

# **Engaging with impact:**

## Targets and indicators for successful community engagement by Ontario's Local Health Integration Networks

### A citizens' report from Kingston, Richmond Hill and Thunder Bay

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## A citizens' report from Kingston, Richmond Hill and Thunder Bay

We know that community engagement matters — especially to our public health system. As Ontario's Local Health Integration Networks strengthen their focus on community engagement, what are the common benchmarks and commitments that citizens think matter most?

*Engaging with Impact* addresses the challenge of evaluating engagement and proposes a series of indicators that can be used to assess performance and develop a culture of engagement across Ontario's public health system.

This report features:

*A special essay on the challenge of evaluating deliberative engagement by Professor John Gastil;*

*Two essays comparing the commitment of Canadian and UK health systems to greater community engagement by the Wellesley Institute and the British think tank, Involve;*

*Interviews with the directors responsible for community engagement in the North West, Central and South East LHINs;*

*An account of three Citizens' Workshops that provide the basis for the recommendations in this report;*

*An engagement scorecard for Ontario's LHINs which proposes principles, recommendations and indicators.*

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This project was commissioned by the Ontario Ministry of Health and Long Term Care, Health System Strategy Division and the Central, North West and South East LHINs.







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# Section 1: Evaluating Engagement

## Introduction

*Engaging with impact: Targets and indicators for successful community engagement by Ontario's LHINs* focuses on the value of community engagement. Specifically, it deals with the challenge of evaluating engagement and proposes a series of recommendations and indicators that can be used to assess performance and develop a culture of engagement that will help to rewrite the relationship between health administrators and their public.

Local Health Integration Networks were created in 2006 with an explicit mandate to engage stakeholders and their communities. More than this, the idea of engagement was central to their rationale. Proponents of the LHIN system argued that regional planning authorities would be better positioned than ministry officials to assess and interpret local needs. LHINs could do this because they would be in closer contact with the communities they served and because of the strength and number of local relationships they could forge and sustain.

Many of Ontario's LHINs have spent their first three years demonstrating the feasibility and merit of this rationale. Using their own expertise and intuition and sometimes relying on simple trial and error, they are working to better engage stakeholders and members of the public and to connect their efforts to other planning and integration processes.

For these organizations, the debate concerning the value of engagement has largely been settled. In its place is the growing recognition that a commitment to integrating engagement into the fabric of their organization requires upending many of the traditional assumptions that have defined health systems planning and public administration.

The capacity to engage with Ontario communities is one of the

LHINs' defining and most distinctive competencies. As this competency evolves, it promises to change how LHINs respond to the interests and needs of their communities and to gradually transform how health systems planning is performed. In this way, *Engaging with Impact* is addressed to those who believe that community engagement can be a major driver of health systems reform.

Despite its length, this report is not exhaustive. Instead, we hope it is stimulating and useful — a first installment amidst a broad range of research and initiatives that the Ministry of Health and Long-Term Care and the LHINs have begun to seed. Our purpose is to offer recommendations and to be ameliorative rather than definitive — a purpose that is consistent with the sentiments of our citizen-participants, who in the course of their work clearly understood that something as complex and amorphous as creating better systems of engagement rarely submits to single measures or immediate solutions.

*Engaging with Impact* begins with an essay by Professor John Gastil from the University of Washington, one of North America's leading theorists concerned with the value of community engagement. Gastil tackles the particular challenge of evaluating deliberative engagement, where citizens and experts work together to examine and solve problems. The essay offers fruitful reading for anyone wrestling with the heightened challenges associated with designing, managing and evaluating intensive engagement processes.

Subsequent papers from the British think-tank Involve and Canada's Wellesley Institute provide a comparative perspective on evaluating engagement within centralized and decentralized health systems.

Involve looks at the efforts being made by the English National Health Service (NHS) to promote and evaluate engagement. In England, a system-wide standard requires health service providers to engage with patients and the public at large. Their paper examines the efficacy of this standard and describes three initiatives that exemplify the NHS's attempts to measure the outcomes of their investments in public engagement.

The Wellesley Institute surveys a range of health agencies in Canada and provides four examples of localized innovation. Without a national standard or champion, interest in incorporating community engagement has only recently begun to mature in Canada. Their paper describes the challenges that need to be overcome for community

engagement to become more deeply embedded within Canadian health agencies.

A fourth paper looks at the experiences of our three sponsoring LHINs, each located in a different part of the province and confronting very different demographic pressures. Interviews with the directors of planning, integration and community engagement at the North West, Central and South East LHINs describe their on-the-ground efforts to build a local practice of engagement that informs the operations of their organizations and the decisions of their boards.

The second section of this report describes three Citizens' Workshops that were hosted in Kingston, Richmond Hill and Thunder Bay between November 27 and December 6, 2008. These workshops involved representatives from each of the sponsoring LHINs, as well as independent experts who offered their insight on the strengths and weaknesses of the health system. Billed as an opportunity to learn and contribute ideas for improving engagement, more than 3,000 invitations were mailed to randomly selected households in each region. Ultimately, 80 citizens came forward to participate during the daylong events. Their work culminated in a series of presentations that are the basis for the principles that underlay the evaluation scorecard found at the end of this report.

### **Creating a culture of engagement**

The overarching theme of this report is how to create a culture of engagement. It is a culture that LHINs, unique among the wider health sector, are singularly able to develop — and it is a culture that citizens want and increasingly expect.

During the workshops, the inseparable nature of engagement and integration also became clear. At its core, integration requires a willingness to try new things, in new combinations. While it is easy to get lost in the technical minutiae of integration agreements, it is harder to remember that integration is first and foremost an act of imagination and guiding that imagination should be a common sense of purpose — a desire to improve the quality and efficiency of health services available to Ontarians. LHINs need to engage the imagination of the public and their health service providers if they are to achieve their objectives for health reform.

In order to create a culture of engagement that helps the LHINs move towards these goals, we urge the following:

## **1. LHINs as health service providers: Community Engagement generates real health outcomes.**

Community engagement is not peripheral but central to the work of Ontario's LHINs. It is the service they provide to the health system in general and to citizens in particular. LHINs must continue to invest in their ability to provide and enhance this service. LHINs should be at the centre of an ongoing and lively conversation about the values, views and priorities of their stakeholders and the public at large.

Building such relationships will help to rebuild citizens' trust in the health system, find new opportunities for integration and increase the sense of shared ownership and responsibility for the performance of the health system as well as for the population's general health and well-being. In this sense, the LHINs are health service providers, and the service they provide is community engagement.

## **2. Citizens are ready and waiting.**

Citizens are willing, capable and ready to make important contributions to the work of Ontario's LHINs. However, the opportunities for citizens to make a contribution either directly or indirectly remains limited and episodic. The professional expertise of health service providers and the input and interest of the public are integral assets that cannot afford to be left on the table. LHINs need to work to make engagement a routine and more visible part of their repertoire. Moreover, because good communication is a precursor to effective engagement, LHINs should work to align their communications and engagement strategies.

## **3. To harness public input, emphasize learning.**

Most citizens are unfamiliar with the inner workings of the health care system and, consequently, with the work of Ontario's LHINs. But citizens are not only willing and ready to make a contribution, they are also eager to learn. They want to become better informed and they want to better understand a system they rely on and value. LHINs can add value to public input by creating opportunities for the public to become better informed. With this in mind, LHINs need to ask for more than public opinion — they must help citizens understand the nature and constraints of their health care system or any other issue they are being asked to address.

## **4. Make it real.**

Facing many competing pressures and demands, citizens have a good sense for the value of their time. They will engage most deeply

and meaningfully when something is real and at stake. Their commitment will always be proportionate to their sense of influence and the likely impact of their contribution. In this way, LHINs will only get out of their efforts at engagement what they are prepared to put in. As our scorecard explains, this means clearly defining the purpose of an engagement and the role the public is expected to play. It means being accountable and responsive to the public's contributions.

### **5. Focus on creating fit-to-purpose engagement.**

LHINs need to expand their repertoire and work to create a better fit between the processes they use to engage the public and the outcomes they expect. In this report, we propose three classifications that describe the characteristics and the objectives of a wide range of engagement processes.

### **6. Community engagement is mission critical.**

Successful engagement is a key to meeting the LHINs' objectives for health systems reform and unlocking the trust, imagination and commitment of health service providers and the public. Poorly designed, incomplete or insincere efforts to engage will only fuel cynicism and estrangement. Learning how to engage with impact is essential for system-wide transformation.

## **Conclusions**

The fact that the LHINs have a clear mandate to invest in community engagement demonstrates that the health system is eager to respond to the concerns, needs and desires of citizens. Translating this mandate into an effective culture of engagement should be a major focus of the LHINs over the next three years.

To help achieve this culture of engagement, the ministry should:

- require dedicated program budgets for the purpose of engaging communities on substantive and ongoing issues
- recognize and reward innovation in engagement
- evaluate the progress of each LHIN to improve its efforts towards this goal

The LHINs should:

- create engagement plans that support and are congruent with their strategic objectives
- diversify and deepen their range of engagement offerings
- align their communications and engagement strategies

- encourage Health Service Providers (HSP) to develop their own engagement plans and integrate these plans with their core operations

Just as preventative health is about ordinary citizens taking control of their lives, engagement is about the capacity of citizens to contribute to the systems that serve them. If there has been a change of philosophy from reactionary to proactive health care provision, an analogous philosophical shift is required to revolutionize the way health care systems work and respond to the needs of citizens. In this light, community engagement is not just a task to be completed. It is an ongoing process through which health outcomes are improved, trust is built, public legitimacy is enhanced and systems transformation can be pursued.



# Section 2: Understanding Engagement

# A Comprehensive Approach to Evaluating Deliberative Public Engagement

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If you turned back the clock just 20 years, it would be difficult to find a person in public office, academia or civil society talking about the virtues of “citizen deliberation.” At that time, a few innovative public deliberation programs, such as the Citizens’ Jury in the United States and the Planning Cell in Germany, existed, but they did so in an unfortunate kind of isolation, sometimes overlooked even by those who would develop deliberative programs of their own in the coming years.<sup>1</sup>

Today, the landscape could not be more different. Growing interest in citizen engagement has spurred a proliferation of new, more sophisticated deliberative practices designed to elicit substantive public involvement in policy-making and public affairs. Now the issue for planners and administrators isn’t scarcity but choice.

With different agencies and organizations deploying diverse approaches to deliberative citizen engagement, it has become more important than ever to take seriously the evaluation of these varied processes. It is not pessimistic to say that we currently have no systematic comparisons of alternative deliberative methods, though many civic reformers, researchers and agency officials have ideas about when to use one process instead of another. To improve our knowledge of deliberation and upgrade the practice of citizen involvement, we must begin to evaluate the design, process and outcomes of our civic engagement activities.<sup>2</sup>

In this chapter, I aim to provide the tools necessary for doing so. I begin by clarifying the meaning of deliberative public engagement and discussing broad evaluation categories. I review each evaluation criterion and suggest measurement tools and then conclude with a summary recommendation for conducting evaluations.

## **Defining Deliberative Public Engagement**

It is imperative that references to deliberative public engagement convey a sufficiently specific meaning so we can distinguish it from generic public involvement processes, such as formal hearings or informal consultations. For the purpose of this chapter, I define this term as an official or quasi-official process whereby policy-makers, policy/scientific experts and lay citizens work together on a public problem or concern, with the citizens carefully examining a problem and seeking a well-reasoned solution through a period of informed, inclusive and respectful consideration of diverse points of view.<sup>3</sup>

Breaking this down, the players in a deliberative public engagement need to include (1) appointed or elected officials with some degree of authority, (2) persons with content-relevant expertise and (3) lay citizens, whether randomly selected or otherwise recruited in a fashion that seeks diverse members of the general public. The citizens are at the heart of the process, but public officials typically serve as the catalyst for initiating the deliberation and facilitating the implementation of its findings. The experts play a role behind the scenes (e.g., preparing briefing materials) or as personal resources that citizens can call on in the course of their deliberations (e.g., as key witnesses). Together, the interplay of these participants constitutes a public engagement process.

For such a process to be deliberative, it must meet a higher standard for the quality of the dialogue, debate, discussion and other talk in which citizens participate. Table 1 shows a definition of a deliberative public meeting that I have found helpful. First, a deliberative meeting involves a rigorous analytic process, with a solid information base, explicit prioritization of key values, an identification of alternative solutions (sometimes pre-configured but often still subject to amendment) and careful weighing of the pros and cons. (Research on group decision-making has found that of these analytic elements, careful consideration of cons is often the key to a high-quality process, and the emphasis on “hard choices” and “trade-offs” in many deliberation processes reflects this.)<sup>4</sup>

Exclusive focus on problem-solution analysis, *per se*, would make our conception of deliberation overly rationalistic and overlook the social aspect of deliberation. One might say that the social component of deliberation is what makes it democratic deliberation, by requiring equal opportunity, mutual comprehension and consid-

eration, and respect. The social requirements also make clear the implicit emphasis on inclusion and diversity in deliberation.<sup>5</sup>

Analytic Process	
Create a solid information base.	Combine expertise and professional research with personal experiences to better understand the problem's nature and its impact on people's lives.
Prioritize the key values at stake.	Integrate the public's articulation of its core values with technical and legal expressions and social, economic and environmental costs and benefits.
Identify a broad range of solutions.	Identify both conventional and innovative solutions, including governmental and non-governmental means of addressing the problem.
Weigh the pros, cons and trade-offs among solutions.	Systematically apply the public's priorities to the alternative solutions, emphasizing the most significant trade-offs among alternatives.
Make the best decision possible.	Identify the solution that best addresses the problem, potentially drawing on multiple approaches when they are mutually reinforcing.
Social Process	
Adequately distribute speaking opportunities.	Mix unstructured, informal discussion in smaller groups with more structured discussion in larger groups. Create special opportunities for the reticent.
Ensure mutual comprehension.	Ensure that public participants can articulate general technical points and ensure that experts and officials are hearing the public's voice.
Consider other ideas and experiences.	Listen with equal care to both officials and the general public. Encourage the public to speak in their authentic, unfiltered voices.
Respect other participants.	Presume that the general public is qualified to be present by virtue of their citizenship. Presume officials will act in the public's best interest.

## **General Evaluation Criteria**

The question of whether a process even aspires to approximate deliberative citizen engagement precedes any serious attempt at evaluation. After all, one can justify the considerable effort evaluation requires only if the process being examined claims to be (or has some reasonable expectation of being) related to the particular ideals of public engagement and deliberation. Presuming that the deliberative engagement program, project or event aspires to these ideals, then the following four evaluative criteria are appropriate for assessing its overall quality on these terms.<sup>6</sup>

When implemented, a deliberative public engagement process should be evaluated on its own terms. That is, the best way to judge its effectiveness is to assess the extent to which it achieves the goals that such a process strives to achieve. Because deliberative engagement programs share some common ideals, however, they do share a concern with (1) design integrity and (2) sound deliberation and judgments. After all, such programs fail immediately if their design or the ensuing deliberation does not meet basic requirements, as described below.

In addition, these engagement processes can be assessed in terms of the outcomes their public events engender. Here, more variation occurs among different programs, and the third criterion thus requires (3) influential conclusions and/or actions. For some processes, it will be enough for deliberation to yield recommendations that carry influence, whereas other programs will emphasize taking direct action, whereby citizens not only talk but work together to exert their influence.<sup>7</sup>

Finally, the greatest variation in purposes comes from the wide range of (4) additional benefits for public life that deliberative engagement processes hope to realize. Herein, I will consider methods for evaluating a range of these, from beneficial effects on individual citizen participants to broader impacts on the community or even the larger political culture. I call this final criterion “secondary benefits” because it reaches beyond the immediate purpose and impact of citizen deliberation, but nearly every deliberative enterprise carries ambitions that extend outward in this way.<sup>8</sup>

The sections that follow consider these four criteria in greater detail and suggest the effective means whereby one might assess the accomplishment of each.

### **Criterion 1: Design Integrity**

A high-quality deliberative engagement process gains its power partly from the integrity of its development, design and implementation. This criterion can be broken down into three more specific sub-components:

1. Unbiased framing. The process by which issues are framed for deliberation should be transparent, subject to open criticism by all interested parties. The resulting issue frame should be a fair representation of conflicting views and arguments. Even when the organizers imagine that they have an undefined, “open” issue frame (e.g., “political reform,” without specifying any options), it’s still the case that they selected that issue and generated language to describe it.
2. Process quality. The deliberative procedures themselves should be developed in consultation with (or at least subjected to comment from) interested parties, particularly those with different points of view on the issue at hand, and the resulting process should be consistent with the best practices for deliberation (e.g., rigorous analytic process for studying the problem and generating and evaluating solutions, along with respectful and egalitarian relations among participants).
3. Representative. The selection of citizen participants should give broad opportunity to all potentially interested parties (excluding only those with public offices or unusually high personal/financial stakes in an issue). The resulting body of citizen participants (hereafter called a “citizen panel”) should prove representative of the general population and, in particular, include representatives from any permanent minorities (i.e., groups for whom public policy consistently goes against their interests) and even smaller-numbered culturally relevant identity groups (i.e., sub-publics or communities who seek visible representation in any public deliberative body).

One can assess these design features through direct inspection of relevant event and design records, along with interviews with organizers and interested third parties. Specifically, I recommend the following evaluation methods:

1. Evaluating the issue frame. Whenever possible, the issue frame’s

fairness should be evaluated before the deliberative body convenes and reaches its conclusion. This way, evaluations will not reflect reactions to the outcomes. A neutral third party (e.g., unaffiliated university researcher or program evaluation specialist) can evaluate independently, through inspection of project documents and procedures, whether the framing process was neutral and transparent, but ideally this process is evaluated by interested parties from all relevant perspectives. The latter approach offers a more varied perspective on the procedure's fairness to the particular concerns of different interest/advocacy groups.

