ENGAGING CIVIL SOCIETY IN SUPPORTING RESEARCH USE IN HEALTH SYSTEMS
Dialogue Summary:
Engaging Civil Society in Supporting Research Use in Health Systems

23 November 2009
McMaster Health Forum
For concerned citizens and influential thinkers and doers, the McMaster Health Forum strives to be a leading hub for improving health outcomes through collective problem solving. Operating at the regional/provincial level and at national levels, the Forum harnesses information, convenes stakeholders, and prepares action-oriented leaders to meet pressing health issues creatively. The Forum acts as an agent of change by empowering stakeholders to set agendas, take well-considered actions, and communicate the rationale for actions effectively.

Authors
John N. Lavis, MD PhD, Director, McMaster Health Forum, and Professor and Canada Research Chair in Knowledge Transfer and Exchange, McMaster University
Ameya Bopardikar and Ben McCutchen, Fellows, McMaster Health Forum

Funding
The stakeholder dialogue, and the issue brief that informed it, were both funded by the Ontario Agency for Health Protection and Promotion, the Public Health Agency of Canada, and the World Health Organization. This work was also carried out with the aid of a grant from the Canadian government’s Global Health Research Initiative, a partnership between the International Development Research Centre (IDRC), the Canadian Institutes of Health Research (CIHR), Health Canada (HC), the Public Health Agency of Canada (PHAC), and the Canadian International Development Agency (CIDA). The views expressed in the issue brief are the views of the authors and should not be taken to represent the views of the funders.

John Lavis receives salary support from the Canada Research Chairs Program.

The McMaster Health Forum receives both financial and in-kind support from McMaster University.

Conflict of interest
The authors declare that they have no professional or commercial interests relevant to the dialogue summary. Select members of the funding organizations reviewed a draft dialogue summary but the authors had final decision-making authority about what appeared in the dialogue summary.

Acknowledgments
The authors wish to thank Ileana Ciurea and the staff of the McMaster Health Forum for assistance with organizing the stakeholder dialogue. The authors also wish to thank Nancy Johnson (Lead, Publications, McMaster Health Forum) for assistance with writing/editing.

Citation

Dialogue
The stakeholder dialogue about engaging civil society in supporting research use in health systems was held on November 23, 2009 at the McMaster Health Forum in Hamilton, Ontario, Canada.

Product registration numbers
ISSN 1925-2226 (print)
ISSN 1925-2234 (online)
# Table of Contents

SUMMARY OF THE DIALOGUE .............................................................................................................................. 4

SUMMARIES OF THE FOUR DELIBERATIONS ................................................................................................. 5

DELIBERATION ABOUT THE PROBLEM ....................................................................................................... 5

DELIBERATION ABOUT POLICY AND PROGRAM OPTIONS ........................................................................... 7

Option 1 – Employ deliberative polling to inform health system policymaking ............................................ 7

Option 2 – Convene deliberative dialogues to inform and influence health system policymaking ............. 9

Option 3 – Use new media to influence health system policymaking ............................................................ 10

Considering the full array of options .................................................................................................................... 11

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS .................................................. 12

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES.............................. 13
SUMMARY OF THE DIALOGUE

Dialogue participants generally agreed that: 1) research evidence is often not used in health systems; 2) civil society is typically not engaged in supporting research use in health systems; and 3) there are few enablers of civil society engagement in supporting research use in health systems. In discussing the second aspect of the problem – civil society is typically not engaged in supporting research use in health systems – a number of dialogue participants observed that the focus of civil society has typically been on specific diseases (that they or their family members live with and that they would like to see get greater attention), programs and services (that they believe to be effective and that they would like to see receive funding), and issues (that affect how diseases are treated or which programs and services are funded). In discussing the third aspect of the problem – there are few enablers of civil society engagement in supporting research use in health systems – a number of dialogue participants noted that little effort has been directed at increasing the demand for research evidence among civil society (e.g., by assisting civil society to see how health system dynamics profoundly influence the diseases, programs and services, and issues that they care about). Dialogue participants also noted that little effort has been directed at improving the supply of relevant and usable research evidence (e.g., by involving civil society in priority setting for research or by enhancing access to research evidence in ways that help civil society to understand its implications in their local context).

