food Policy Council, and been instrumental in serving as a platform for dialogue (including bimonthly public meetings) between diverse food system stakeholders.

Lessons Learned

Reflecting on the foundations and future of the TFPC, key lessons along two themes emerge.

First, the TFPC has been a successful and tangible expression of what is often referred to as “the convening power of food.” While the TFPC has had to continually reflect upon its membership to ensure that it has remained appropriate, strategic, and able to provide input on an array of current and emerging policy concerns, the TFPC has nonetheless demonstrated a consistent capacity for bringing people together across sectors, disciplines, and even political stripes to work on food issues in common. To be relevant, the TFPC has to continue to evolve as a resource to its members—fulfilling networking and professional development needs, as well as facilitating the discussion of issues (including by experts) that are relevant to practitioners and advocates working on food issues.

Second, while the TFPC does not have access to specific municipal policy levers, it has been instrumental in working with communities, policymakers, and city councillors to identify opportunities where policy change is needed and to provide advice. As a policy platform, the TFPC facilitates the expression of community interests, but it cannot directly institutionalize them. Its liaison role, therefore, is one that needs to be supported and cultivated. The TFPC must also continue to balance its deliberations on a broad and growing range of potential food system issues with the strategic identification of specific opportunities for action.

SUMMARY

Context: Municipal Policy

Location: Toronto, Ontario

Method of Engagement: Food Policy Council—food policy councils are known worldwide as an innovative way to engage citizens in policy making related to the food system, including issues of agricultural production, public health, economic development, community wellbeing, social justice, and environmental sustainability.

Who was Engaged: The TFPC was the first food policy council in Canada and celebrated its 20th anniversary in 2011. It operates as a subcommittee of the Toronto Board of Health and is supported by a Coordinator who is an employee of Toronto Public Health. Members of the TFPC include city councillors and citizen volunteers from diverse organizational and community backgrounds who embody a broad array of thinking about food and health. Members do not represent their organization or sector; they are charged with bringing their experience and strategic perspective to the City of Toronto.

Topic of Engagement: Food systems, food security, food and health.

To Whom Were the Results Reported: Toronto Public Health and Toronto Board of Health

Methods of Dissemination: Variety of methods for dissemination and communication, including bimonthly public meetings, special forums, email listservs, a website and blog, social networking sites, and other targeted communications to stakeholders in the city, across Canada, and internationally. The TFPC Coordinator and members also represent the TFPC at various events, meetings, and conferences.

Lessons Learned: 1) Food and food policy councils have a convening power across issues, sectors, disciplines, and even political stripes; and 2) The TFPC is a successful and influential platform, but it needs to balance deliberations on a broad range of food system issues that could be addressed with strategic identification of specific opportunities to act.

For More Information:

Official website: <http://www.toronto.ca/health/tfpc/>

Official blog: <http://tfpc.to/>

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