2. Evaluating process quality. This follows the same basic protocol as issue frame evaluation, with two exceptions. It is useful to get preliminary process assessments before deliberation begins, but whenever possible it is helpful to complement these with assessments during and after deliberation. The actual implementation of the deliberative procedures may shape the final evaluations thereof. To ensure commensurate evaluations, it is also important to discuss with each evaluator – including interested parties – the conception of deliberation underlying the process design. (This parallels the present chapter's effort to carefully define deliberation.)

3. Assessing representativeness. The final body of citizens who attend the event (versus those who register or pledge to attend) should be surveyed to determine their relevant demographic and ideographic (attitudinal) characteristics. These characteristics can then be compared against relevant census and survey data for the targeted geographic/political region. This can be more expensive when the target area does not have a readily available census or survey profile, as in the case of a watershed, transit area, biozone or other non-standard region.

#### **Criterion 2: Sound Deliberation and Judgment**

Beyond their process features, deliberative civic engagement programs should show signs of high-quality judgment. Thus, they should produce the following outcomes:

1. Manifest disagreement. Public deliberation should include periods of debate among the citizens (hereafter called “panelists,” as in the instance of a “citizen panel”) on both questions of fact and more fun-

damental moral issues. The absence of such a clash would suggest excessive consensus-seeking among citizens who surely have genuine differences in experiences and values.

2. Supermajorities. Deliberative groups should be able to work through their differences and often reach broad agreement when assessing initiatives. Narrow majority views should sometimes grow into large majorities, and minority viewpoints should sometimes prevail.
3. Informed and coherent judgments. Citizens' judgments should develop in light of the information presented, the views put forward and the careful, honest discussions among participants. As a result, participants should demonstrate more informed and coherent views on initiative-related issues after participating in panel discussions. Participants should be able to give reasons for their views and should be able to explain the arguments underlying alternative points of view.  
One can assess these outcomes through direct observation of the deliberative process, complemented by systematic surveys and interviews with participants, event moderators and other interested observers.
4. Assessing disagreement level. Systematic coding of an audio (or preferably video, for ease of transcription) record of the deliberation can establish whether disagreement took place. This can be complemented with interviews of participants to determine whether they subjectively experienced such disagreements and whether there were any potential disagreements they chose not to bring forward (i.e., internally censored).<sup>9</sup>
5. Assessing supermajorities. This is assessed directly from the event records when formal votes are taken by the citizen deliberators. In all cases, it helps to survey the participants afterward, to find out the degree to which they (privately) supported any final recommendations.
6. Evaluating judgments. The citizens' final judgment should be evaluated by a neutral third party, as well as interested parties, to obtain their varied assessments of its soundness. In these cases (and

those where no final judgment is reached), it is also helpful to combine an analysis of the deliberation with a survey of participants, so that one can assess the degree to which the information and perspectives provided in the event shaped citizens' individual views on the issue. In particular, post-deliberation citizens should be more knowledgeable, have better correspondence between their views and relevant facts, and understand the cons of whatever recommendation they ultimately made.

### **Criterion 3: Influential Conclusions/Actions**

Once implemented, successful deliberative processes should show clear evidence of their influence on the policy-making process or on the actions of the wider public. Depending on whether they emphasize policy recommendations and/or direct action, effective deliberative citizen engagement should produce the following results:

1. Influential recommendations. Deliberative engagement processes should prove to be an effective mechanism for making a policy proposal succeed or fail in light of the citizens' recommendations. Specifically, when a clear majority of panelists favour a particular policy initiative, its chances of prevailing should increase, and the reverse should be true when citizens oppose a policy.
2. Effective, coordinated action. Deliberative bodies that attempt to generate change through direct action should be able to coordinate their post-deliberative efforts to thereby change the relevant voluntary actions taken by the larger public, which may indirectly spark policy changes (depending on whether the citizens' action plan involves public policy change).

One can assess these outcomes through institutional, policy and sociological analysis, which involves a history of the relevant policies and public actions through examination of records and interviews with officials, activists and lobbyists.

3. Assessing influence. This is a tricky undertaking because it is often difficult to establish baseline probabilities of policy outcomes.<sup>10</sup> The most effective approach is probably employing a third-party evaluator who combines all relevant documentation with interviews, preferably both before and well after a deliberative event. Long-term assessment, in particular, could determine whether the influence of

the deliberative engagement builds (or erodes) over time.

4. Assessing action effectiveness. The same basic methods apply to action as to policy, with the emphasis shifting from policy analysis to sociological investigation. The latter should entail large-scale longitudinal surveys to assess public behaviour.

#### **Criterion 4: Secondary Benefits**

If deliberative processes are implemented and the evidence shows that they are reaching sound and influential judgments and/or transforming public action, that would be enough to warrant their widespread adoption. Nonetheless, it is important to examine other potential outcomes because many deliberative civic engagement programs stress the impact they have on the participants themselves, the wider public or macro-level political processes. To give a sense of the range of these secondary benefits in relation to governance, herein I describe and suggest evaluation approaches for three: transforming public attitudes and habits, changing the attitudes and habits of public officials and altering strategic political choices.<sup>11</sup>

1. Transforming public attitudes and habits. In the long term, deliberative panels could transform not only their participants, but also the larger public. Those participating in, engaged with or captivated by the panels should report stable (or rising) levels of public trust and signs of reduced civic neglect. Voter turnout in elections might increase, and citizens should develop political beliefs (e.g., a sense of political self-confidence) conducive to varied forms of public participation (e.g., attending public meetings, using public affairs media).
2. Changing public officials' attitudes/behaviour. Citizen deliberation could also change how public officials think and behave in relation to the larger public. Government officials could develop more favourable views of the judgments that citizens make during deliberative events. Officials should also demonstrate an awareness of the importance of citizen deliberation and come to respect panel judgments. As a sign of improved leadership, elected representatives (and agency officials) could also begin to step away from conventional public opinion on initiatives in anticipation of deliberative panel judgments to the contrary.

3. Altering strategic political choices. In addition, the public deliberation could change the strategic choices made by political campaign professionals during initiative campaigns. Panels will have succeeded in transforming the electoral environment if initiative and policy campaigns begin to focus more of their energy on addressing the issues raised by deliberative panels (e.g., holding debates focused on panel issues) and incorporating deliberative panel results into campaign advertising. A more far-reaching effect of the panels could be the emergence of routine pilot-testing potential initiatives with low-cost varieties of “deliberative polling,” trying to understand how the public will view the initiative after deliberating.<sup>12</sup>

The methods of evaluation used to assess these secondary outcomes would be as varied as the potential impacts themselves.

Measuring shifts in public attitudes and habits. One can assess impacts on participants and the larger public through survey research and inspection of election records (in those countries where voting is not mandatory). Examples abound for what to include in such surveys and how to assess it, but the best examples include longitudinal assessment (to establish change over time), comparison groups (to differentiate deliberation’s impact from those effects of other social/political forces) and a wide variety of measures (e.g., breaking down efficacy into multiple sub-components, such as self-efficacy versus collective efficacy, i.e., a sense of effectiveness when acting in a group).<sup>13</sup>

4. Measuring changes in public officials’ attitudes/behaviour. To assess changes in public officials, survey methods likely will fail, owing to poor response rates conventionally obtained among elites. Instead, one should assess these outcomes through interviews with public officials and in-depth, longitudinal legislative and policy analysis that compares processes before and after the deliberative civic engagement, in light of other changes in the political/legislative environment.

5. Detecting shifts in strategic political choices. One can assess these outcomes through interviews with public officials, lobbyists, campaign officials and political activists. This can prove especially challenging, as it requires accessing internal strategic decisions (or documentation thereof) within organizations whose interests may not be well served by such investigation. If one can obtain such data,

however, it is possible to detect signs of the deliberative process exerting its influence. For instance, policy initiatives that fail to pass muster in trial runs (i.e., in the mock deliberative polls described above) are subsequently withdrawn; this can indicate that anticipation of the eventual deliberative citizen engagement process is causing more careful vetting of the proposals such a group might put before policy-makers and the general public.

### **Conclusion: Integrating Evaluative Methods**

Table 2 summarizes the preceding discussion and breaks down evaluative methods into two columns. The first describes a “basic evaluation” – those methods most readily deployed on a modest budget and within a narrower time frame. The second column augments these basic methods with additional assessment tools, which may require more labour, money and time. Whether the evaluation requires more than a basic method depends on the resources and goals, but it is important to recognize the limitations of the basic evaluation approaches in terms of their reliability and validity.

In conclusion, it is important to consider how one integrates these various evaluation metrics. That is, how does one move from separate assessments of each criterion (or sub-component) to an overall evaluation of the deliberative citizen engagement process as a whole? This depends, again, on one’s conception of the project, but the following approach will apply to many such programs.

Each of the three elements of design integrity count as pass-fail elements, and a subpar evaluation on any one of these yields a negative summary evaluation of the entire process. That is, if any aspect of the design failed to meet basic standards for integrity, the other outcomes of the process are all suspect.

The three elements of sound deliberation and judgment should be viewed as parts of a coherent whole, such that one arrives at a single assessment of deliberation/judgment in light of each element. The third of these might be most important (i.e., the coherence and soundness of the group’s judgments), but this should be weighed by how rich the disagreement was and how effectively the group could move toward a supermajority. Outstanding performance on two of these criteria might obviate lower performance on another, but outright failure on either the first (disagreement) or third (quality of judgment) should yield an overall assessment of program failure.

Criterion	Basic Evaluation	Additional Evaluative Method
<b>Design Integrity</b>		
Unbiased framing	Third-party document inspection prior to deliberation	Inspection by interested parties
Process quality	Third-party inspection of procedure instructions and direct observation of process	Inspection by both third-party and interested parties before, during and after deliberation
Representative	Compare citizen participant demographics with census data	Conduct detailed survey of citizens and target population to check for differences in both census and attitudinal variables
<b>Sound Deliberation and Judgment</b>		
Manifest disagreement	Direct inspection of deliberation for signs of disagreement	Survey participants to judge their subjective experience of disagreement and check for self-censorship of potential disagreements
Supermajorities	Check final vote tallies	Survey participants to learn their degree of private support for their public recommendations
Informed and coherent judgments	Third-party assessment of the citizens' final judgment in light of available information	Inspection by interested parties and survey of participants' relevant knowledge/perspective
Influential conclusions/actions	Third-party document inspection prior to deliberation	Inspection by interested parties
Influential recommendations	Third-party assessment of policy impact	Take longer-term assessments to capture gradual/eventual impact (or detect erosion of influence)
Effective, coordinated action	Third-party assessment of impact on public behaviour	Inclusion of large-scale, longitudinal population surveys

Criterion	Basic Evaluation	Additional Evaluative Method
Secondary Benefits		
Transforming public attitudes and habits	Post-deliberation survey of participants	Longitudinal survey (and analysis of voting records) for both deliberation participants and wider public
Changing public officials' attitudes/ behaviour	Interviews with public officials	Legislative and institutional policy analysis
Altering strategic political choices	Third-party assessment of changing political climate	Intensive interviews and strategic document analysis within policy-relevant interest/advocacy groups

The influential conclusions/actions criteria are different in that some programs will emphasize only one – or even neither – of these criteria. All deliberative citizen engagement programs, however, should orient toward one or the other to at least a degree, lest deliberation become seen as “merely” discussion, disconnected from action. Even then, poor performance on a program’s relevant influence criterion does not impugn the entire exercise; rather, it suggests the need for improving the component of the program that leverages influence.

Finally, assessment of secondary benefits stands apart from these other criteria in that program success may not require evidence of these impacts. If a program is well designed, deliberative and influential, these become “bonus” effects, not strictly necessary for justifying the citizen engagement program per se. In the long run, however, these secondary benefits could be of tremendous value for a public and its political culture. A more engaged public, legitimate institutions and responsible, deliberative politics could dramatically increase the capacity for shared governance and public action and, ultimately, yield much better public policy. Such potential impacts should be assessed, for evidence of these changes could increase the estimated value of deliberative citizen engagement, thereby warranting the time and resource expense it requires.

# The Canadian Experience: Observations and Lessons from the Canadian Health Sector

Brian Eng, Wellesley Institute

This chapter evaluates the effectiveness of community engagement and public participation efforts in Regional Health Authorities (RHAs) in Canada. An extensive review of the literature examining public engagement theories and evaluative methodologies and interviews with health care and other social services practitioners helped establish some common themes and directions in public engagement. Though not meant to be comprehensive, case studies are included that represent a more detailed investigation of particular public engagement processes.

Because health care delivery is a provincial responsibility, RHAs across Canada operate independently of one another. Even RHAs within the same province have significant differences in approach and methodologies. This is largely due to the fact that the legislation and policies that are used by provinces to mandate community engagement for RHAs are often very general in their requirements and reporting frameworks.

The literature and interviews suggest that in regions where a commitment to public participation in a health care delivery system is being implemented in a meaningful way, there is a growing consensus about what constitutes an effective engagement, in terms of both processes and outcomes. Outcomes are increasingly measured by population health and patient-centred metrics such as increased involvement in health programs and client satisfaction with health care service. Common themes for effective processes in public engagement are often defined using terms such as respect, diversity, meaningful participation, accountability and equity.

A growing body of work in the field of community engagement evaluation categorizes three types of evaluation – summative, formative and developmental. Summative evaluations measure

the outcomes that are the end result of engagement exercises, such as uptake of services, client satisfaction, better health outcomes. Formative evaluations measure progress in achieving process-oriented goals, such as participant satisfaction with the process, appropriate information, meaningful dialogue, adequate representation of community diversity. Developmental evaluation is an emerging field that attempts to measure change and is used in engagement efforts that are working on complex problems in which outcomes tend to be unpredictable and goals, purposes, contexts and so on may change as the engagement process develops. An example is attempting to measure the relative impact of particular processes in moving toward change is the way systems function.

Summative evaluation has been used extensively in the health care system – even prior to the advent of community engagement processes. The metrics and indicators are well understood, and there is a general consensus about how to apply them.

Formative evaluation is less well developed in public engagement activities in the health sector. There are some promising initiatives in this area and a growing body of practice in the health care and other social services sector around evaluation of processes such as stakeholder analysis, comprehensible information dissemination and accountability. It is important to note that formative evaluations take place regularly in engagement processes, albeit on an ad hoc and often personal basis. Practitioners often point to the need for more rigorous methodologies that can transcend personal and institutional bias (both positive and negative) and where the tools and outcomes are comparable across engagement activities.

Developmental evaluation is very much an emerging field and is not being addressed in any significant way in the health sector. Engagement in the health sector is still driven mostly by the needs of health authorities to deliver health care programs. While the definitions of health care programs has expanded beyond access to medical care and now includes programs to encourage healthy living, the engagement processes are still driven by predetermined goals and anticipated outcomes that lend themselves to summative and formative analysis. However, as health authorities begin to grapple with their role in looking at the broader social determinants of health and the systemic changes required to make progress in these areas, developmental evaluation will become increasingly important in

engagement processes.<sup>1</sup>

The case studies in this chapter will help to illuminate some of these concepts and provide some indicators of common themes and challenges.

### **Drivers for change**

Since the mid-1990s, governments in Canada have been devolving the responsibility for allocating resources in social services delivery to community levels. The theory behind this action is that local communities are better at determining their social service needs than centralized bureaucracies. The relative merit of this approach is still open to debate, but the process is well advanced in many areas.

With this devolution of responsibility has come a greater emphasis on finding ways to involve the community members, sector organizations and other partners in discussions and decision-making about resources allocation. Public participation, community consultation and community engagement have become important cornerstones in the delivery of social services.

Traditionally, community engagement generally meant informing the public about available services and encouraging them to use those services. This is now being augmented by processes such as roundtables, advisory committees, town halls and open forums, where community members and stakeholders receive information, discuss options, and sometimes have decision-making power about the nature of services.

This is certainly the case in the health sector. Provincial governments across Canada are moving away from the model of directly funding service delivery organizations such as community health centres (CHCs) and hospitals. They are establishing Regional Health Authorities and local networks responsible for developing comprehensive service delivery programs. In many cases, the provincial government requires these regional bodies to have a community engagement strategy to inform and guide the development of their plans.

The traditional method of public participation in health care delivery was through involvement on the boards of directors of self-governing institutions such as community health centres and hospitals. These bodies were funded directly by the government and may or may not have had other community engagement strategies to

develop their programs. A report commissioned by the Association of Ontario Health Centres in 2006 indicated that this model was changing significantly.

Across Canada, there has been a general shift in how public participation in health care is being carried out. Community governance has been shifting away from direct democracy of locally elected community boards toward engagement through various other mechanisms such as information sharing and consultation, and by the establishment of community advisory committees, councils or groups. From the perspective of governments, devolved authority to regional structures and the encouragement of citizen participation in planning and priority setting through these various means is seen as moving health care closer to communities. But locally governed community health organizations and individual community members see these trends as a movement toward more remote and centralized governance. Although community engagement is being promoted as a means to involve citizens in health care planning, empowerment of local citizens (including the most vulnerable populations) achieved through local community governance may be declining.<sup>2</sup>

Given the caution expressed in this report, it is clear how important it is to have an evaluation framework of community engagement to determine whether the goals of community involvement and empowerment are being met.

### **Cape Breton**

The Cape Breton District Health Authority (CBDHA) is one of nine health authorities in Nova Scotia. It is primarily a rural catchment with several medium-sized towns and an urban centre of 25,000 people in Sydney.

The Nova Scotia Health Authorities Act requires that each District Health Authority (DHA) establish Community Health Boards (CHBs) to serve as the “eyes and ears” of the community. This is a primary vehicle for public consultation and participation in Cape Breton. There are six CHBs in the Cape Breton DHA that cover a range of rural and urban catchments. Board members are recruited through local advertising and word of mouth.