In discussing three options for addressing the lack of civil society engagement in supporting research use in health systems, most dialogue participants felt that deliberative polling, deliberative dialogues, and new media all have a role to play. That said, several dialogue participants were drawn more to the collaborative nature of deliberative dialogues and to new media’s potential for giving civil society greater control over the decisions that will affect them, than they were to the consultative nature of deliberative polling. The challenge, almost all dialogue participants argued, was matching a given approach and its design to the issue at hand and the local context at the precise time when a window of opportunity opens. Dialogue participants identified the potential for the manipulation of deliberative polling by those commissioning a poll (which is always a risk for consultative approaches), the need for capacity building both for those organizing deliberative dialogues and for those participating in these dialogues (in order for the dialogues to be truly collaborative), and the need for much more evaluation of new media’s ability to support research use. Dialogue participants diverged in their views about whether the presence of senior government officials (like Ministers) would help or hinder deliberative dialogues in the particular political systems with which they are each familiar.

Many dialogue participants agreed that the implementation of these options likely requires moving forward on two parallel tracks: 1) raising awareness about the approaches using easy-to-understand materials that describe: each approach, how to adapt the approach to particular issues and contexts, “alarm bells” that signal a looming problem in its use, and how to evaluate its impact and the factors that influence its impact, and 2) increasing the demand for and supply of relevant and usable research evidence.
SUMMARIES OF THE FOUR DELIBERATIONS

DELIBERATION ABOUT THE PROBLEM

Most dialogue participants took as a given that research evidence is often not used in health systems. However, one dialogue participant distinguished between evidence of lack of use (which is our principal focus) and lack of evidence about use (which may be due to reporting issues, among other reasons). Many dialogue participants recognized that research evidence can help to clarify problems, frame and assess options, and identify barriers to implementation as well as strategies to overcome these barriers. One dialogue participant, looking at the issue from a complementary perspective, argued that research evidence can be used in civil society organizations’ policies and programs, as well as in their advocacy efforts targeted at the systems in which their organizations work. A number of dialogue participants pointed out that there may sometimes be important reasons for research evidence not being used. For example, research evidence may be competing against the beliefs that underpin indigenous health systems and the complementary and alternative medicine used in these systems. Research evidence may also be competing against stakeholder pressure, institutional constraints, and a variety of external factors (such as donors, in the case of low- and middle-income countries).

Many dialogue participants agreed that civil society is typically not engaged in supporting research use in health systems. Several dialogue participants pointed out that the focus of civil society has typically been on: 1) specific diseases that they or their family members live with and that they would like to see get greater attention; 2) specific programs and services that they believe to be effective and that they would like to see get funding (as one dialogue participant put it, “they already know the answer”); and/or 3) specific issues that affects how diseases are treated or which programs are funded.

These participants argued that the more personal the interest, the narrower the range of evidence that is typically drawn upon. One dialogue participant observed that the focus among research funding agencies has until now been largely on the role of researchers in supporting research use in health systems, and particularly on their dissemination activities, and not on civil society at all.

Box 1: Background to the stakeholder dialogue

The stakeholder dialogue was convened in order to support a full discussion of relevant considerations (including research evidence) about a high-priority issue in order to inform action. Key features of the dialogue were:
1) it addressed an issue currently being faced in federal, provincial, and territorial publicly funded health systems;
2) it focused on different features of the problem, including (where possible) how it affects particular groups;
3) it focused on three options (among many) for addressing the policy issue;
4) it was informed by a pre-circulated issue brief that mobilized both global and local research evidence about the problem, three options for addressing the problem, and key implementation considerations;
5) it was informed by a discussion about the full range of factors that can inform how to approach the problem and possible options for addressing it;
6) it brought together many parties who would be involved in or affected by future decisions related to the issue;
7) it ensured fair representation among policymakers, stakeholders, and researchers;
8) it engaged a facilitator to assist with the deliberations;
9) it allowed for frank, off-the-record deliberations by following the Chatham House rule: “Participants are free to use the information received during the meeting, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed”; and
10) it did not aim for consensus.

The stakeholder dialogue also included a simulation of each of the three options, which can be hard to describe and arguably need to be experienced in order to be fully understood. The simulations provided a structured opportunity for dialogue participants to experience each approach.