CHBs provide advice to their health authorities about the needs of their community. Depending on the CHBs’ internal infrastructure capabilities, this advice can result from internal board discussions or

public consultations such as community forums.

As well, CHBs distribute funding to community agencies implementing DHA programs. They are required to report back to the DHA about the use of those funds and the impact on health outcomes in their community.

The Cape Breton District Health Authority (CBDHA) provides a summative evaluation across the district of this information and makes it available to the public on its website. This evaluation includes a description of key indicators of health and lifestyle outcomes. A progress report is updated each year.<sup>3</sup>

One problematic process is the recruitment and retention of CHB members. An ad hoc evaluation using an informal survey method and conversations with existing and past board members identified key issues such as volunteer burnout, transportation and understanding the role of CHB members.

CHBs communicate with one another within each region and across the province through a council of chairs, enabling them to evaluate their experiences with other engagement processes that have similar mandates. In fact, a new staff position – Community Health Board coordinator – was recently established at the Cape Breton District Health Authority after members heard about the effectiveness of similar staffing components in other health authorities in the province.

The CBDHA interviewee indicated that formative evaluation of CHB work is on the agenda. At the moment, there are limited tools in use, but additional tools are being contemplated. The interviewee expects that the major challenges will be financial if the implementation is resource-intensive. It is assumed that there will be significant support from senior staff and policy-makers at the health authority. According to the interviewee, “They are not afraid of change.”

### **Winnipeg Regional Health Authority**

The Winnipeg Regional Health Authority (WRHA) has a thorough and well-researched Community Development Framework.<sup>4</sup> The framework promotes the region’s organizational development and facilitates networking, inter-sectoral collaboration, public participation initiatives and local area development. The framework defines community, establishes a participation model and outlines methods of public participation.

The WRHA offers the following rationale for having a comprehensive community development model.

Community development empowers people to have more control over the decisions that influence their own health and the health of their community through increasing personal control over their own health behaviour change and by addressing the underlying health determinants such as poverty, housing, or environmental threats. The concept of empowerment is focused on achieving equity in health and increased public participation in health program decision-making.

The public participation process involves six advisory councils and dozens of place-based and program-specific working groups. Rigorous evaluation determines whether the advisory councils are representative of the community's diversity. Potential advisory council members are interviewed and asked to provide information about themselves, including self-identification with minority or marginalized groups. Advisory council members are chosen with a view to the overall makeup of the councils being representative of the community. There is also an evaluation framework for the work of the councils based on self-reported perceptions of the work and processes of the group, as well as indicators of community interest in participating in the work of the councils. These reports are rolled up and analyzed by staff to the health authority and reported to the WHRA board.

The framework also outlines extensive evaluation tools for the various working groups. These tools are used by facilitators to monitor the progress of the group as it defines goals, begins to understand issues, assesses participation and so on. This process has been in place for a short time only and, at present, is used primarily by the facilitators to track and refine processes. However, the WRHA interviewee felt that standardizing the evaluation will help to create a more general picture of the effectiveness of the community development model once the resources are in place to do a full-scale rollup of the information. The interviewee also indicated that one of the purposes of the standardization was to find evaluative tools that fit with models that are more prevalent and understood in the health care community. In other words, to find models and tools that evaluate qualitative factors in a culture that is more used to and adept at using summative, quantitative tools.

An example of an innovative WRHA development is in their work with other government departments and social service agencies. The models and evaluative tools along with human resources are now being made available as a part of an inter-sectoral collaboration, and it is hoped that comparing outcomes across sectors will help to refine the evaluative tools and the methods and processes of public participation.

### **Saskatoon Regional Health**

In many ways, Saskatchewan has one of the longest histories of public participation in health care. When one staff member at the Saskatoon Health Region was asked, “Why do you engage the public?” they answered, “Because we are the province of medicare.” The Saskatoon Regional Health interviewee reinforced this point by saying that the region is itself as a steward of public funding and felt an obligation to engage the public for effective resource allocation.

There is a legislative requirement in Saskatchewan to have public input into the health care system. However, the province does not monitor this except as a complaint-based system. The Saskatoon Health Region has a clear Community Development Framework.<sup>5</sup> Like many others, it has identified reasons for community engagement that include encouraging community participation in health, focusing on the creation of healthier communities and expanding the understanding of factors that sustain health of communities. It also identifies principles and methods.

According to the interviewee, there is very little rigorous evaluation of the program as a whole. However, there is evaluation of particular initiatives, primarily driven by external funders. The example cited was of an Aboriginal partnership in which they will be hiring an evaluator to assess the outcomes of the program and, as how well important values such as respect, equity, integrity and so on are being incorporated and to help drive the engagement process.

The Saskatoon Health Region realized that its advisory council system seemed to be “floundering,” so it surveyed advisory council members about what was working and what was not and asked for suggestions about what could be improved. Implementing these recommendations, however, has been hampered by a recent change of government that has resulted in a “transition” period while the government examines new bureaucratic processes. The interviewee

recalled that this kind of delay has happened in the past and offered the opinion that formative evaluations of this kind are most useful when they can be applied over time since they are intended to measure progress rather than outcomes. The evaluations become ineffective when there is constant restructuring and repositioning of formats and methodologies that are the result of bureaucratic or political imperatives rather than of the evaluations themselves.

The Saskatoon Health Region comprises both the urban centre of Saskatoon and surrounding rural areas. The interviewee mentioned one rural community engagement focused on using discretionary public funding to preserve a local acute care facility. The questions were asked: "How do you evaluate that engagement outcome against the fact that it seems relatively clear that the same amount of resources put into programs for healthier living, coupled with programs to reimburse transportation costs for medical care in the nearby urban municipality, will result in better health outcomes for the community as a whole? Are people not receiving the right information? Are they not assimilating it?" In other words the question that is being asked is how to evaluate whether or not the engagement is meaningful.

The Saskatoon Health Region is keen on developing a better understanding of community engagement and how it can be effectively evaluated. To this end, it is involved with a Regional Inter-sectoral Committee that has commissioned an evaluation of public participation in social service delivery in the province.

### **Vancouver Coastal Health**

Vancouver Coastal Health (VCH) includes 25% of the population of British Columbia in an area that covers the city of Vancouver, its suburbs and as far along the coast as Powell River. VCH has five Community Health Advisory Committees: three are geographically based, one works with the Aboriginal community and, in 2006, a Palliative Care Community Reference Committee was established. As well, VCH delivers numerous project-based engagement exercises intended to provide advice to the health authority on program development.

In 2006, VCH hired a consultant to help staff develop evaluation methodologies and tools. The resulting framework identified the

purpose of the evaluation as to “assess the practice (or process) of carrying out community engagement processes and the impact (outcome) that they have on VCH decision making.”<sup>6</sup> The framework also established a set of questions for consideration.

A set of surveys to be completed by participants and project leaders at the conclusion of selected community engagement consultations was created as an evaluation tool. Follow-up surveys are also sent out. Several different templates have been developed for use in different contexts.

The process evaluation is intended to evaluate a broad range of process-oriented questions, including demographics and participant motivation and satisfaction. Sample questions include “Did participants feel like their opinions matter to the organization?” and “Did they have enough information to be able to contribute fully?”

The outcome evaluations have their own particular nuance in that they are not evaluating program outcomes in the traditional sense. Instead, they are being used to determine the value of community engagement (CE) processes to particular projects. For example, questions are asked to determine whether project leaders “feel that the CE process was useful to their project outcomes” and what motivates project leaders to “integrate a CE process into their project work plan.”

The intention of the VCH staff has been to compile these reports as part of their yearly reporting process. However, as with many other engagement processes, it is a challenge to find the staff time and other resources to properly systemize, collate and analyze these reports. As the VCH interviewee put it, there is a constant need to “do, do, do.” Time spent in evaluative work by department staff can be perceived as time taken away from delivering the community engagement program.

Nevertheless, VCH staff do spend time in ad hoc evaluation and process analysis as part of their ongoing work. This is a natural part of the day-to-day discussions and collaboration among staff. The interviewee did offer the observation that a more systematic approach to collating the learnings from these evaluations might prove valuable in bridging the culture gap between the community development functions and the health care delivery functions. But she offered the caution that any evaluative process needs to be used, analyzed and understood in terms of the contexts in which engage-

ments take place. Any attempt to overly systemize evaluations in an attempt to make them applicable across wide varieties of engagement processes will likely result in failure due to receiving insufficient information or the potential for misinterpreting information without knowing the context.

### **St. James Town Initiative**

One of the many things to be learned about evaluation from other fields of community engagement practice in the health care sector is the burgeoning field of Community-Based Research (CBR). During the development of CBR projects, formative, process-based evaluations are often used to define and often refine the purpose, scope and methodologies of the project.

The St. James Town Initiative of the Wellesley Institute, for example, was envisioned by its initiators as a research project that would look at neighbourhood factors in newcomer health outcomes. It is well known that new immigrants to Canada tend to be healthier than the general population but that their health outcomes decline over time. There is a general understanding about the drivers of this phenomenon in terms of lower incomes and more difficult access to culturally appropriate health care. The Wellesley Institute wanted to examine neighbourhood factors in a distinct geographic area that has a high immigrant population. North St. James Town in Toronto was a likely candidate. The methodology initially envisaged was a qualitative study that would follow a select group of individuals and families for a period of time using periodic surveys, focus groups and so on. There was also an intention to do a quantitative study.

Staff at the Wellesley Institute began to work with community-based organizations in St. James Town to recruit people for the qualitative study and to seek input on the indicators. Almost immediately, the community members engaged in an ad hoc formative evaluation to determine whether they wanted to participate. The Wellesley Institute was told that if the sole purpose of the engagement was to learn more, then St. James Town community members weren't interested, concluding: "Our community has been studied to death. What we need is action."

The Wellesley Institute repurposed the engagement to include an action component, evaluating the initial methodologies to deter-

mine whether they could result in action. They concluded that they had to introduce some new, more participatory research components that would allow community members to define early in the process some areas of action that might be pursued as the engagement proceeded. As a result, the first methodologies employed in the qualitative research were Photo Voice, Community Mapping and Concept Mapping. This allowed participants to make an early identification of neighbourhood factors that might be actionable.

### **Common Themes**

Some common themes have emerged from the research.

First, the health care system is relatively adept at using summative, quantitative evaluations to assess the impact of community engagement and public participation processes. It can look at program evaluations, uptake models and so on to determine whether health outcomes are improving as a result of engagement. The indicators and metrics are reasonably well understood and agreed upon. The evaluations have expanded beyond just access to medical services and now include other elements of population health.

Second, it is clear that ad hoc formative evaluations take place during many engagement processes. These are natural and often unintended evaluations that occur because facilitators or participants want to know that their efforts are effective and valuable. Interviewees and other practitioners have indicated that more rigorous formative evaluations would be valuable in assessing and improving engagement processes.

Third, as the health care sector moves into more complex engagement processes that examine the larger systemic issues that impact health outcomes, more complex evaluative tools will need to be developed and used to assess the outcomes and processes of the engagements.

### **Challenges**

There are a number of challenges in evaluating community engagement and public participation in the health sector, particularly from the view of formative or developmental evaluation.

One challenge is that common definitions or formulations of various key terms and components do not exist. What is pub-

lic participation in one place is analogous to civic engagement in another and community development somewhere else. There are no common definitions of key community, stakeholder, user and so on. Goals and principles of community engagement vary from one process to another. This occurs not only in the health care sector but across the entire field of community engagement and development. Advances have been made in this area,<sup>7</sup> but further opportunities exist to refine our definitions by collaborating across processes. One benefit would be to move the formative evaluations from the ad hoc and self-reported methods to more rigorous methods in which the outcomes and learnings can be more easily shared across jurisdictions and sectors.

Another challenge is that the more rigorous evaluations tend to be resource-intensive. The long-term benefits of diverting resources, particularly in the health care sector, from immediate problem-solving into evaluation have to be clearly articulated. As well, the level of funding required can sometimes be unpredictable at the start of an engagement process. This is problematic for funders, who require predictable costs.

On the cultural front, large institutions often resist new tools and techniques. Without a champion of innovation within the institution, there is a tendency to use what appears to have worked in the past. There is also a resistance to evaluating for outcomes that appear to be outside the scope of the engagement process. While strengthening trust in democratic processes is regularly identified by practitioners as a probable and desirable outcome of a successful engagement, there is very little work being done by institutions to identify this and to try to monitor outcomes. Community capacity building is also often cited as a goal of community development and engagement processes. But it is hard to find any indication that this is being monitored or evaluated in any significant way.

There is also some resistance on the part of the participants in the process. Many of the new evaluative tools are highly resource-intensive in terms of both the time required from participants in the engagement and from facilitators and evaluators. It also requires a substantial buy-in from the participants. This can be particularly difficult if some individuals feel they have time constraints. There is also a tendency to want to “roll up the sleeves” and work on the problem, and people may not appreciate the value of regular breathing spaces

to evaluate where they are and where they might be going.

### **Conclusions**

The health care system in Canada has undergone fundamental restructuring in the last 20 years. There has been a greater emphasis placed on public participation in developing and allocating resources, setting priorities and creating programs. The degree to which this call has been taken up has varied considerably across the country.

It is important to note that most health care authorities and institutions are in the business of allocating resources, developing policies and creating programs that address particular health problems. However, it must be recognized that many public engagement processes (particularly those that genuinely involve grassroots community members) will tend to move beyond these limitations to address the larger issues of public policy, community values, equity and accountability, therefore:

### **Use a mix of evaluative methods**

There are dozens of possible community engagement tools available, ranging from public awareness programs to online surveys, focus groups, public meetings, citizens' assemblies, advisory councils and community health boards. People will participate in these forums by a variety of means. They may volunteer to be part of a process. They may be randomly selected. They may be elected from their communities or appointed by institutions.

Because of this variety of methodology, a variety of evaluation tools must be available to determine whether the engagements are effective. Traditional summative methods may be most useful for groups working on particular programs. More formative evaluations methods may be necessary to determine the effectiveness of those engagements working to define values and priorities. Developmental evaluations will be most useful in complex collaborative efforts seeking systemic change.

### **Plan for evaluation**

Evaluation needs to be addressed at the beginning of the process. Particularly with formative and developmental evaluation; the engagement participants should be involved in the planning process from the start. Effective community engagement is an iterative,

evolving process, and regular evaluation of the process itself will lead to outcomes that have greater impact.

Plan for different forms of evaluation for different types of engagement and even for different stages in particular engagements. Focus groups that are empowered to develop new programs may need specific data sets and benefit from summative forms of evaluation. Citizens' assembly engagements may need to evaluate the quality of information being provided to them as they go through their process. Advisory councils may need to evaluate whether they are representative of the community they speak for or work with.

### **Be flexible**

Use the outcomes of evaluation to rethink priorities, directions and methods being used. The impression that original goals aren't being reached shouldn't be seen as failure. The engagement process may be raising new questions, problems and solutions that need to be explored further. Be ready to use different evaluative processes as needs and directions change.

### **Learn, share and collaborate**

Good practices, resources and even talent related to evaluative methods should be shared, both within the health care sector and with the broader social service and community development sector. This is particularly true in the use of formative and developmental evaluation. These types of evaluation tend to focus on processes that are experiential and often values-laden. The more we can begin to identify common definitions and methodologies, the more we will be able to compare outcomes across different engagement processes. While it is important to be able to nuance and adapt definitions and tools to different contexts, it is also important to develop shared understandings of broad-stroke concepts. This will lead to evaluative methods and tools that will produce more meaningful learnings and improve the effectiveness of community engagement and public participation.



# The English Experience: Evaluating Patient and Public Engagement in Health

Edward Anderson and Emily Fellen, Involve

“You will be involved. The local NHS [National Health Service] will involve patients, carers, the public and other key partners. Those affected by proposed changes will have the chance to have their say and offer their contribution. NHS organizations will work openly and collaboratively.”

– NHS Next Stage Review: Leading Local Change, May 2008

This chapter examines existing indicators used in England to measure meaningful engagement and public confidence in the health care sector.<sup>1</sup> It also examines the challenges that exist in measuring patient and public involvement in health and lessons that can be learned from the British experience. Recommendations and conclusions are drawn from a comprehensive literature review as well as interviews with five leading engagement specialists in the health field, carried out in late 2008. These experts are spearheading many of the initiatives to improve the quality of health engagement evaluation and assessment.

Traditionally, the National Health Service (NHS) has afforded very limited involvement to patients and the public. NHS culture assumed that patients are passive recipients of health care services and that their needs were best anticipated and managed through top-down structures that left little room for meaningful consultation or devolved autonomy. Today, that culture is changing. The desire to sustain public confidence and a newfound recognition of the expertise and experience of patients is driving calls for innovation and reform.

## **Drivers for change**

Three reasons explain the shift toward greater patient and public

engagement. First, across the wider public sector, the appetite among civil servants for involving citizens in service design and decision-making exercises has grown. This appetite stems from the practical desire to improve the quality and responsiveness of public services, and serves a secondary interest by connecting the experience of public services to a broader democratic agenda. The drive for public and patient engagement in health care should be viewed within this wider context.

Second, a new focus on prevention and behavioural change has emerged within the health sector in order to meet the needs of an aging population, the rising cost of medical interventions and the growth of complex chronic disease. Practitioners and health administrators have come to view enhanced engagement as an important tool for encouraging behavioural change and healthy living.

Third, a series of widely publicized incidents required NHS administrators to restore public trust in the health service and its governance. An early example was the 2000 Kennedy Inquiry into the high mortality rate at a children's heart surgery in Bristol. Among its recommendations, the inquiry's report included no fewer than 10 recommendations aimed directly at the issue of public involvement and empowerment.

### **Key developments and challenges**

Legislative and regulatory changes have also had a powerful effect. Since 2001, all health bodies in the United Kingdom have been required to consult and involve patients in service planning and operation. As of October 2008, these requirements were extended to include relevant communities in assessing commissioning decisions. The new duties, embedded in section 242 of the National Health Service Act 2008, extend patient and public engagement from the service delivery arena to strategic decision-making. Increasingly, patients and the public are being viewed as full operational and strategic partners in the provision of British health care.

Another key change has been the introduction of new structures for engagement, such as Local Involvement Networks (LINKs) set up in early 2008. Designed to provide a link between citizens and services, these networks are a vehicle for ongoing engagement. LINKs have been established alongside local councils. Unlike previous NHS engagement structures that relied on artificial or unrecognized health

boundaries, LINks serve existing and well-established communities and integrate easily with local governance structures.

But despite new on-the-ground infrastructure such as LINks and a strong legislative mandate, the NHS faces difficulties in implementing section 242 of the 2008 NHS Act. Little headway has been made in gauging the uptake or success of these recent requirements.

Some existing indicators show troubling developments. For example, public trust in NHS is in decline; the British Social Attitudes Survey 2006 highlighted that just 12% of respondents had a great deal of trust that the NHS would “spend money wisely for the benefit of citizens.”<sup>2</sup> The challenge of accurately and meaningfully measuring the impact and quality of public engagement is not unique to the health arena, although it does face its own particular obstacles.

First, any indicators of successful engagement need to take into account the variety of organizations working within the health field; good engagement practices at a commissioning organization are likely to look quite different from the engagement practices among service providers. There is also a considerable difference between engaging patients in their own care and engaging members of the public in policy-making or planning.

Second, the NHS has traditionally been driven by quantitative targets and indicators based on clinical outcomes. These “hard” targets are not well suited or easily adapted to the qualitative and highly contextual work of patient and public engagement. Not surprisingly, many researchers and organizations have struggled to develop robust indicators that can measure meaningful engagement outcomes.

Moreover, most efforts at engagement do not typically yield immediately identifiable and causal clinical improvements. These shortcomings can fuel a clash among clinicians, administrators and proponents of engagement who argue that scarce resources should be spent on these activities.

A third challenge is the relative novelty of engagement for the NHS and the constant change of NHS policies, structures and priorities, which has hampered attempts to evaluate and reflect on health engagement structures. This bureaucratic churn has muddied the waters and made it difficult to properly evaluate the efficacy of many programs and initiatives.

Together, these factors explain why a definitive framework for assessing engagement has yet to be developed in the United

Kingdom, though efforts by the Healthcare Commission, the Department of Health and the National Centre for Health and Clinical Excellence are each underway.

### **The evaluation of health engagement in England**

Drawing on interviews with individuals at the forefront of the engagement in the health arena – and in particular with individuals involved in setting up frameworks for evaluating engagement – this section examines the extent and quality of evaluations of Patient and Public Engagement (PPE) activity in England. It then looks at specific case studies and outlines several of the methods for evaluating public engagement in health currently in use in England. It concludes by elaborating on the themes emerging from the literature review and interviews, and discusses what needs to happen in order for a framework for evaluation to be most effective.

An appendix has been provided as a reference for those unfamiliar with the structures and institutions of the NHS health system.

“Our strategic goal is now to have a government structure and a framework that promotes local ownership of these issues. We want a central framework and local organizations to work with it to develop their own nuanced approach.”

– Interviewee

The interviews revealed widespread concern that the instruments currently used to measure engagement in health in England are largely ineffectual. The Department of Health has yet to develop a set of indicators for measuring the quality and extent of participation in health care decision-making. Several interviewees stressed that such an instrument would need to allow for the complexity of the context, as well as the requirements and outcomes of a given activity. An evaluation framework would need to be both quantitative and qualitative. An effective framework would take into account the purpose of each engagement exercise.

The current regulatory standard against which health services measure their engagement activity is Core Standard 17. Each year, the NHS Trusts must assess their progress against the standard as part of the Healthcare Commission’s Annual Health Check. Core Standard 17 stipulates that “the views of patients, their carers and

others are sought and taken into account in designing, planning, delivering and improving health care service.”

Currently the vast majority of Trusts declare themselves to be meeting the PPE standard effectively. However, it has been argued that this indicator is by no means comprehensive enough and is therefore an insufficiently robust mechanism by which to measure engagement. Self-reported outcomes, especially on a contested topic such as engagement, are open to accusations of bias and manipulation. Resistance to evaluation comes from a number of sources, including managers who remain unconvinced by the merit of engagement and who do not wish to be regulated on this, and also from some engagement practitioners who worry that an overly prescriptive and target-driven regulatory regime may do more harm than good.

Others voice concern about the skewing affect of poorly designed indicators that can create perverse incentives for administrators and undermine strategic thinking.

“When it comes to indicators, I think that where a government focuses its attention, people jump. But there is something very double-edged about the distortion of resources. When talking to PCTs [Primary Care Trusts] about whether they would buy a co-production<sup>3</sup> model they might say ‘oh yes yes, but it doesn’t fit our strategic priorities this year.’ They have those priorities either because there is loads of money there or they are underperforming on that target.”

– Interviewee

A robust evaluation framework must therefore be flexible enough to take into account the context, structures and processes as well as the desired outcomes. But it must also be sensitive enough to address both the strategic directives defined centrally by the Department of Health and the needs and abilities of front-line organizations.

“I think that nationally we can define the broad shape of the things we want to look at, and it is then down to people locally in Primary Care Trusts and local organizations to find individual ways of measuring those for their local circumstances.”

– Interviewee

One of the strongest themes emerging from this research was the huge variety of engagement scenarios and rationales; for example, the distinction between engaging with the individual and with the community. A clear agenda has emerged within the U.K. health service to grant individuals the power to make informed decisions about their own health care plans. According to one of our interviewees, this is a more urgent necessity than the need to involve communities in strategic policy- and decision-making about services, given that the NHS has historically been a paternalistic organization that affords little knowledge and control to service users.

“There is a lot of evidence that engaging people as individuals in their own health care can be effective, but there is very little evidence that engaging people as communities can be effective. That doesn’t mean that there is evidence that it isn’t effective. From a U.K. perspective, where much of the emphasis has been on collective engagement rather than individual engagement – although that is beginning to change – the policy has been focusing on the least evidence-based component and ignoring the most evidence-based component.”

– Interviewee

Given the intricacies of engagement activities and the types of discourse surrounding the motivations for involvement, this chapter will now consider three case study evaluations of engagement activity, drawing on the indicators used for each. The case studies were chosen to reflect some of the broad types of engagement activity in the NHS and how best to evaluate them. At present, much of the useful learning to be done around the evaluation of PPE in England can be obtained by looking at evaluations of one-time engagement activities. The first is an evaluation of a one-off policy consultation, the second is an example of how central targets are measured and progress assessed and the third is an example of an evaluation of an engagement structure as a whole.

### **Our Health, Our Care, Our Say**

The Your Health, Your Care, Your Say process of 2005 was one of the largest British listening exercises on health issues. It led to the

development of the Our Health, Our Care, Our Say White Paper, a ten-year plan to make community-based services more flexible, tailoring them to the needs of individuals and increasing patient choice and control over treatments.<sup>5</sup> The listening exercise was evaluated in late 2005. Its objective was to assess the extent to which the methodology employed to engage patients and the public met the objectives of the engagement and to influence future engagement activities.

In many ways, this evaluation exemplifies how some one-off engagement exercises are assessed. The methods included first-hand observations of the events, as well as evaluation interviews with participants, facilitators, policy-makers, stakeholders and organizers.

An evaluation scheme<sup>6</sup> was developed that included an assessment of:

- public and participant interest in the outcomes of the listening exercise and the subsequent policy
- the attitudes toward the exercise by those involved and the perception of the importance of the exercise by participants
- the trust that participants had in the process.

The process was successful in some regards, such as the positive evaluation by participants, organizers and policy-makers; the flexibility of the process to the findings gathered; and the commitment and integrity to the exercise displayed by those involved. The effectiveness and quality of follow-up exercises worked less well, and the evaluation also found a lack of transparency in linking the outcome (the White Paper) to the activities of the participants.

This evaluation is interesting because it not only assessed the consultation in terms of the design of the exercise and the hard outcomes (e.g., the policy itself), but it also considered the “soft outcomes” (e.g., participants’ attitudes to the process and the degree to which they felt they were engaged). Clearly subjective outcome measures, such as public confidence in the process and attitudes toward health-care organizations before and after the exercise, are important metrics of success.

There are important distinctions between evaluating one-off engagement activities (such as a consultation – with clear boundaries and constraints) and evaluating ongoing engagement activities (such as LINks) that are more nebulous in character. As a one-off engage-

ment activity, the Our Health, Our Care, Our Say initiative relied on a straightforward evaluation framework, and one that can be adapted and used again for other closed consultation activities.

Evaluations of ongoing activities that need to take into account more complex causal relationships require a different framework. The ongoing work of Primary Care Trusts (PCTs) in public engagement, for example, must be evaluated using a more flexible approach that takes into account progress over time, the context such as the institutional cultures, and the regional differences among the Trusts.

### **Evaluating PCT engagement activity**

In late 2008, the Department of Health launched a program for “world class commissioning” to enable all PCTs to make the best commissioning decisions for their communities and patients.

Traditionally, commissioning decisions were made on the basis of clinical merit by experts without public or patient input. Now, PCTs will be held to account under an assurance system developed alongside the program. These metrics are instructive of the range of measures likely to be used more widely across the NHS to assess progress toward central targets on engagement. The commissioning assurance handbook<sup>7</sup> states that a PCT’s abilities to engage will be assessed across three elements – outcomes, competencies and governance – using techniques such as self-assessment and feedback from partners. Some of the indicators and evidence outlined in the handbook are listed below.

Indicator	What the PCT would need to demonstrate (examples)
Influence on local health opinions and aspirations	<ul style="list-style-type: none"><li>The PCT has strategies in place for communicating effectively with the local population</li><li>Agreement from stakeholders that the PCT has shaped the opinions and aspirations of the local population</li></ul>
Public and patient engagement	<ul style="list-style-type: none"><li>The PCT has a strategy in place to engage patients and the public and is able to demonstrate the effectiveness of this strategy through evaluation</li></ul>

	<ul style="list-style-type: none"> <li>Patient and public information is used to directly impact on quality and improvement</li> <li>The local population agree that their views are listened to</li> </ul>
Delivery of patient satisfaction	<ul style="list-style-type: none"> <li>The PCT can demonstrate that the commissioning decisions are driven by patient feedback<sup>8</sup></li> </ul>

Note that the metrics cover three types of indicators: formal requirements (does the Trust have a policy at all?), subjective stakeholder measures (what do the Trust's stakeholders think?) and impact measures (did the Trust's engagement actually impact on decisions?).

These three measures rely on different approaches to capturing data. The example above illustrates an approach to assessment that is common whenever progress against central targets needs to be measured.

This framework also encourages individual Trusts to select local outcomes. It does not, however, allow for much depth of understanding of the “soft outcomes” or the context of the process. It leaves little room for examination of the organizations’ motivations for undertaking engagement or the contextual factors in place.

The next example outlines an attempt to produce a framework for evaluation that takes into account the specific context of the activity and the anticipated outcomes that might be particular to an organizational or regional level.

### **Patient Advice and Liaison Service (PALS) Evaluation**

A 2008 evaluation of the national Patient Advice and Liaison Service (PALS) program assessed how far PALS has contributed to changing NHS culture by putting patients and service users at the centre of service planning and delivery. To conduct their analysis, the researchers used a “realistic evaluation framework.”<sup>9</sup>

Realistic evaluation is designed to provide a middle way between traditional experimental methods of quantitative inquiry and less reliable qualitative techniques. The analysis allows for some hypothesis testing based on anticipated self-reported outcomes. Taking contextual factors into account can enable causality to be ascertained between soft (attitudinal) and hard (policy) structural changes derived from the program.<sup>10</sup> This kind of assessment is particularly

useful when an entire engagement structure is being reviewed as opposed to one-time exercises or limited target areas. The case study methodology employed in the evaluation (alongside various other methods of inquiry) allowed for the mapping of varied and intricate causal pathways; case studies were examined in order to test whether the contextual factors and mechanisms in place would lead to anticipated outcomes. The main task was to assess whether the context hindered or enabled the mechanisms in place to exert change and result in anticipated favourable outcomes. This type of evaluation places the engagement intervention squarely into the context in which it operates and tries to untangle soft and hard structural changes. It is particularly useful when an entire engagement structure is being reviewed as opposed to one-off exercises or limited target areas.

The research team used the same framework identified in the Department of Health's national core standards for PALS. Anticipated outcomes were drawn from the following criteria:

- PALS is identifiable and accessible to the community served by the Trust/PCT.
- PALS will be seamless across health and social care.
- PALS will be sensitive and provide a confidential service that meets individual needs.
- PALS will have systems that make their findings known as part of routine monitoring in order to facilitate change.
- PALS enables people to access information about Trust services and health and social care issues.
- PALS plays a key role in bringing about a culture change in the NHS, placing patients at the centre of service planning and delivery.
- PALS will actively seek the views of service users, carers and the public to ensure effective services (DH, 2003a).<sup>11</sup>

## **Recommendations**

The interviews and literature review confirmed that the NHS in England is not conducting PPE as effectively as it could be. Changes to the way health engagement is evaluated and regulated are needed to increase the benefits to the NHS, patients and the public. In spite of the absence of an exhaustive evaluation framework in England,

there is much work that can be done to work toward this aim. This section considers what needs to be in place to make evaluation of this activity truly meaningful.

### **The need to develop shared definitions**

Key concepts such as “engagement,” “participation” and “community” are poorly defined across the health sector. Without shared meaning, the measures and indicators used to assess them will not be replicable or comparable.

### **Proven value**

The benefits of PPE to the health sector must be clear and proven. Health professionals rely on evidence-based clinical research.

Research on patient engagement has made important strides, but research on the benefits of community engagement in health planning and systems design lag behind. Despite the inherent challenges, PPE must work to establish its credibility within this paradigm.

### **The importance of stability**

It is vital that systems in place for securing PPE are given the time to establish themselves and operate under frameworks and mandates that have been clearly articulated to enable early and continuous evaluation. As this chapter has outlined, there has been plenty of innovation in this area, such as LINks replacing the Patient and Public Involvement forums. However, there is the danger that the regular transformation of services can lead to a lack of consistency in delivering PPE, and can often result in previous learnings being forgotten or needlessly having to be rediscovered.

### **A culture shift required**

A commitment to PPE must become commonplace within the NHS. To achieve this, PPE must be embedded in processes such as contracting services and commissioning cycles. It needs to be entrenched as an ethos within the NHS rather than being paid lip service through one-time engagement activities. PPE should be seen as a way of working and ought to be built into all stages of decision-making rather than tagged on to the end of a process as an afterthought.<sup>12</sup> One-time engagement activities are easier to evaluate, but a more complex framework of PPE will be required to enable this cultural change.

Given the varied work going on in PPE, there is a real need to share learning within and between institutions. The health care sector could learn much from the community engagement activities of the social care sector. Organizers of community engagement initiatives might do well to draw upon some of the learning from the innovative techniques currently being developed in patient-led service design.

“I think there are some very inspiring practices probably in the learning disabilities field around people’s own budget for care. It is almost where big commissioning meets little commissioning and I don’t think PCTs know how to do that. They have £X million pounds worth of hospital, so how do they package that up into discrete units for a person with diabetes? That would be interesting to think about and could be inspiring.”

– Interviewee

### **Internal development**

Any regulations or evaluation frameworks need to be accompanied by development and training for staff. At present there are big deficits in the ability of services to deliver effective PPE practices. The roles of patient and professional are changing, and these new understandings need to form part of the training of health professionals. Some commentators have stated that before community involvement in decision-making is measurable, we need to address the imbalance of power in individuals’ day-to-day dealings with the NHS. Involvement needs to begin with the core interaction between patient and practitioner. One interviewee stated that efforts to measure community involvement in health have so far been unsuccessful and that it is far easier to measure individual empowerment in care planning than an acute care area.

Once these needs have been met, a framework for evaluation would need to incorporate experiential, qualitative data and analyze outcomes of activity while remaining flexible enough to be applicable across the different institutions and their varying agendas. As we have seen, it is possible to deliver an evaluation of a one-time program, which remains tailored to the context and purpose of the engagement activity. This was achieved in the case of the PALS evaluation, which used a “realistic evaluation framework” that focused

on context and qualitative data. Because this is a theory-laden approach that requires significant development and alteration before and during the process, logically it would be difficult to apply to national or ongoing evaluation. The assumptions behind this approach could, however, be drawn upon. For example, a framework for analysis should take into account the contextual factors such as the amount of senior-level support for engaging patients and the public, the community served by the organization, or the amount of time and resources ring-fenced. Outcome indicators for PPE are unlikely to be set in stone because of the intricacies of a given situation, so an evaluation framework must allow for flexibility in the choice or design of these indicators by the institutions being evaluated. In particular, it is important that local NHS structures are able to adapt their success measures to what matters to their local participants.

From the interviews it is clear that the work completed so far in evaluating engagement in health must not go to waste; any national evaluation framework needs to incorporate existing measures and metrics. As this chapter has stated, in England, we are currently at the stage where the Department of Health is working through a series of existing data sets in order to identify indicators under the broad headings of engagement and involvement. The Department of Health is about to begin a procurement process for consultancy time to take this further. Time will tell whether the outcome of this process will lead to a flexible, responsive yet comprehensive framework able to incorporate the experiential and qualitative data so vital to understanding quality in this area. In many ways the coming years will be critical in the future direction that PPE in health takes, in large part based on how the NHS chooses to measure success.