Participants’ views and experiences and the tacit knowledge they brought to the issues at hand were key inputs to the dialogue. The dialogue was designed to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. The dialogue was also designed to generate action by those who participate in the dialogue and by those who review the dialogue summary and the video interviews with dialogue participants.
Dialogue participants identified the tremendous diversity within civil society, and in opportunities for their engagement, as a key issue that has likely hampered (and will hamper) efforts to engage civil society in supporting research use in health systems. On the one hand, the diversity within civil society was taken as self-evident. One dialogue participant noted that there are 500 non-governmental organizations (NGOs) in a single region in the Canadian province of Quebec, many of which are dedicated to a single cause and none of which can be said to have a “peak association” that can represent a number of them. On the other hand, several dialogue participants argued that we need more research on civil society, including research about their goals and funding, as well as research about how they see their role in health systems and their need for different types of research evidence to inform and influence health systems. On the subject of funding, one dialogue participant said: “we need to know whether they are ‘grassroots’ organizations that are locally funded by committed individuals or whether they are ‘astroturf’ organizations that are centrally funded by a pharmaceutical company.”

Turning now to diversity in the opportunities for engaging civil society, dialogue participants noted diversity both across sectors and across political systems. Sectors differ, for example, in whether government is a regulator/standard-setter (as with the environmental sector in most countries), funder, or both (as with the health sector in Canada). Sectors also differ in whether civil society has a stake in the system (as is not the case in health systems where the “social majority don’t have access to the system in the first place”), and in whether civil society engagement is valued (as it can be in the primary healthcare sector in many countries) or not (as is typically the case in tobacco control). Likewise, political systems can differ in the opportunities that they present for civil society engagement. One dialogue participant contrasted Chile, with few or no opportunities for engagement, and Brazil, which provides a tremendous number of opportunities. Another participant contrasted democratic and authoritarian regimes, and noted that in the latter: 1) health can be one of the few acceptable reasons for social gatherings and hence can be a gateway for social change; and 2) new media can be particularly powerful because of how it gives voice to those outside the regime and how it in turn influences the “old media.”

Dialogue participants identified three additional considerations related to engaging civil society in supporting research use in health systems: 1) nature of engagement desired, 2) optimal timing for engagement, and 3) accountabilities for engagement. One participant argued that civil society engagement needs to be an active process and embedded within a broader civil society engagement initiative. Another dialogue participant argued for the need to engage civil society early in any decision-making process about health systems. A third participant argued that civil society engagement in decision-making needs to be a legislative requirement, as it is in Brazil, whereas another participant argued that accountability to the people who an organization serves needs to be an explicit requirement of many healthcare organizations (which are now more focused on guarding their turf).

Dialogue participants spoke at length about the lack of enablers of civil society engagement in supporting research use in health systems, often focusing on the little effort that has been directed at increasing the demand for research evidence in policymaking about health systems and at increasing the supply of relevant and usable research evidence. One dialogue participant summed this up by saying that there have been too few enablers for civil society to recognize that “policymaking needs more rigour” and that “research needs more relevance,” and to push for (and respond to) changes in both spheres.

Beginning on the demand side, dialogue participants noted that little effort has been directed at:
1) establishing incentives or accountabilities for staff in Ministries of Health and healthcare organizations to use research evidence in policymaking about health systems and in communicating the rationale for policy decisions (e.g., mandating that “no one can bring forward proposals without evidence to support them,” including civil society) and ensuring that there are enough capable staff to execute this function well (and not spend all of their time “putting out fires”);
2) assisting policymakers and stakeholders (like civil society) to see how research evidence can inform their decision-making and advocacy, as well as how allowing ideology to triumph over research evidence can
lead to reputational damage (as one participant argued was the case in Canada with harm-reduction interventions such as safe-injection sites and opioid-substitution therapy);  
3) assisting civil society to see how health system dynamics profoundly influence the issues that they care about (as one participant argued should be done with Canada’s lack of a national catastrophic drug program), how long time horizons may yield greater impacts than short time horizons, how tradeoffs need to be made, and how “research can help to shine a light on problems” that their values tell them are unfair;  
4) building the capacity of policymakers “to bring research evidence into decision-making” (e.g., capacity-building workshops and related tools); and  
5) building the capacity of civil society to engage in advocacy in general and to support research use in health systems in particular (one participant argued that civil society’s lack of health systems research literacy has meant that its inputs have sometimes been seen as naïve and insufficiently attuned to the complexities of health systems).

Turning now to the supply side, dialogue participants noted that little effort has been directed at:  
1) establishing incentives or accountabilities for researchers to produce research evidence that is seen as relevant to and usable by civil society, as well as by policymakers and other stakeholders (as well as to demystify health systems research for civil society and to engage them in the research process);  
2) engaging civil society in priority setting for research so that it meets their needs or fills gaps that they recognize as important (one dialogue participant noted that Canada’s national priority-setting exercise for health systems research doesn’t meaningfully engage civil society);  
3) disseminating research evidence when civil society needs it and in a way that they can make sense of the research evidence and use it in their advocacy efforts (and in their own policies and programs), which could include engaging “knowledge brokers” who can act as “match makers” between researchers and civil society; and  
4) enhancing access to research evidence in ways that help civil society to find the research evidence quickly and to understand its implications in their local context (one dialogue participant used male circumcision as an example of a potential approach to HIV prevention but one that might have different implementation strategies among sex workers and among different tribal groups and one that requires consideration of the implications for women).

DELIBERATION ABOUT POLICY AND PROGRAM OPTIONS

Dialogue participants discussed three options that had been “worked up” in the Issue Brief as concrete examples of what could be done differently.

Option 1 – Employ deliberative polling to inform health system policymaking

Some dialogue participants liked deliberative polling’s sequencing of opinion polling, exposure to balanced information (including research evidence), small-group discussions, and repeated opinion polling. These dialogue participants felt that deliberative polling could be a helpful tool in some situations, particularly alongside other consultative approaches like citizen consensus conferences and formalized civil society engagement processes like those used in Brazil. Other dialogue participants felt that deliberative dialogues (Option 2) and new media (Option 3) offer more promise for supporting research use in health systems.

A number of dialogue participants were less interested in the deliberative polling of citizens than they were in the deliberative polling of civil society leaders and representatives or of opinion leaders within civil society more generally. This realization led some dialogue participants to ask what criteria or process could be used to identify these individuals. One participant suggested four criteria that could be used to select the civil society organizations from which leaders and representatives could in turn be selected: 1) the organization embraces
principles of good governance, 2) it has a large membership base, 3) it has stable funding with “no strings attached,” and 4) it is without political interference in its decision-making.

Dialogue participants identified a number of design features that were critical to the success of any deliberative poll: 1) timing - it was seen as much better to conduct deliberative polling earlier rather than later in a decision-making process; 2) sample – while representativeness is key for the deliberative polling of citizens, other factors were seen as much more important for the deliberative polling of civil society leaders (such as the criteria listed above to select the organizations from which leaders would be drawn); 3) briefing materials – being clear about the limitations of research evidence was seen as important, as was presenting research evidence in ways that could be understood even by those with limited health systems research literacy; and 4) focus – a participatory approach to the setting of questions, informed by someone with strong survey design experience, was seen as ideal.

Dialogue participants identified advantages and disadvantages to deliberative polling, as well as potential implementation challenges. In terms of advantages, dialogue participants noted its focus on mass opinion rather than elite opinion, feasibility (particularly when a rapid consultation is needed), creation of a common starting point through research evidence, and potential to identify priorities for future research. Dialogue participants noted, as one key disadvantage, how polls in general are often seen with suspicion and how deliberative polls may be reductionistic and subject to manipulation by those commissioning them. As one dialogue participant said, they “could hurt choice and mislead.” Additional disadvantages included the perception that deliberative polls do not create accountability (“it’s about consultation, not about collaboration or control”) and lack any formal relationship to the democratic process. In terms of implementation challenges, dialogue participants were most concerned about communication. Several asked how the findings from deliberative polling can be communicated effectively to policymakers and other stakeholders.

The simulation of a provincial public health agency’s meeting with select civil society representatives — to plan a deliberative poll to inform the agency’s response to an H1N1 outbreak (in particular how it prioritizes groups to receive a vaccination) — elicited for many dialogue participants a new set of insights related to design issues and to the suitability of deliberative polling to particular circumstances. In terms of design issues, dialogue participants noted the importance of clarity about: 1) the goal (e.g., consultation about options versus informing communication or assessing the persuasiveness of communication about a chosen option); 2) the number of polls that would be needed (e.g., one for each of 14 regional health authorities within a province or one for an entire province) and the time frame in which they would be required; 3) criteria for selecting a stratified random sample of citizens (e.g., region, age, co-morbidities such as immune impairment or chronic conditions, and ethnocultural group); 4) information that would be shared (e.g., what’s the difference between H1N1 and the regular flu, what’s the emerging evidence, and possibly what other jurisdiction are doing) and attention to different cultural meanings associated with the information and how it is presented; 5) questions that would be asked; and 6) other provisions such as confidentiality and costs (e.g., use web-based mobile telephone calls to reduce costs).