The five experts consulted for this chapter were all unanimous in their feeling that currently there are no robust indicators or mechanisms for measuring good-quality engagement. This is due in part to a lack of research in this field, but also results from the ever-developing nature of PPE and the lack of support for the process in some sectors of the NHS. Moreover, the nature of PPE as a sometimes organic and complex phenomenon makes it a difficult subject matter to evaluate. This means that there is urgent need to develop shared understandings of the key concepts so they can be broken down and organized into methodologically sound, comparable indicators. Despite the early stage that we are at in England at developing our

indicators of engagement, there are some transferable lessons to be learned. This chapter concludes by highlighting three of the key principles for an evaluation based on the learning gathered through the interviews and literature review.

### **Evaluation should be holistic**

“Everything that can be counted does not necessarily count; everything that counts cannot necessarily be counted.”

— Albert Einstein

Although targets have clear benefits in driving up performance in certain areas, easily measurable targets can lead to box-ticking exercises. An evaluation should therefore take into account the wider impact of engagement at an individual level as well as an institutional level. Measures of success need to be focused on outcomes that matter to patients and the public and not what is easy or expedient to measure.

### **Evaluation should be grounded in the given context**

An evaluation should also take into account the structure and the context of an organization. Who supports engagement within the organization? How much does the PPE feed itself in the day-to-day delivering and commissioning of services? The following is a useful formula for examining whether a process was tailored to the situation:



This framework highlights that the process indicators (effectiveness, appropriateness and satisfaction with the process) are only part of the overall picture. A meaningful evaluation needs to consider how and why the purpose was set, the context in which the engagement took place and the needs of the various stakeholders involved.

### **Evaluation should be patient-focused**

In order to assess the effects of engagement, an evaluation should

take into account the voices of those who were involved using measures and indicators that make sense to them. Do they feel that anything changed as a result of the process? Would they undertake the activity again? This requires the use of qualitative techniques alongside more robust data in order to understand experiential components of engagement. A failure to do this risks creating structures that tick boxes for civil servants in Whitehall but that fail the patients and public they were set up to support.

### **Conclusion**

This chapter has examined the extent and quality of the evaluation of engagement in health practices in England today. It has highlighted some of the transferable lessons from the experience in England, including the standards that need to be in place before a regulatory evaluation approach can be successful. The criteria for evaluation presented in the previous section have emerged in part through the themes prevalent in the interviews with U.K. specialists in this field, and also by drawing on Involve's experience of health engagement and evaluation.

The systems in place in England for measuring effective patient and public engagement are not yet effective. Trusts are measuring themselves favourably against the current standard in place, but this indicator does not facilitate sophisticated measurement and evaluation of practices and outcomes. The case studies in this essay outlined some of the approaches that have been used to measure the impact and effectiveness of engagement in the British health care system. Given the abundance of variables, from different types of engagement methods and motivations for engagement to the differences between national and local organizations, it will be difficult – but not impossible – to develop a method of evaluation flexible enough to be used on multiple occasions so that standardized comparisons of engagement exercises can occur. At least in the context of health care in England, evaluation should also offer more than an account of engagement. Evaluation should drive good practices in the NHS through training and development in the field of public and patient engagement.

Organisation	About	Evaluation activity
Department of Health	The Department of Health is responsible for setting the standards in health care and the allocation of resources across the country,	Undertakes consultation on policy change and strategy, provides arms-length funding to regulators and the NHS centre for involvement, commissions independent bodies to conduct research and evaluation of engagement.
The Healthcare Commission	The Healthcare Commission <sup>2</sup> is the English independent regulatory body that conducts annual checks of NHS organizations by cross-checking declarations made by NHS Trusts against other forms of evidence such as third party commentaries. <sup>3</sup>	The annual check currently includes an assessment of how well organizations fare against Core Standard 17 of the NHS Act 2006, which states that patients and public should be involved in decision-making.
NHS Centre for Involvement	The NHS Centre for involvement was established in 2006 as a key body in the developing and establishment of effective involvement and engagement practice in the health field. Funded by Department of Health.	The centre works with the NHS and other organizations in supporting a culture of engagement and developing tools to support open dialogue and involvement.
Primary Care Trusts	These Trusts manage the primary care services in a local area and decide which health services a community needs. They are responsible for all first point-of-call services such as GPs, dentists, opticians and pharmacies. These Trusts make up a large proportion of the health service, receiving 80% of NHS funding. <sup>4</sup>	Trusts' commitment to engaging with patients and the public is assessed in the annual self-assessment under Core Standard 17.
Local Involvement Networks	These local networks will assist NHS provider organizations in engaging with the local community by providing a network of individuals and voluntary and community organizations. LINks replace the earlier Patient and Public Involvement forums.	Provide a pool of stakeholders that services might want to engage with, also have the power to gather information in order to hold services to account.
Patient Advisory and Liaison Service (PALS)	PALS work across organizational boundaries to provide advice and information to patients. PALS liaise with the relevant departments and organizations within the NHS. The service is intended, not only, to respond to queries and requests for information but also to relay these concerns to the relevant services, identifying gaps and room for improvements.	This service is subject to scrutiny under a set of core national standards and an evaluation framework.

# Learning from the LHINs

Beth Kapusta, John Grant and Chi Nguyen, MASS LBP

In a small Northern Ontario community, a group of seniors met with health service providers and representatives from their Local Health Integration Network (LHIN) to discuss the Aging at Home Strategy. At this session, seniors reported having difficulty getting to their appointments at the local clinic. The problem was scheduling.

The special bus service that transported seniors to their appointments operated a limited number of days per week, making it difficult to coordinate appointments with available transportation.

The clinic's scheduling assistant was surprised to hear about the transit issue. It was the first she had heard about the problem. The transit operator also regretted the situation but was already stretched to capacity. The scheduling assistant assured everyone that she could change the clinic's booking schedule to give preference to seniors when transportation was available. This issue and a very simple solution might never have been found if the LHIN had not brought people together to discuss services.

This story is one small example of what Ontario's 14 LHINs have discovered over the past three years: community engagement enhances our understanding of community needs and can often lead to greater efficiency and better outcomes.

This chapter explores the efforts of three LHINs to engage their communities. It is based on a series of interviews with the directors of planning, integration and community engagement and their senior consultants. We thank Nancy Sears and Julie White of the South East LHIN, Kim Baker and Sandi Pelly of the Central LHIN, and Laura Kokocinski and Kristin Shields of the North West LHIN for their insights and time.

Their observations help us to understand how their efforts to engage their communities are evolving. As they continue to refine

their work and explore new methods of engagement and evaluation, each LHIN has established its own distinctive approach.

### **The North West LHIN**

The North West LHIN extends from west of White River to the Manitoba border and from Hudson's Bay south to the United States. Among the LHINs, the North West has the smallest population spread over the largest geographic area. The distribution of its population makes it difficult to reach out to the public. Nevertheless, the North West's many small communities are very clear about their concerns and priorities. The North West LHIN understands how important it is that the public can express those concerns and feel heard.

According to Laura Kokocinski and Kristin Shields, initial efforts to inform the population about the North West LHIN quickly became interactive as members from each community came forward to share their perspectives on the quality and accessibility of care in the region. In short order, these consultations began to focus on identifying service gaps and prioritizing improvements.

The North West LHIN has developed several community partnerships, but because the population is thinly distributed, these initiatives often involve smaller discussions, roundtables and advisory groups. Shields notes that the North West LHIN has “tried larger forums, since that is the best way of reaching the greatest number of people. But it doesn’t work very well when you’re dealing with sensitive topics. People tend to be more honest when you are talking to them directly in smaller settings.”

The North West LHIN has also developed an email distribution list that includes more than 1,000 names so that it can quickly garner feedback on important issues. It has also identified local community champions who can assist the LHIN to access remote and marginalized communities. The LHIN is careful to check this input against the contributions of other stakeholders. It has also developed a feedback survey, which it uses to evaluate many of its public meetings and track their success over time.

The North West LHIN has also sought to deepen its relationships with Aboriginals, francophones and seniors, and it has employed specific engagement strategies for each.

The North West LHIN has shown that it is committed to work-

ing with citizens, and its many initiatives have influenced the work of other LHINs across Ontario. However, as Kokocinski explains, the most important measure of their success is the response the North West LHIN receives from its community: “To hear the population say we are getting this right is our reward.”

### **The Central LHIN**

The Central LHIN covers an area that spans some of Canada’s fastest growing and most diverse postal codes, immediately north of the HWY 401 to the rural farmlands south of Lake Simcoe. The Central LHIN began its efforts at engagement with a series of community roundtables for residents and health service providers. According to Kim Baker and Sandi Pelly, the Central LHIN has worked especially hard to engage with health service providers across the region. In their view, health service providers have special and largely untapped insights about the needs of patients and the wider community. The LHIN has tried to ensure that these front-line perspectives are used to inform policy development.

The Central LHIN prefers to invest in community engagement by supporting the efforts of service providers to develop their own engagement initiatives. Baker points to the work she has recently done to begin developing community engagement plans for the region’s hospitals. The Central LHIN prefers to work with its service providers in part because of the challenges associated with reaching out to such a large and growing population of 1.6 million residents. According to Baker, “The Central LHIN has 30 staff in the office and we simply do not have the ability to get out and talk to as many people as we’d like. We work with our service providers to help make these connections happen,” says Baker.

Central LHIN staff understand the importance of relationships to their work. “We want to get meaningful feedback as opposed to going out and telling people who we are and what we do.” The LHIN has worked to develop relationships with the leaders of many key communities. It relies on these leaders to accurately represent the interests of their communities and again helps to manage the challenge of engaging such a large and diverse population. As a result, Pelly describes her job as “half networking, half stakeholder relations.”

The Central LHIN also understands that engagement is a two-

way street. As Pelly explains, “Effective engagement occurs when people see that their concerns are being validated.” To this end, the Central LHIN has also used open houses and roundtables to facilitate discussions between citizens and health service providers, and recognizes the potential of these citizen-to-expert exchanges. Additionally, the LHIN has from time to time used surveys, focus groups and open meetings to assess public sentiments on particular issues.

Ultimately, Pelly notes that the “challenge is to sustain a balance” between engaging with experts, stakeholders and the public at large. This balanced approach fits well with the needs of the region and the current capacity of the LHIN. In the future, Central plans to pursue more elaborate and direct community engagement processes. According to Baker, this is all part of meeting the demands of the LHIN’s mandate. The goal is “to make engagement purposeful and meaningful for everyone.”

### **The South East LHIN**

The South East LHIN recognizes the value of engagement for boosting health outcomes. It views citizens as an important source of feedback concerning the performance of the region’s health services. It acknowledges that until recently, this important resource has gone largely untapped. Nancy Sears and Julie White both want to develop more systematic and ongoing engagement opportunities that provide regular information to health planners while restoring trust in the health system.

Like many of their peers in 2005, the South East LHIN embarked on an extensive process that saw their CEO and chair travel to dozens of information and listening sessions throughout the region. Since then, the South East LHIN has initiated a much wider range of one-on-one citizen discussions and has conducted many focus groups to assess public sentiments on a variety of issues.

In early 2008, senior staff embarked on an engagement process of delegated decision-making. The result was the Citizens’ Regional Health Assembly (CRHA), which brought together almost 100 citizens and practitioners for two days to generate the LHIN’s vision. As White explains, “This was a big step for us because it required us to surrender control for the very principles that would guide our work as an organization. But we thought it was important to

demonstrate that we really were listening, and we wanted to show that we were taking the public's input seriously. Delegating the development of our vision to a group of citizens and practitioners was a powerful gesture that should illustrate our commitment to community engagement."

The South East LHIN recognizes that developing a systematic, ongoing approach to engagement and fostering a "listening" culture takes time and a lot of work. But the LHIN is confident it has made significant steps in this direction. Following the Citizens' Regional Health Assembly, the LHIN sent the final report to each of the participants, along with a document that responded to questions that were not answered during the Assembly process. For Sears, this was an important gesture and one that the participants appreciated. She sees this commitment to detailed follow-up as an important benchmark for future activities.

The South East LHIN is working to make better use of the knowledge and experience of its health service providers and connect these insights with the needs and priorities of the public. It believes that more innovative forms of engagement are essential to brokering deeper and more meaningful connections to its community and its stakeholders.

### **Learning and Knowledge Sharing among the LHINs**

Leaders at all three LHINs stressed the importance of sharing knowledge and continuous learning. The Ministry of Health's Community Engagement Health Planners' Toolkit is widely viewed as an effective and useful resource, but many wish that more advanced materials were also available. Specific guidance on the fitness of particular tools to different engagement challenges would also be valuable.

Although the LHINs were established to address local concerns, they recognize how important it is to maintain close links and learn from each other's efforts and experiments. Currently, these efforts are shared anecdotally but several people expressed a desire to see more opportunities to regularly review the range of their work.

According to Sandi Pelly of the Central LHIN, video conferencing may be an effective way for staff from different LHINs to share their knowledge and experiences. "I really enjoyed a Ministry of Health video conference that over 150 people attended. Each LHIN contributed at least one video and we heard from speakers from

across the province. It really got people thinking and excited about what was happening in each other's backyards.”

The LHINs are also keen to connect to national and international fora where they can learn from and contribute to conversations concerning new methods for community engagement. They expressed admiration for some of the progressive Aboriginal initiatives underway in Western Canada as well as for the work of Vancouver Coastal Health, a much respected pioneer in this field. Some LHIN staff members have completed the public engagement program at California’s Fielding Graduate University and almost all are involved with the International Association for Public Participation (IAP2).

### **Defining Success**

The LHINs recognize that transparency and reciprocity are essential components to effective engagement. As Sandi Pelly points out, “Engagement only becomes effective when people begin to see that their concerns are being heard.” For Nancy Sears, “engagement is about creating an opportunity for citizens to make a real contribution.”

Successful engagement processes should help foster a sense of respect for the complexity of many health issues. They should help citizens and stakeholders to better understand the trade-offs and difficult choices that often must be made by health system administrators.

As Laura Kokocinski puts it, “Word of mouth is important in a small region. If we are doing well, people will come back. When we did our Integrated Health Services Plan, we went back to our community and invited the people who had originally participated to vet the document. We heard that we had listened because they could see their words in the document.”

Her colleague Kristin Shields expresses a similar sentiment: “I think you validate the findings of a report when it comes out and people say, ‘I can see my voice reflected in here,’ or ‘this really sums up what I said.’”

When it comes to designing a public event or meeting, the LHINs have learned about the many factors that contribute to its success. The timing of events, the choice of venue, who is invited, how they are invited, how exercises are structured, how discussion groups are formed and facilitated and how much free time is avail-

able for participants to socialize and get to know one another are just some of the many important components. They also noted that clarity about the scope and objectives of each engagement exercise is crucial to determining good event outcomes.

The LHINs also recognize the importance of strong communication skills and instincts. According to Julie White, “You need to present information in language that people can understand. I’ve been in rooms where it’s been impossible to understand what doctors and other experts were trying to say. Everyone needs to feel comfortable and then people will want to be engaged and contribute to the conversation.”

But Laura Kokocinski of the North West also cautions that LHINs should work to foster the autonomy and capacity of their stakeholders: “At the end of one session, people said, ‘This is just excellent! We’ve never been at a table like this before,’ and they started solving problems among themselves. They asked us to come back and facilitate another meeting. We said, ‘No, we do need to do that. If you feel it’s important enough to get together for more discussion, we’ll support you, but we don’t need to be involved for you to carry on this conversation.’”

The LHINs are also mindful to recognize that success can also come from failure or mistakes. “Every time we do a community engagement, we’re always learning from our past,” notes Kokocinski. For instance, “We have learned that in smaller communities, we cannot compete with something like the NHL finals.”

Lastly, as the LHINs become more established partners in community health care provision, their ability to sustain long-term relationships will become even more important. According to Nancy Sears, “It’s about building confidence and managing expectations, and over the long-term working in a way that earns respect.”

### **Evaluating Engagement**

Leaders from each LHIN expressed a desire to improve the quantitative and qualitative measures to assess their engagement efforts. Routine quantitative measures capture data such as the number and diversity of participants, as well as their satisfaction with a given meeting or program. More difficult to quantify is the cumulative effect and comparative benefits of many different meetings, or particular engagement strategies.

Currently, the LHINs rely on surveys and response forms as the most common format for evaluation. These surveys are used to assess how participants feel about being involved in an engagement process. Surveys can also be used to determine which parts of an engagement process participants felt were most effective, useful, informative or enjoyable. Surveys can also provide insight into the private thoughts of participants, which may, in some cases, be different from the thoughts and concerns expressed publicly in plenary or small group sessions.

In addition to monitoring the feedback from response forms, Kristin Shields recommends keeping track of the number of participants who maintain contact with the LHIN following a public engagement session.

To provide consistency to their efforts to track their progress, the Central LHIN has developed the SMILE Sheet a survey that participants use to provide feedback on an activity or meeting. The North West LHIN has developed its own Engagement Evaluation Reports. The template for these reports has been shared with other LHINs, which have begun to use them for their own purposes.

Typically these forms ask:

- Did we meet our objectives?
- What worked well?
- What could have been done better?
- What might be done next time to improve the process?

Success is measured by:

- the accessibility of engagement activities
- the positive response rate to initial invitations
- the degree of engagement of attendees
- the degree to which the engagement activity was responsive to the needs of the population being served
- the degree to which participants developed a better understanding of the issue(s) being discussed at the engagement activity
- the participants' interest in future participation opportunities.

Some LHINs see the development and standardization of new evaluation tools as the next stage in the expansion and improvement of their engagement initiatives. All 14 LHINs are working with Professor Julia Abelson from the Centre for Health Economics and Policy Analysis at McMaster University to develop new quantitative indicators and qualitative measures for evaluating community engagement exercises. It is generally agreed that more sophisticated evaluation frameworks will help capture some of the more complex and intricate concerns and questions raised by the participants and the organizers of public engagement processes.

Table 1: Use of engagement tools in community

Engagement Tool	NW	SE	Central
Citizen forums (using random selection)	✓		
Open houses	✓	✓	✓
Public meetings/presentations	✓	✓	✓
Focus groups	✓	✓	✓
Working groups with citizen involvement/representation	✓	✓	✓
Surveys/Evaluation forms	✓		✓
Advisory teams	✓		✓
Expert panels	✓		
Community events (with targeted communities such as Aboriginals)	✓	✓	✓
Speaker series	✓		
Roundtable discussions	✓		✓
Small group and one-on-one conversations	✓	✓	
Direct discussion with community leaders	✓	✓	✓
Drop-in conversation with public	✓	✓	✓
Media/press (to publicize events/issues)	✓		✓

The table on page 69 provides a summary of the South East, North West and Central LHINs' engagement efforts. The North West and the Central LHINs have used advisory teams, and the North West LHIN has convened expert panels and even held speaker series to help inform interested members of the public.

All three LHINs have held open houses and public meetings in which members of the general public were invited to engage with one another and their health care providers. The North West and South East LHINs have also led a series of small group sessions or one-on-one conversations. These are an important means by which to develop constructive relationships between citizens and their health care professionals, but they are very resource-intensive. The roundtable discussions employed by the North West and Central LHINs serve a similar function.

Each of the LHINs have also used the media to communicate with the public, but by and large, they have yet to use this coverage to promote or support existing engagement opportunities.

Table 2: Technical tools for engagement

Technical Tool	NW	SE	Central
Website	✓	✓	✓
Web-based surveys	✓		
Collaborative web-based tools			✓
Webinars for service providers		✓	✓
Video conferencing	✓		
YouTube	✓		
Phone-based surveys	✓	✓	✓
Email networking	✓	✓	✓
Databases	✓	✓	✓
Newsletters	✓		
Public service announcements/Ads/Posters	✓	✓	✓

Table 2 shows that each of the three LHINs has adopted a variety of technical tools to help manage their engagement efforts and reach out to citizens and health care practitioners. All three LHINs have websites, use email networking and keep databases. The North West LHIN has adopted the most varied collection of communication tools to meet the needs of a population spread out across vast distances in the northern part of the province. The North West LHIN uses conference calls and newsletters to engage and inform stakeholders and citizens. It has even used the YouTube website to communicate with those citizens who might otherwise be difficult to reach. The Central LHIN's focus on engaging health care service providers is reflected in its use of collaborative web-based tools and web-based seminars.

### **Conclusions**

This chapter should help demonstrate that a vital conversation about effective community engagement and the need for more thorough evaluation is underway among three of Ontario's LHINs. We have drawn five lessons from our conversations with the South East, North West and Central LHINs:

1. Ensuring that people feel welcome, are equipped to participate and that their opinions and concerns have impact are the first steps toward building a culture of engagement.
2. The LHINs have begun to use and adapt a variety of engagement tools, but funding pilot projects and championing more ambitious programs could accelerate innovation. Achieving a more sophisticated community engagement practice among Ontario's LHINs requires a sustained commitment to experimentation and learning.
3. Many of the engagement initiatives currently undertaken are ad hoc and episodic. LHINs should work to develop strategic, annual engagement plans that complement the operations and objectives of the organization and establish a yearly cycle for engagement.
4. The introduction of reliable, holistic and standardized evaluation criteria for engagement activities is welcomed by the LHINs. It will create new opportunities for comparison and improvement.

5. The relationship between LHIN communications and engagement initiatives is weak and can be improved. These initiatives should become a centrepiece for the LHINs' communications strategies, demonstrating the LHINs commitment to engagement while encouraging more citizens and stakeholders to become involved. By and large, these initiatives provide positive and compelling stories that deserve to be told to a wider audience.

Overall, the LHINs are making important strides and they recognize the potential of community engagement to make a difference in the provision of better attuned health care services.

In a small way, the story at the beginning of this chapter helps to illustrate this point. When a group of seniors in a Northern Ontario community met with health service providers and LHIN representatives. They had a problem with no apparent solution. In the end, the process of coming together to talk about a common problem provided the occasion for a simple solution: the clinic's scheduling assistant gave preference to seniors at times when transportation was available. This is not an unfamiliar or complicated story. Whether large or small, simple solutions to seemingly intractable problems can often be found when people come together to share their observations, concerns, expectations and expertise. This practical philosophy should be the basis for the LHINs' approach to community engagement. We worry that LHINs that underestimate the capacity and willingness of citizens to play an expanded and useful role are failing to equip themselves with the public insight and confidence they require to fulfill their mandates.

# Working with the Citizens' Workshops on Engagement and Health

Chi Nguyen and Peter MacLeod, MASS LBP

“We've all seen ads in the local papers announcing public meetings where we can learn more about an important issue and have our say. Input from the public is increasingly important to how governments and public agencies set policies and take decisions that affect you and your family.

“But something that should be easy – like holding a public meeting – can sometimes be very difficult. For organizers, it can be hard to attract a wide and representative range of people. For participants, it is not always clear what happens to their input when decisions are made.

“Local Health Integration Networks want to do a better job engaging with you and we want you to be a part of a conversation that will improve how we engage with hundreds of thousands of other people who call South East Ontario home.”

– Invitation letter to 1,000 households in South East Ontario

In early November 2008, 3,500 letters were sent to randomly selected households in South East, Central and North West Ontario. The letters invited citizens to spend a day with their Local Health Integration Network (LHIN) to learn about its work and their region's health care system. But these workshops were more than information sessions. They were part of the *Engaging with Impact* research project that culminates in this report. In this way, the Citizens' Workshops on Engagement and Health were designed to provide advice to the Ministry of Health and the LHINs that would help them improve their efforts to engage with citizens and better meet public expectations.

The workshops took place on consecutive Saturdays between November 27 and December 6, at the new Invista Arena in Kingston, the Rouge Woods Community Centre in Richmond Hill and at the library of Westgate Collegiate and Vocational Institute in Thunder Bay.

Citizens were selected from across each region and many travelled great distances to participate in the workshops. They drove from towns such as Sharbot Lake and Maitland in the South East, Alliston and Newmarket in the Central region, and Sioux Lookout, Kenora, Atikokan and Dryden in the North West.

Others had only to travel a few blocks and a few were surprised to meet neighbours and reunite with old friends when they arrived. But for the majority of participants, the workshop was something entirely new: a day spent in the company of strangers, meeting experts and administrators, learning about a health system they relied upon but struggled to understand, and attempting to describe frustrations they had often felt but never had a chance to express.

The South East, North West and Central regions provided different perspectives – each related to their demographic profile and the concerns of their region.

Conversation among South East participants focused on the difficulties of aging and the needs of seniors. Central participants concentrated on the importance of communication, the navigability of the system and the pressures of a growing population on scarce health resources. North West participants discussed the provision of timely information, the importance of mobility and the needs of those with complex chronic diseases living at a distance from major towns and medical centres.

Each session was hosted by a lead facilitator, who began by welcoming participants and thanking them for volunteering their Saturday to help improve the LHIN's public engagement efforts. LHIN administrators echoed these sentiments.

A quick activity broke the ice. Participants were asked to close their eyes and raise their hands in response to questions about the health care system. The purpose of this activity wasn't to show the ignorance or expertise of those in the room but rather the range of opinion and beliefs. Many of the questions had surprising answers that upended conventional wisdom. For instance, most participants were surprised to learn that their LHIN performed more favourably

than the provincial average on a range of health indicators.

Next, participants heard from an outside expert who spoke candidly about the inner workings of Canadian health care, and then they provided their own assessment of the challenges facing the LHINs. This “Health Care 101” was intended to deal with the shibboleths and mythologies that frustrate many discussions about health care and to put everyone on the same page.

By inviting an independent authority to supply a key piece of the day’s curriculum, the organizers were also signalling that they were willing to hear criticism and speak frankly about the complexity and shortcomings of the health care system.

In Kingston, participants heard from Duncan Sinclair, the former dean of Queen’s University Medical School. Sinclair explained the evolution of the Canadian health care system and spoke about the absence of system-level leadership. He acknowledged the rising costs of health care and worried that unless the system is reinvented to focus on “wellness” rather than “sickness,” the status quo will ultimately become unaffordable.

In Richmond Hill, Professor Raisa Deber from the Department of Health Policy, Management and Evaluation at the University of Toronto spoke about the incredible complexity of the health care system. Deber explained that it’s no surprise how much misinformation exists, given the number of competing levels of government, agencies and providers, each responsible for supplying one piece of the health care puzzle.

In response to a question about the accessibility of health care, Deber encouraged participants to think about the appropriateness of care. Because very few of us need the health care system at all times, we should try to think about how health resources can be appropriately and efficiently allocated – which could mean that those same services aren’t always close by or immediately available.

Lastly, Deber also discussed the difficulties implicit in measuring health performance. She cautioned that indicators are often inexact and regularly fail to tell the whole story. It was important advice as the participants set out to propose indicators that the LHINs could use to gauge the efficacy of their public engagement efforts.

In Thunder Bay, Carl White, the former president and CEO of the St. Joseph Care Group, discussed the challenges of integrating and restructuring the health care system and the government’s new

focus on stewardship. He also explained why he believes a renewed focus on mental health and community-based care for the elderly is essential.

White also mentioned the importance of developing electronic health records. This sparked an animated conversation among the participants, who agreed that the transition to electronic records was long overdue.

Following the presentation of their local expert, each workshop heard from a senior LHIN staff member. This “LHIN 101” explained the advent of the LHIN system, the role of LHINs within the provincial health system, how LHINs work to meet the needs of their region – and, most importantly, how they have attempted to make community engagement a central part of their mission.

Participants also learned about many of the demographic trends in their LHIN and how their LHIN is attempting to respond to their population’s changing needs.

During the South East workshop, participants heard from Paul Huras, the LHIN’s CEO, who explained the challenges and expense of providing health care to Ontario’s fastest-aging region. Still, Huras considers the region fortunate. The South East enjoys the benefits of a regional teaching hospital and six other hospitals, as well as a strong network of community services and family health teams. Huras also explained the many efforts his team has made in its first three years to engage with citizens throughout the region. “It’s important that we have the courage to hear and the courage to learn from citizens,” he said.

In the Central LHIN, Kim Baker, the senior director of planning, integration and community engagement, also provided the participants with an overview of the region and its demographics. Central LHIN is unique for its diversity and fast-growing immigrant communities. It works to balance the heavy demands of its densely populated southern region with its rural northern region, which sits along the southern shores of Lake Simcoe. As in many rural parts of the province, proximity to health services is the principal concern here.

The Central LHIN’s senior engagement consultant, Sandi Pelly, joined Baker to discuss the challenges associated with engaging a diverse and growing community. As Pelly explained, they have broken the LHIN into seven distinct planning areas. As the

needs of each area differ, so do their efforts to engage local citizens and patients. The Central LHIN has also established a community leaders group, which is helping the LHIN to reach out to different ethno-cultural communities. Like Huras, both Baker and Pelly emphasized the importance of learning from their efforts while widening the range and frequency of opportunities available to citizens to contribute their input.

In Thunder Bay, the North West LHIN's CEO, Gwen DuBois-Wing, was happy to welcome participants to the workshop. Like her colleagues in South East and Central Ontario, she began with an overview of the region and the recent work of the North West LHIN. Not surprisingly, her presentation emphasized the difficulty of providing care across a sparsely populated region that encompasses almost half of Ontario's total landmass. The size of the North West LHIN and the remoteness of many of its communities complicate not only the provision of health services, but also her efforts to effectively engage with citizens and patients across the region. The LHIN is investing in tools for online engagement and hopes this will be a more cost-effective method to better sustain important relationships and gather meaningful public input.

Despite the hardships associated with providing health services across the north, the North West LHIN has an avid and perhaps heightened sense of mission – a sensibility that was echoed by many of the participants themselves.

Following each LHIN's presentation, the lead facilitator, Peter MacLeod from MASS LBP, conducted a brief session intended to explain the role of the workshops within the larger research program and discuss the challenges of public engagement.

MacLeod described the connection between engagement and Ontario's democratic traditions and the reasons public engagement is a growing imperative for all public services. He pointed to Ontario's recent Citizens' Assembly on Electoral Reform as an example of the willingness and ability of citizens to play a greatly expanded role in public affairs. MacLeod also provided a template for distinguishing among different kinds of engagement. As he explained, too often consultation is really a one-way conversation, or else it becomes adversarial and unrepresentative. Though it might not be appropriate or realistic to expect that every public conversation devolve a major decision to its participants, it should be clear exactly "what's

on the table.” Public agencies need to demonstrate a willingness to use public input and make that input integral to their own decision-making process.

Over the course of each workshop, participants asked tough questions meant to clarify and provoke. Many chose to share personal experiences as either patients or caregivers. Few hesitated to express pride or frustration with local providers. Several South East participants felt that the region’s mental health services were inadequate. Central participants were frustrated that the system was not easier to navigate. The Expanding the Doorways to Care program, which provides system navigation support and services, was suggested as one practical way to address this issue. Several participants in the North West LHIN singled out a high-performing and technologically sophisticated family health team in Dryden, Ontario, as an example of local excellence.

With the conclusion of the morning’s presentations, the participants were assigned to working groups of four to eight people, and with a facilitator they began to get to know one another over lunch. As part of their homework prior to the workshop, the participants had been asked to talk with friends and family about their experiences at other public meetings or discussions. They took turns going around their table sharing what they had heard.

Many of the same stories turned up at each table. Most people had attended a town hall meeting where a few people had dominated the microphone and poisoned the discussion. Several participants recounted friends who, out of a “sense of civic duty,” regularly attended various local meetings and consultations. Still, each admitted that they doubted whether their participation really made much difference. Too often it felt like the real decision had already been made.

In Thunder Bay, several people had been consulted on the design and development of the regional hospital. By sharing their stories, the participants recognized that they had a lot in common and that many of their experiences were not at all unusual.

Next, each table was briefed on their tasks for the afternoon. During each workshop, the morning was spent learning and the afternoon was spent on group activities that would culminate in a series of recommendations. Each group began by discussing and reaching a common definition for “community engagement.”

Examples of their definitions include:

“Community engagement is local, diverse and representative, involves effective communication with sincerity and follow-through, directs change, is about responsibility and accountability.”

“Good community engagement needs to be representative of the population. People need to be treated honestly and respectfully, provided with accessible and understandable information and all inputs must be treated meaningfully.”

“Community engagement is a process for meaningful public input and dialogue. Results will be clear and progressive, taking into account diverse voices at table. Community engagement is accessible and interactive.”

Each group then produced a list of principles they believed could be observed, and used it to test whether meaningful efforts at community engagement were taking place. After an hour-long discussion, the groups paused to share their work and compare lists. Each list was entered on a screen at the front of the room so the participants could compare and discuss the results. (See Appendices for a complete list from each workshop.) Duplicates were eliminated and each group was asked to select the three principles they believed, were most important.

Each group then spent the balance of the afternoon working to develop specific proposals. These proposals used a simple template that helped each group to organize its work. Each table was handed three large foam-core triangles. At the top, or summit, they were asked to label one of their three principles. Beneath it, they were asked to identify two or three goals that would support the attainment of their principle. Finally, beneath their goals, each group was asked to propose indicators: concrete measurements that would supply evidence for their goals.

One table in Kingston began with the principle of “good communication.” Their goals included raising public awareness of the LHIN and taking greater care to use clear language in its reports and advertisements. They suggested that these goals could be evaluated by (1) focusing on the usefulness of the LHIN’s website and the

frequency with which the site is accessed and updated; (2) mapping the suitability of the pathways citizens and patients follow to obtain information; (3) measuring the readability of its materials and setting a standard for future publications; and (4) reviewing whether the range of materials the LHIN publishes is complete, easily accessible and suited to the interests of the region.

In Richmond Hill, one table proposed “accountability” as its principle. Their goals included raising overall confidence in the region’s health system and putting more information in the public domain.

Their first goal would be measured by a regular survey that would track public attitudes within the region, and possibly the creation of a regional health ombudsperson. They proposed that their second goal be satisfied with a new policy on public disclosure that would require service providers and the LHIN to release information about the quality and availability of services.

In Thunder Bay, one table, frustrated with pro forma consultations, suggested that “sincerity” be a guiding principle. They proposed an important but challenging goal: that “the staff of the LHINs demonstrate true empathy for the people and acknowledge their particular needs.” For them, they wanted evidence that would ensure a climate of mutual respect, real dialogue and full transparency. They suggested doing more to collect and use feedback from consultations and asked that staff be held accountable for low scores and poor results.

During the final plenary, representatives from each table presented their triangles and led the workshop through their lists of principles, goals and indicators. Many were clearly thought through and received applause from the audience. Others were well intentioned but incomplete or difficult to evaluate. It was a lesson for everyone on the complexity of finding quantitative measures for highly subjective experiences and qualitative goals.

Following the presentation, the triangle templates were collected and brought to the front of the room. The last task was to cluster the principles from the different tables in related groupings, or “mountain ranges.”

In the South East, the principles “meaningful,” “real influence” and “task appropriate” engagement were arranged in one cluster. In the Central LHIN, “community ownership,” “purpose-driven,”

“responsive” and “representativeness” became another. In the North West LHIN, “transparency”, “sincerity” and “plain language” formed one popular cluster. These clusters, along with the principles, goals and evidence they supply, form the foundation for the engagement scorecard proposed in the next session of this report.

Not surprisingly, among the many principles discussed during each workshop, several were specific to their region, but many more were universal. The following principles were discussed during each workshop and, as such, they have been afforded special weight in the development of the scorecard.

- Accountability
- Commitment
- Representative
- Openness
- Responsive
- Task appropriate
- Informative
- Accessible
- Good communication

With the completion of the clustering exercise, each workshop drew to a close. Participants were invited to share any last thoughts or offer feedback on the day.

Several participants admitted that they hadn't been sure what to expect, but that the format and purpose of the workshop represented real change. It was clear that there was still a lot of work to do. The principles they had identified were each valid, but the goals and indicators still needed to be refined. The participants generally agreed that they had provided valuable insight, but their insight needed the expertise and goodwill of the LHINs and the ministry if it was to have the impact they hoped for.