In terms of the suitability of deliberative polling to particular circumstances, dialogue participants identified a number of factors that might lead them to use deliberative polling: 1) urgency of the issue (a deliberative poll can be done quickly, but at the same time “it can be time consuming to do right”); 2) visibility of the issue (a deliberative poll can inform assessments of the likely uptake of a flu shot when the public and media are intensely focused on its benefits and risks, the development of an implementation plan, and the development of a good communications plan even if the deliberative poll played little or no role in the decision); 3) genuine uncertainty about what to do or how to communicate a decision about what to do (and “not with the intent to manipulate”); 4) choices likely to be driven by values and preferences; 5) availability of funding and a “reachable” population (geographically, linguistically, culturally); 6) availability of civil society organizations that can inform the design (and one dialogue participant noted that a deliberative dialogue, which is the focus of the next option, could be used to inform the design of the deliberative poll); and 7) availability of research evidence with which to prepare briefing materials (e.g., risk groups and safety and efficacy of a vaccine).
Option 2 – Convene deliberative dialogues to inform and influence health system policymaking

A number of dialogue participants embraced deliberative dialogues as an approach and felt that they are a particularly good way to engage civil society organizations, particularly if they are embedded in an ongoing process of civil society engagement. A few dialogue participants argued that deliberative dialogues, including the preparation for them and the de-briefing and communication efforts that follow them, can be seen as a way to build health systems research literacy among civil society organizations.

Dialogue participants considered the same four design features that they discussed for deliberative polling, however, they sometimes came to different conclusions about which features were critical to the success of a deliberative dialogue: 1) timing - it was seen as potentially better to convene a deliberative dialogue later in a decision-making process (once the issues have become clearer) or even after a decision has been made (if the focus is on how to achieve the greatest value for money or how to support implementation), or else to leave the agenda much more open if convening a dialogue earlier in the process; 2) sample – a stakeholder mapping process and explicit selection criteria such as those used by the McMaster Health Forum were both seen as helpful, but participants also argued for defining what constitutes a “member in good standing” of civil society, avoiding “fake” representation (by “professional” civil society representatives) and the exclusion of “true” representatives, and being “open to learning from others who aren’t used to learning from others”; 3) briefing materials – circulating the material in advance was seen by dialogue participants as critical, particularly if participants are “mired in the issue and need to start from a better place,” as was placing the supporting documents in the public domain and providing technical assistance to those who might need support to understand them fully; and 4) focus – a participatory approach to establishing the focus of the deliberations (e.g., a problem, options, implementation considerations and next steps for different constituencies), informed by someone with strong dialogue design experience, was seen as ideal, much like it was for the setting of questions for a deliberative poll. One dialogue participant also emphasized the importance of select “ground rules,” such as expecting participants to have read the briefing materials prior to their arrival, and (through good chairing) keeping focused on the agenda (e.g., “getting negativity out of the way,” keeping the dialogue moving forward, “not being distracted by other grievances,” but also “not ignoring politics”).

Dialogue participants identified advantages and disadvantages to deliberative dialogues, as well as potential implementation challenges. In terms of advantages, dialogue participants noted particularly their potential to create a “level playing field.” Participants used words like “interactive” and “participatory,” and phrases like “puts everyone on an equal footing,” “everyone has a voice,” “everyone hears what each other is saying,” “everyone learns from and gains respect for each other,” and “each person gives as well as gains.” Other advantages included: the range of issues that can be addressed (whereas deliberative polling was seen by some as better for selecting from among discrete options), the greater depth with which issues can be explored, flexibility in the planning stage but especially in execution, feasibility in a range of contexts, potential for empowering civil society organizations, potential for immediate influence, and the expectation that all participants must take some responsibility for action (and “if they don’t, others will know”). Dialogue participants noted a number of potential disadvantages of deliberative dialogues, including the high level of research literacy that may be required of participants (although one participant noted that a pre-dialogue workshop could give those with limited research literacy the chance to build their capacity to participate), the risk of introducing or increasing cleavages between groups if participants are labeled unfairly, the risk of manipulation by those organizing the dialogue (although this was seen as a much smaller risk than with deliberative polling), and the lack of accountability by those commissioning a dialogue (while a dialogue is more collaborative than consultative, it still does not give control to civil society, although reporting back to communities can begin to establish some degree of accountability). Possible implementation challenges ranged from supporting civil society organizations’ consultations with their members before participating in a dialogue (just as researchers must do a broad literature review before participating in an expert panel) to working out the unique sensitivities that emerge in bringing the approach out of controlled environments and
Engaging Civil Society in Supporting Research Use in Health Systems