Participant feedback from each workshop can be found in the Appendices.





# TRANSPARENCY

- facts, information
  - ↳ budgets, costs
- results publicly presented understa
- simple language - clear
- process - communication & impac
- wellness education + prevent expa

# COMMITMENT

- providers + consumers bo
- in attendance <sup>(minimum)</sup> / trustwa
  - ↳ decision-makers / transpa
- defined goals / target
  - ↳ criteri

## access

- different appr
- cultural dive  
    → language

## responsiveness

- timely
- specific targ

## transparency

- publicity / a
- information
- substance







## Accountability

Good community engagement needs to be representative of the population. People need to be treated honest, & resp. fully, provided w/ understandable information & all input must be treated meaningfully.

(2-1-1)

Organizers allow for different types of learning - e.g.

• cross-seg.

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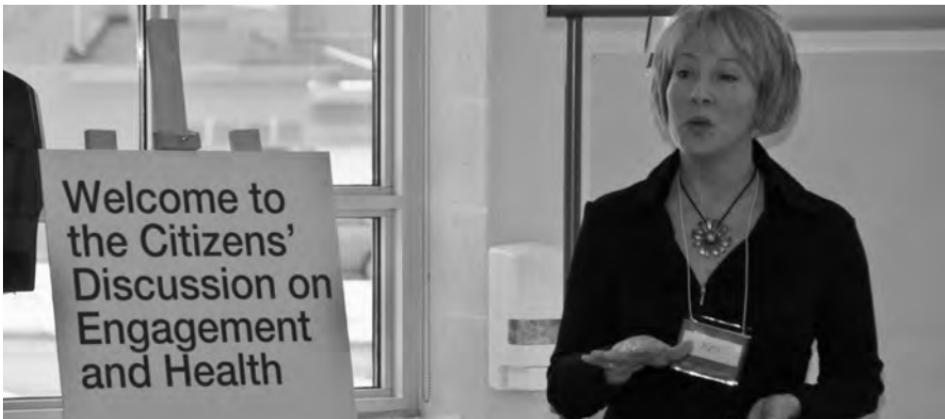
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# Section 3: A Scorecard for Evaluating Engagement

# A Scorecard for Evaluating Engagement

The following scorecard is based on our research and the contributions of the members of the Citizens' Workshops on Engagement and Health. It is intended to help guide Ontario's LHINs in the development of their engagement strategies and evaluation protocols and provide the Ministry of Health and Long-Term Care with measures that can be used to assess performance and compliance.

The scorecard is divided into five consecutive goals necessary to realize a culture of engagement: (1) value public input, (2) clarity of purpose, (3) well-defined roles, (4) accountability and (5) responsiveness and good communication.

Each of these five goals is based on a series of principles, first articulated by members of the Citizens' Workshops on Engagement and Health. Recommendations and suggested indicators accompany each goal.

Principles	Value Public Input	Recommendations	Indicators
<p>LHINs should work to demonstrate to their communities that they value public input.</p> <p>LHINs should work to expand the range of opportunities for citizens to provide input and participate in decision-making, systems-design and priority-setting exercises.</p> <p>LHINs should work to integrate opportunities for community engagement and learning into their routine operations.</p> <p>Citizens and stakeholders should be treated graciously and their contributions recognized and lauded.</p>		<p>Develop and maintain an annual calendar of engagement opportunities that supports corporate objectives and cycles</p> <p>Classify and track the range of annual engagement offerings</p> <p>Develop and promote a policy on accessibility that demonstrates a willingness to accommodate special needs</p> <p>Provide consistent and thoughtful follow-up to participants in a timely fashion</p> <p>Document and promote engagement offerings and their outcomes</p> <p>Create a dedicated budget for community engagement activities and specify a percentage for investment in innovation and experimentation</p> <p>Develop and implement an Integrated Community Engagement Strategy as a supplement to the integrated Health Service Plan</p> <p>Table an annual “What we’re learning from our community and stakeholders report” with the LHIN board</p> <p>Cultivate a culture of engagement excellence with HSPs; offer community engagement training and mandate the provision of HSP engagement plans that demonstrate the use and integration of public input</p>	<p>Does the LHIN publish an annual engagement strategy?</p> <p>Does the LHIN build on its engagement efforts year-on-year and can it demonstrate this progression?</p> <p>Does the LHIN track the ratio of deliberative to informative engagement activities?</p> <p>Does the LHIN use standardized criteria to evaluate the success of each activity?</p> <p>Do the cumulative reports of its engagement activities demonstrate public satisfaction and sustained improvement?</p> <p>Does the LHIN provide staff with a dedicated budget for engagement activities?</p> <p>Can the LHIN demonstrate participation from diverse and representative communities that is appropriate to its demographic profile?</p> <p>Can the LHIN demonstrate that engagement activities are generating heightened confidence and sustained engagement?</p> <p>What percentage of its catchment is aware of and has a good opinion of the LHIN?</p> <p>What percentage of its catchment has participated in a LHIN’s sponsored event, or has been consulted by an area HSP?</p>

	<p><b>Clarity of Purpose</b></p> <p>LHINs should work to ensure that citizens and stakeholders understand the rationale and utility of their engagement exercises.</p> <p>LHINs should clearly state and disclose the process, objectives, motivations and anticipated value of their engagement exercises.</p>	<p>Develop an “engagement framework” that clarifies and documents the design, delivery, outcome and evaluation of each engagement exercise</p> <p>Work to ensure that engagement exercises are fit-to-purpose</p> <p>Adopt a policy on plain language and employ editorial and creative expertise to maximize the legibility of LHIN external communications and documents</p> <p>Develop and delineate approaches and programming that vary for episodic and ongoing engagements</p> <p>Does the LHIN evaluate the legibility of its materials?</p> <p>Does the LHIN use an engagement framework to support its planning?</p> <p>Can participants and LHIN staff explain the purpose of a consultation and are their expectations satisfied?</p> <p>Does the LHIN track and categorize public comments and requests?</p> <p>Do LHIN staff value public input and are they using engagement strategies to inform their work?</p>
		<p><b>Well-Defined Roles</b></p> <p>LHINs should work to ensure that citizens and stakeholders understand their role within an engagement exercise as well as the scope and likely impact of their contribution.</p> <p>Develop a policy on the selection or intake of participants that differentiates between occasions for stakeholders, randomly selected participants and open admission or a combination thereof</p> <p>Whenever possible, supplement an engagement exercise with presentations and materials from a range of independent experts</p> <p>Emphasize learning and consider the range of learning modalities</p> <p>Does the LHIN have a policy regarding the public composition of its engagement activities?</p> <p>Do participants, staff and presenters understand their role and believe they can have an impact?</p> <p>Do participants report feeling better informed?</p> <p>Do participants report articulating their needs and interests?</p>

		<b>Well-Defined Roles</b>	<b>Indicators</b>
<b>Principles</b>	<b>Recommendations</b>		
	Be sensitive to the impact and skewing effect health professionals can have when they participate in deliberative exercises with laypeople	<p>Do participants report feeling more likely to work with others to address their needs and interests?</p> <p>Do participants report feeling more likely to address the LHIN about their concerns and ideas?</p>	<p>Are reports and LHIN documentation made easily available?</p> <p>Is non-proprietary data published in accessible formats for Web 2.0 applications by third parties?</p> <p>Does the LHIN's communications strategy support its engagement activities?</p> <p>Does the LHIN monitor its reputation as a "fair-dealer" among its stakeholders and public? Can it supply evidence of this reputation strengthening?</p> <p>Does the LHIN provide the results of regular internal reviews concerning the processes, costs and outcomes of engagement activities?</p> <p>Does the LHIN submit its engagement practices to external evaluation every three years, in correspondence to the triennial IHSP?</p>
	<b>Accountability</b>	<p>LHINs should share the results of the evaluation metrics they use to track and improve the engagement efforts.</p> <p>LHINs should be the source of fair and complete answers to honest questions about the health system.</p> <p>LHINs should work to build public confidence in the administration of the health system.</p> <p>LHINs should work to make the priorities and complexity of the health care system easier for citizens to understand, navigate and influence.</p>	<p>Develop self-, participant and external evaluation protocols that track success and encourage refinement and learning</p> <p>Develop a communications strategy that emphasizes the value of community engagement</p> <p>Develop an explicit competency and reputation for stepping into hard and adversarial situations and resolving controversy using fair and transparent processes</p> <p>Improve the accessibility and legibility of LHIN reports and documentation; adopt an open-source ethos for non-proprietary health information</p>

<b>Responsiveness and good communication</b>	
<p>LHINs should promote the results of public input and engagement.</p> <p>LHINs should provide direct and timely answers to the community and work to become a trusted source of information and guidance.</p> <p>The work of the LHINs should be known and appreciated by their communities.</p>	<p>Establish a target to address public inquiries, including complaints and requests for information within one week</p> <p>Track initiatives, changes and improvements that result from engagement activities</p> <p>Regularly inform the community regarding current and future initiatives; provide local health system status updates through direct mail and other media</p> <p>Follow-up with citizen participants to provide an account of their influence and impact</p> <p>Does the LHIN supply citizen relations data concerning public inquiries and response satisfaction?</p> <p>Can the LHIN point to substantive integration opportunities that arose from its engagement exercises?</p> <p>Do the LHIN's communications efforts reach a significant majority of its public?</p>



# Appendices

# Definitions of community engagement

The following definitions were generated during a warm-up exercise by each of the citizen workshops.

## **Kingston**

Community engagement is a shared responsibility to make democratic decisions.

Community engagement is getting to know community values, thoughts, demographics and problems. It is about understanding your customer base, having two-way communication in a transparent and accessible manner that is not reliant on technology.

Community engagement is an accessible process for meaningful, progressive, interactive input with a diverse community.

## **Thunder Bay**

Community engagement is participation from diverse, northern participants who are given equal opportunity to be heard and to contribute to the development of a working action plan, which makes us feel informed, good and healthy. Community engagement requires northern input and northern feedback with the LHINs.

Community engagement is local, diverse and representative, involves effective communication with sincerity and follow-through, directs change, is about responsibility and accountability.

Community engagement is involvement, two-way dialogues,

tolerance, participation, passion/caring, commitment and warmth, conducted in appropriate conditions.

Community engagement is an issue-based, local process that is patient-centred and accountable, outcome-based, and flexible, honouring and respecting diversity through transparent communication and involvement of communities at large.

Community engagement should be at the forefront of managing health care. Feedback mechanisms are needed. The person hearing the message needs to be able to respond. The community needs to feel ownership and believe in the system.

Community engagement is local, strives toward consensus, involves service-users, is active and involves new experiences and is always two-way.

#### **Richmond Hill**

Good community engagement needs to be representative of the population. People need to be treated honestly and respectfully, provided with accessible and understandable information and all inputs must be treated meaningfully.

Community engagement is a process for meaningful public input and dialogue. Results will be clear and progressive, taking into account diverse voices at table. CE is accessible and interactive.

Community engagement is:

- interactive
- people with like commitments getting together to do a task
- involvement
- testing a plan
- comprehensive
- representative of the community
- accessible – (know what it is, can engage, equity)
- meaningful
- transparent

# Members of the Citizens' Workshops on Engagement and Health

## **Kingston, Nov. 22, 2009**

Thomas Tomkow, Kingston  
Frances McLean, Kingston  
Ralph Raike, Kingston  
Suzanne Hamilton, Kingston  
Denise Kerr, Kingston  
Ben Hall, Kingston  
Gordon Ball, Kingston  
Frank Molnar, Godfrey  
Janet Lee, Kingston  
Bonnie Cheung, Kingston  
Sadiya Ansari, Kingston  
Barbara Matthews, Kingston  
Levina Collins, Kingston  
Brian Steele, Sharbot Lake  
Patricia Forsdike, Kingston  
June Beebee, Kingston

## **Richmond Hill, Nov. 29, 2009**

Judy Smith, North York  
Catherine Black, Thornhill  
Yolanda Masci, Woodbridge  
John Howe, Newmarket  
Andrea Journeaux, North York  
David Brown, North York  
Charanjit Bambra, North York  
Alan Xu, Richmond Hill  
Thomas Hay, Richmond Hill  
Lorna Taylor, Markham  
Eddie Nguyen, North York  
David Scott, Alliston  
Charlie Chun Min Xu, Thornhill  
John Leung, Thornhill  
Doris Chan, Thornhill  
Janet King, North York  
Valerie Clark, Markham  
Benjamin Lie, Richmond Hill

## **Thunder Bay, Dec. 6, 2009**

Stephanie Jones, Maitland  
Denise Miault, Kenora  
Ron Ross, Thunder Bay  
Mikael Mantyla, Atikokan  
Anne Carr, Thunder Bay  
Londie Harrisson, Thunder Bay  
Donna-Lynn Wiitala, Thunder Bay  
William Hicks, Thunder Bay  
Len Strehlow, Thunder Bay  
John Molenbroek, Murillo  
Ken McGratten, Thunder Bay  
Robert Olenick, Thunder Bay  
Rob Murphy, Thunder Bay  
Sarah Kerton, Thunder Bay  
Colleen Gibson, Thunder Bay  
Brian Thomas, Thunder Bay  
Marie Warren, Atikokan  
Frank Mastrangelo, Thunder Bay  
Fay Clark, Atikokan  
Raymond Iwanonkiw, Neebing  
Sandy Kennedy, Thunder Bay  
George Saavinen, Thunder Bay  
Seida Meyer, Dryden  
Ron Thorburn, Dryden  
Kenina Kakekayash, Sioux Lookout  
Gaetan St. Hilaire, Sioux Lookout  
Sharon Leif, Dryden  
Marie Warburton, Atikokan  
Leslie Soucky, Marathan  
Tom Parker, Thunder Bay

# Indicators and ideas exercise

Members of each workshop completed a series of “mountain templates”. Working in groups, the members identified the overarching goals or values they sought to realize and supported those goals with a strategy for achieving them. In many cases, they suggested evidence that would indicate progress toward their stated strategies and goals.

## **Richmond Hill, Central LHIN**

### **1. Goal:** Commitment to engagement

**Strategy:** Providers and consumers both in attendance, trustworthy, open transparency in decision-making, defined goals/targets, measurable criteria, specific issues/agenda attainable agreed-upon specific outcome, reporting back/feedback in timely manner and budget reasonable

### **2. Goal:** Promote access to engagement

**Strategy:** Different approaches, cultural diversity, removing inhibitors, multiple formats, material in print, visual/auditory, multiple language, disabled access, advertisement information widely accessible, multiple locations, community papers

### **3. Goal:** Patient and citizen centred engagement

**Strategy:** Seamless interaction and service delivery, agencies listen, responsiveness from HSPs, willingness to adapt systems to patients LHINs to improve integration/accountability

**Evidence:** Patient satisfaction, interaction between agencies for the patient, improved access to patient services, more evaluation of groups, integration with accountability agreements, indicators of patient experience survey, follow up letters, independent audit/evaluation

### **4. Goal:** Participants are respected

**Strategies:** Something real at stake, no time wasting, written invitations with clear expectations, guaranteed feedback from LHIN, more engagement opportunities

**Evidence:** Outlines citizens' contributions, newsletter to participants and press with feedback, people told what difference they made, open to all questions

### **5. Goals:** Representative of community

**Strategy:** Reach out to faith groups, disease groups, language groups, community organizations, service providers, use traditional and social media

**Evidence:** Numbers of representatives from groups increasing, informative presentations, dialogue, discussion, high engagement, number of ideas

generated, policy changes, implementations that serve needs of patients/ community, monitor feedback

**6. Goal:** Clear intent, purpose-driven engagement

**Strategy:** Make engagements issue based, i.e., hospital closure, major concern

**Evidence:** # of citizens responding against # citizens invited, LHIN communicates in plain language, purpose is clear, % of people at engagement who understand why they are there, a sense that citizens understand the “5 Ws” of an engagement.

**7. Goal:** Responsive to input

**Strategy:** Acknowledgement that citizens have been heard

**Evidence:** % of citizens surveyed who indicate that they've been heard, participants receive copy of report, results from engagement, provides explanation how decision was made, public informed prior to major decisions in a timely fashion

**8. Goal:** Effective communication

**Strategy:** Two-way dialogue, facilitate communication

**Evidence:** OHIP card renewal includes

info sheet from LHIN, LHIN provides citizens priority setting and funding allocation info for decision-making, Info sheets available at clinics, hospitals and other health-related sites, periodic population survey to assess key concerns

**9. Goal:** Community ownership

**Strategy:** Opportunities for community discussion, helping to set priorities (planning/integration/evaluation)

**Evidence:** Public confidence in LHIN and health system improves, increase in community/citizen input, more seats at more tables, regular surveys to measure effectiveness

**10. Goal:** Fiscal accountability

**Strategy:** Public money spent wisely and not wasted, people provided with or can access necessary information, LHINs report to public on spending

**Evidence:** Relationship of spending to results is explained

**Thunder Bay, NW LHIN**

**1. Goal:** Use of technology

**Strategy:** To implement and use communication technology to bring all members together to the greatest

degree possible <b>Evidence:</b> # of video conferences/ teleconferences, # of communities, # of hits on website/downloads, show innovation for increased access, reduced costs	accessible) <b>4. Goal:</b> Enhanced accountability
<b>2. Goal:</b> Improved communication  <b>Strategy:</b> Communication is constant, understandable, gets to the point effectively with all parties	<b>Evidence:</b> Effective, efficient, timely management of the services funded by the LHIN, LHINs should share information about the different services (and how they are used) with the public, LHINs regularly ask if the needs of communities are being met, accounting that we understand, # of patients satisfied, # of people who trust the system
<b>Evidence:</b> # of hits on website, # of calls on specific issues, complaints addressed within 7 days, complaints resolved within 1 month, # of workshops, info sessions put on by LHINs per year, % of people surveyed who are aware of the LHIN	<b>5. Goal:</b> Develop an engagement action plan  <b>Strategy:</b> Healthy people providing continuous feedback to health system
<b>3. Goal:</b> Integrity  <b>Strategy:</b> Acting in an equitable, transparent and honest manner in reflecting the needs of the community and potential influence of input. Treat people like people, keep promises and do what is "right"	<b>Evidence:</b> Holding meetings/community forums, bridging the gaps in services, collecting data and evidence about services, health and wellness needs are being met, an action plan is effectively communicated through different media
<b>Evidence:</b> Quality of feedback, rationale behind decisions and how public input contributed to them, involvement of representative, cross-section of the public (culture, age, gender, income, education etc.), citizen satisfaction (variety of means of providing input & receiving feedback should be available/	<b>6. Goal:</b> Common understanding  <b>Strategy:</b> To build agreement and understand by creating opportunities for the public to express their opinions  <b>Evidence:</b> Enhanced feedback,

peer review (in or out of province), report back to participants before before publishing findings and conclusions.