into local communities (such as civil society demanding that the dialogue be the beginning of ongoing deliberations, not a one-off event).

The simulation of a Ministry of Health-convened meeting with select civil society representatives – to plan a series of five deliberative dialogues with a broad range of civil society in order to inform/influence how a newly elected government approaches the execution of its campaign promise to introduce national health insurance – elicited for many dialogue participants a number of insights related to design issues and to the suitability of deliberative dialogues to particular circumstances. In terms of design issues, dialogue participants noted the importance of clarity about: 1) the goal (e.g., collaborating with civil society, building consensus and support and/or informing communication plans); 2) the number of dialogues that would be focused on particular groups and the time frame in which all five dialogues would need to be completed; 3) criteria for selecting participants (e.g., whether the Minister’s presence would disrupt a dialogue or signal its political importance, whether “external” individuals like World Bank staff would be invited, and whether to invite industry representatives and, if so, how to choose them); 4) information that would be shared and attention to different cultural meanings associated with the information and how it is presented; 5) separate deliberations that would be planned; and 6) other provisions such as providing training and paying per diems to civil society representatives before the dialogue and dealing with divergent findings (if consensus was not the objective, as would be mandatory in some countries, like Brazil).

In terms of the suitability of deliberative dialogues to particular circumstances, dialogue participants focused on two of the same factors that they discussed in relation to deliberative polling. First, two dialogue participants argued that deliberative dialogues might be particularly helpful when choices are likely to be driven by values and preferences, but also by stakeholders’ tacit knowledge and by real world views and experiences. Second, several dialogue participants argued that the availability of funding and a “reachable” population (geographically, linguistically, culturally) might be even more important than they are with deliberative polling (e.g., large geographic areas can have a big impact on the cost of a deliberative dialogue). One dialogue participant also noted – after participating in the simulation – “how sensitive the process may be to who is sitting around the table.” Several dialogue participants found that the simulation underlined for them the importance of “finding the right people, training them, and then coaching and supporting them.”

Option 3 – Use new media to influence health system policymaking

Dialogue participants’ views were mixed about the use of new media – mass-short-messages (MSMs) and other mobile phone-based strategies, as well as online petitions and other internet-based approaches – to influence health system policymaking. Some participants liked the approach, and felt that it had the potential to be very powerful, particularly if it was informed by deliberative polling and deliberative dialogues. One dialogue participant argued that “injecting research evidence into the conversation can help.” Other dialogue participants felt that new media are helpful to raise awareness and mobilize, but not to educate. A recurring struggle during the dialogue was to keep focused on considering new media as an approach for engaging civil society in supporting research use in health systems while still recognizing it as an approach that civil society would ultimately control. This recognition meant narrowing the focus to identifying enabling roles (e.g., providing evidence-informed messages for civil society to consider for their campaigns, establishing platforms that civil society could use at no or little cost), rather than using new media directly (which is what many dialogue participants were more familiar with).