#### **7. Goal:** Sincerity

**Strategy:** LHIN staff demonstrates true empathy for the people and acknowledges their particular needs

**Evidence:** The LHINs and the community jointly recognize and reward the efforts on all sides, LHINs create an atmosphere of mutual respect, full disclosure, openness, transparency and dialogue

#### **8. Goal:** A personable experience

**Strategy:** To engage members of a community in an approachable, comfortable, caring and sincere manner

**Evidence:** Feedback from engagement process, LHIN evaluates itself and reports on commitment to be personable, e.g., lists considerations when planning a workshop, meeting people at the door, name tags, number of participants

#### **9. Goal:** Transparency

**Strategy:** Motives, goals and objectives are clear so that citizens understand decision-making processes

**Evidence:** Timely evaluation, ask whether people understood purpose of engagement, policy decisions are justified to public within 3 months through 3 media outlets

#### **10. Goal:** Plain language

**Strategy:** Provide communications in a variety of media and languages in plain words (or alternative formats, i.e., visual) that are culturally accurate and sensitive and have been tested with pilot groups. Plain language does not use acronyms, defines terms and uses small, simple words.

**Evidence:** LHIN communications will be judged on provision of contact info & availability of contact person, number of requests for clarification, availability of alternative formats (visual, text, electronic), existence of plain language policy, provision of plain language summaries of technical reports, etc.

#### **11. Goal:** Demonstrable results

**Strategy:** The LHINs make an active commitment to advocate on behalf of the community by bringing forward the suggestions from the people affected and returning with honest reports and meaningful results

**Evidence:** LHINs report back on a regular basis, setting timelines in advance, LHINs set up a mechanism

for follow-up, feedback, two-way dialogue and personal contact

#### **12. Goal:** Diversity

**Strategy:** To integrate information from both the mainstream population as well as from the marginalized populations most common to northern communities

**Evidence:** Information provided in languages appropriate to communities (French, Ojibway, Cree, Ojicree), use of plain language, geographic diversity, # of ways to outreach to different aspects of the communities, going directly to Aboriginal communities, use of community hubs (seniors groups etc.), offering more opportunities for engagement

#### **13. Goal:** Empowerment

**Strategy:** Gives people choices/opportunities to feel heard, valued, included and informed

**Evidence:** Improve/publicize centralized information resources, LHINs should measure how well service providers give out information (physicians, CCACs, Family Health Teams etc.), survey citizens—do you feel heard?, response cards after citizen consultations

#### **14. Goal:** Cross-section of population is engaged

**Strategy:** Represent the LHIN by including the spectrum of its population. This includes the disabled, non-English speakers, elderly, visible minorities, young adults and all socio-economic classes. This can be achieved by a variety of incentives (covering expenses) and methods (targeted recruitment, personalized invites etc.).

**Evidence:** LHIN's representation judged on: seats on board for laypeople with term limits, cooperation with community organizations, representative diversity, control for demographics when spots are limited

#### **15. Goal:** Be local

**Strategy:** To ensure all citizens have the opportunity to participate in the decision-making process that affects their communities

**Evidence:** The LHIN sets up a long-term and solid presence in the community to ensure a constant dialogue between citizens and LHINs, where people can go get answers, LHINs have regular community reviews wherein they address the particular concerns of the community and are accountable for producing results

## **Kingston, SE LHIN**

### **1. Goal:** Have real influence

**Strategy:** Everyone is treated with respect, dignity, etc, provide the information so that informed decisions can be made, opportunity for communities to give feedback

**Evidence:** Feedback from LHIN to explain rationale behind decision-making

### **2. Goal:** Good communication

**Strategy:** Use plain language and ability to communicate in different languages, different points of contact, let community know the LHIN exists, let them know what the LHIN is

**Evidence:** Internet website updates on current projects, findings, etc., pamphlet at all service providers made available to community

### **3. Goal:** Accessibility

**Strategy:** Location of session, time meetings to avoid workdays, accessibility for disabled, strong advertising and outreach, suitability of the room, duration of commitment, financial considerations

**Evidence:** Number of sessions throughout program, number of people

attending each session, different ways that participants are solicited, number of repeat participants, number of opportunities

### **4. Goal:** Openness

**Strategy:** To be receptive to change and to share ideas through a transparent process

**Evidence:** Public availability of transcripts and videos (through media), consistent policy on participant selection process, % of participants that understand the purpose of the engagement (survey)

### **5. Goal:** Accountability

**Strategy:** To be answerable to the community about processes and decisions

**Evidence:** Follow-up: LHIN to board, individuals to community, LHIN to community, LHIN contact with participants for formal updates and informal dialogue, number of reports downloaded from the website, response time to requests for information

### **6. Goal:** Inclusive

**Strategy:** To ensure the diverse voices of the community are heard

**Evidence:** Ensuring access (wheelchair

access, child care, money considerations, etc), recording demographic profile of group (e.g., Age, gender, ethnicity, etc), multiple channels of engagement (e.g., Phone survey, email survey, focus groups), number of methods, number of participants

**7. Goal:** Responsiveness (and effective listening!)

**Strategy:** Timely feedback and report back, provide opportunities for ongoing input, effective communication plan with community, more collaboration/integration aiming health service providers, knowing what the “plan”/course of action, senior representative LHIN present at meeting, provide straight answers, input is documented and given due consideration, option to receive info by various means (e.g., email, letter, website)

**8. Goal:** Task appropriate

**Strategy:** The right timing, amount of time, group for the task, process for the task

**Evidence:** Attendance and participation, success in achieving goal(s), process went as planned, did everyone contribute appropriately? have opportunity to do so?, did anyone dominate? expert opinion on process

**9. Goal:** Meaningful

**Strategy:** Integrity, opportunity to give input, be heard, goal is achievable and cost-effective. Reflective of all opinions. There is accountability — report back to group, leads to an outcome, process is real — will have an effect, content/task is substantive

**Evidence:** Outcomes are published (plans, reports), opinions are recorded, process, subject, outcome given visible priority, results in change, high degree of satisfaction

**10. Goal:** Leadership

**Strategy:** Experience, knowledge and skill re: process and people in group, good communicator with integrity, commitment, visibility

**Evidence:** Productive, goal achieved, lack of frustration/confusion in group, focused and motivated, on task

# Endnotes

## A Comprehensive Approach to Evaluating Deliberative Public Engagement

<sup>1</sup> For the history of a variety of deliberative public engagement practices, see John Gastil and Peter Levine (Eds.), *The Deliberative Democracy Handbook* (San Francisco, CA: Jossey-Bass, 2005).

<sup>2</sup> Examples of such process-choice charts include those produced by McMaster University ([www.vcn.bc.ca/citizens-handbook/compareparticipation.pdf](http://www.vcn.bc.ca/citizens-handbook/compareparticipation.pdf)) and the International Association for Public Participation ([www.iap2.org/associations/4748/files/spectrum.pdf](http://www.iap2.org/associations/4748/files/spectrum.pdf) and [www.iap2.org/associations/4748/files/toolbox.pdf](http://www.iap2.org/associations/4748/files/toolbox.pdf)).

<sup>3</sup> This definition is adapted from John Gastil, *Political Communication and Deliberation* (Thousand Oaks, CA: Sage, 2008).

<sup>4</sup> Mark Orlitzky and Randy Y. Hirokawa, "To err is human, to correct for it divine: A meta-analysis of research testing the functional theory of group decision-making effectiveness," *Small Group Research*, 32 (2001), 313–341. The National Issues Forums is one such process that stresses trade-offs ([www.nifi.org](http://www.nifi.org)).

<sup>5</sup> Lincoln Dahlberg, "The Habermasian public sphere: Taking difference seriously," *Theory and Society*, 34 (2005), 111–136.

<sup>6</sup> After all, nothing is learned when one's research simply establishes that a program intended simply to "inform" the public does not engage citizens in a meaningful dialogue. Similarly, little is gained when a program with no clear values or intentions — but clearly no deliberative element in its design — turns out, on closer inspection, to indeed lack deliberative features.

<sup>7</sup> To get a sense for more action-oriented engagement, see examples in Matt Leighninger, *The Next Form of Democracy: How Expert Rule Is Giving Way to Shared Governance — and Why Politics Will Never Be the Same* (Nashville, TN: Vanderbilt University Press, 2006).

<sup>8</sup> Leighninger (note vii) stresses such impacts. For a readable account of the wider aims of deliberative democracy, see Amy Gutmann and Dennis F. Thompson, *Why Deliberative Democracy?* (Princeton: Princeton University Press, 2004).

<sup>9</sup> For a range of measurement methods for assessing deliberation (beyond merely disagreement), see Laura Black, Stephanie Burkhalter, John Gastil and Jennifer Stromer-Galley, "Methods for analyzing and measuring group deliberation," in Lance Holbert (Ed.), *Sourcebook of Politi-*

*cal Communication Research: Methods, Measures, and Analytical Techniques* (New York: Routledge, in press).

<sup>10</sup> For a good example of an attempt to assess a range of policy-relevant impacts, see David H. Guston, "Evaluating the first U.S. consensus conference: The impact of the citizens' panel on telecommunications and the future of democracy," *Science, Technology, & Human Values*, 24 (1999), 451–482.

<sup>11</sup> Inventories of these empirical impact claims appear in: Stephanie Burkhalter, John Gastil and Todd Kelshaw, "A conceptual definition and theoretical model of public deliberation in small face-to-face groups," *Communication Theory*, 12 (2002), 398–422; Simone Chambers, "Deliberative democratic theory," *Annual Review of Political Science*, 6 (2003), 307–326; Michael X. Delli Carpini, Fay L. Cook and Lawrence R. Jacobs, "Public deliberation, discursive participation, and citizen engagement: A review of the empirical literature," *Annual Review of Political Science*, 7 (2004), 315–344; and Gastil (note iii).

<sup>12</sup> This would be lower-grade equivalents of the polls described by James Fishkin and

Cynthia Farrar, "Deliberative polling: From experiment to community resource," in Gastil and Levine (note i).

<sup>13</sup> On varied measures of attitudinal impact in longitudinal data, see John Gastil, Laura Black, Eugene P. Deess and Jay Leichter, "From group member to democratic citizen: How deliberating with fellow jurors reshapes civic attitudes," *Human Communication Research*, 34 (2008), 137–169. On assessing change in voting behaviour resulting from deliberation, see John Gastil, Eugene P. Deess, Phil Weiser and Jordan Meade, "Jury service and electoral participation: A test of the participation hypothesis," *Journal of Politics*, 70 (2008), 1–16. On different approaches to measuring efficacy, see John Gastil, "Adult civic education through the National Issues Forums: Developing democratic habits and dispositions through public deliberation," *Adult Education Quarterly*, 54 (2004), 308–328.

## **The Canadian Experience: Observations and Lessons from the Canadian Health Sector**

<sup>1</sup> Information about developmental evaluation was obtained during interviews with Mark Cabaj of the Tamarack Institute and from Jamie A. A. Gamble, *Developmental Evaluation Primer* (Montreal, PQ: J.W. McConnell Family Foundation, 2008). Available at [www.mcconnellfoundation.ca/utilisateur/documents/EN/Initiatives/Sustaining%20Social%20Innovation/A%20Developmental%20Evaluation%20Primer%20-%20EN.pdf](http://www.mcconnellfoundation.ca/utilisateur/documents/EN/Initiatives/Sustaining%20Social%20Innovation/A%20Developmental%20Evaluation%20Primer%20-%20EN.pdf).

<sup>2</sup> *A Review of the Trends and Benefits of Community Engagement and Local Community Governance in Health Care* (Toronto, ON: Ktpatzer Consulting, 2006). Available at [www.aohc.org/app/wa/doc?docId=157](http://www.aohc.org/app/wa/doc?docId=157).

<sup>3</sup> *Strategic Directions (2003–2008)* (Cape Breton Island, NS: Cape Breton District Health Authority, 2008). Available at [www.cbdha.nshealth.ca/StrategicDirectionsProgressReport\\_%209%20February2008.pdf](http://www.cbdha.nshealth.ca/StrategicDirectionsProgressReport_%209%20February2008.pdf).

<sup>4</sup> *Community Development Framework* (Winnipeg, MB: Winnipeg Regional Health Authority, 2007). Available at [www.wrha.mb.ca/community/commdev/files/CommDev\\_Framework\\_07.pdf](http://www.wrha.mb.ca/community/commdev/files/CommDev_Framework_07.pdf).

<sup>5</sup> Saskatoon Health Region. Programs & Services Community Development ([www.saskatoonhealthregion.ca/your\\_health/ps\\_community\\_development.htm](http://www.saskatoonhealthregion.ca/your_health/ps_community_development.htm)).

<sup>6</sup> “Evaluation Framework for the Vancouver Coastal Health Community Engagement Department.” Unpublished document.

<sup>7</sup> For more information about Photo Voice, Concept Mapping, and Community Mapping see the St. James Town Initiative website: [www.sjtinitiative.com/](http://www.sjtinitiative.com/).

<sup>8</sup> For some very influential documents on this topic, see Center for Disease Control and Prevention. Principles of Community Engagement ([www.cdc.gov/phppo/pce/index.htm](http://www.cdc.gov/phppo/pce/index.htm)) and Sherry Arnstein, “A Ladder of Citizen Participation.” Available at <http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html>.

### **Key Interviews**

Rick Blickstead, Chief Executive Officer, Wellesley Institute

Jeanette Edwards, Regional Director, Primary Health Care, Winnipeg Regional Health Authority

Shan Landry, Vice-President, Community Engagement, Saskatoon Health Region

Melissa Lee Roth, Community Health Coordinator, Cape Breton District Health Authority

Margeth Tolson, Community Engagement Leader, Vancouver Coastal Health

### **Additional Resources**

*Health Evidence Network, What Is the Evidence on Effectiveness of Empowerment to Improve Health?* (Copenhagen, DK: World Health Organization, 2006). Available at [www.euro.who.int/Document/E88086.pdf](http://www.euro.who.int/Document/E88086.pdf).

Amanda Sheedy et al., *Handbook on Citizen Engagement: Beyond Consultation* (Ottawa, ON: Canadian Policy Research Network, 2008). Available at [www.cprn.com/documents/49583\\_EN.pdf](http://www.cprn.com/documents/49583_EN.pdf).

Tamarack Institute (<http://tamarackcommunity.ca/>).

Griffiths University Urban Research Toolbox. Evaluating Community Engagement ([www3.secure.griffith.edu.au/03/toolbox/evaluating\\_engagement.php](http://www3.secure.griffith.edu.au/03/toolbox/evaluating_engagement.php)).

## **The English Experience: Evaluating Patient and Public Engagement in Health**

<sup>1</sup> Given the differences in health care structures in various parts of the United Kingdom, this chapter has chosen to focus on England in order to provide clear findings.

<sup>2</sup> Peter Taylor-Gooby (2006), cited in David Levy, *An Independent NHS: what's in it for patients and citizens* (Oxford: Picker Institute, 2008).

<sup>3</sup> By two of the expert interviewees in this research.

<sup>4</sup> The term “co-production” refers to a process whereby decision-makers work with service users, service providers or citizens to develop a service or make a decision that is acceptable for all concerned.

<sup>5</sup> [www.dh.gov.uk/en/Healthcare/Ourhealth/careoursay/index.htm](http://www.dh.gov.uk/en/Healthcare/Ourhealth/careoursay/index.htm)

<sup>6</sup> D. Warburton, *Evaluation of Your Health, Your Care, Your Say Final Report* (London: Department of Health, 2006). Available at: [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4138622](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4138622).  
Department of Health, *World Class Commissioning: Commissioning Assurance Handbook* (London: Department of Health, 2008). Available at: [www.dh.gov.uk/en/Healthcare/Ourhealth/careoursay/index.htm](http://www.dh.gov.uk/en/Healthcare/Ourhealth/careoursay/index.htm)

<sup>7</sup> Adapted from Department of Health, *World Class Commissioning: Commissioning Assurance Handbook* (note ix) p. 77 .

<sup>8</sup> D. Evans et al., *National Evaluation of Patient Advice and Liaison Services (PALS)* (Bristol: University of the West of England, 2008). Available at: <http://hsc.uwe.ac.uk/net/research/Data/Sites/1/GalleryImages/Research/PALS%20Exec%20Sum.pdf>.

<sup>9</sup> For more information about realistic evaluation, see R. Pawson and N. Tilley, *Realistic Evaluation* (London: Sage Publications, 1997).

<sup>10</sup> Cited in D. Evans et al. (note xi) p. 22. Available at: [www.pals.nhs.uk](http://www.pals.nhs.uk).

<sup>11</sup> A. Andersson, J. Tritter and R. Wilson (Eds.), *Healthy Democracy: The Future of Involvement in Health and Social Care* (London: Involve and NHS Centre for Involvement, 2007).