Dialogue participants discussed only two of the four design features that they discussed for deliberative polling and deliberative dialogues. Design features like timing and sample were not perceived to be as relevant when civil society was “in the driver’s seat,” as envisioned with this option. However, briefing materials (or in this case, messages) were seen as critical given the need to achieve both brevity (given short attention spans and, sometimes, the nature of the technology) and understandability (given the wide range of literacy levels). Similarly, focus was seen as critical given that neither health systems nor research evidence are “seen as sexy” (so getting attention is difficult) and given that health systems issues can be quite complex (so “having
everyone learn something, but no one know everything’ is a significant risk). As one dialogue participant said, perhaps new media are “good for things like vaccine campaigns but not for issues that involve complex considerations or actions,” which is often the case with health systems policymaking. Dialogue participants identified advantages and disadvantages to new media in general (as opposed to using new media to influence health system policymaking in particular), as well as potential implementation challenges. In terms of advantages, new media approaches were seen as being more democratic than traditional ones (given the large penetration of technology like mobile phones even in many impoverished settings). New media approaches were also viewed as having a built-in “multiplier effect,” and as being able to provide a sense of engagement or empowerment (and even strengthen democratic processes). The disadvantages of new media approaches included their potential to polarize (unlike deliberative polling and deliberative dialogues and, as one dialogue participant pointed out, this is how they motivate people to do things) or to turn people off if done poorly and leave them satisfied with a fairly passive gesture like forwarding a message. Participants were also concerned about the potential of new media approaches to be used to manipulate (e.g., used to promote what governments want or hijack for political ends) and monitor (in countries where the use of new media is heavily regulated or even banned). The implementation challenges identified by dialogue participants included: the fact that the new media landscape is already noisy and cluttered (including by industry) and evolving rapidly, the difficulty of identifying groups or organizations that are well suited to playing enabling roles, the challenge associated with “losing the author” of messages so quickly in the dissemination process, and the lack of research evidence about whether, how, and under what conditions it “works.”

The simulation of a civil society organization-convened meeting of a broad range of civil society representatives – to plan an effort to mobilize civil society in the lead up to the World Health Assembly with the aim of holding World Health Organization (WHO) member states accountable for poorly informed recommendations about health systems – elicited for many dialogue participants a number of insights related to design issues and to the suitability of deliberative dialogues to particular circumstances. In terms of design issues, dialogue participants noted the importance of clarity about: 1) the goal (e.g., communicating breadth of opposition, which means identifying group-specific recommendations that have done harm, such as recommendations for women who are victims of sexual violence); 2) the number of new media approaches and how they would be sequenced (e.g., mobile phones to get mass meetings organized, listservs to engage people in online polling, and websites for those who want to learn more, all of which would be undertaken in the countries where WHO Executive Board members are based); and 3) criteria for selecting civil society organizations with which to work in each country (e.g., People’s Health Movement, which has branches in many countries). One dialogue participant noted that traditional media (e.g., radio) may be a helpful complement to new media in countries where traditional media are still heavily relied upon and where there are inequities in access to new media (e.g., men may control access to mobile phones).

In terms of the suitability of new media to particular circumstances, dialogue participants identified three general factors likely to be conducive to the use of new media: urgency of the issue (given new media can mobilize civil society very rapidly), visibility of the issue (given the many issues competing for attention), and the availability of research evidence from which messages can be distilled for different groups.

**Considering the full array of options**

After deliberating about each of the three options, several dialogue participants suggested elements of a fourth option, which involves increasing the demand for research evidence in policymaking about health systems. They suggested two types of activities, one of which is building interest in health systems, particularly in countries where civil society is not organized around health systems (as one dialogue participant argued it is in Brazil, El Salvador, and Thailand). One dialogue participant suggested building out from the social determinants of health where there are established constituencies or focusing on particular topics that are germane in particular countries (e.g., “primary healthcare systems have been devastated by vertical programs,” “citizens aren’t offered proactive and coordinated chronic disease management,” and
Engaging Civil Society in Supporting Research Use in Health Systems

“health systems determine whether effective programs, services, and drugs get to those who need them”).
The second type of activity is building health systems research literacy through both capacity-building workshops (for policymakers, journalists, and civil society) and the dissemination of tools and resources (to assist with finding and using research evidence and overcoming obstacles to using research evidence).

In discussing three options for addressing the lack of civil society engagement in supporting research use in health systems, most dialogue participants felt that all three approaches – deliberative polling, deliberative dialogues, and new media – all have a role to play. That said, several dialogue participants were drawn more to the collaborative nature of deliberative dialogues and to new media’s potential for giving civil society greater control over the decisions that will affect them than they were to the consultative nature of deliberative polling. The challenge, almost all dialogue participants argued, was matching a given approach, and the design of the approach, to the issue at hand and the local context at the precise time when a window of opportunity opens. One dialogue participant argued that there was a need to learn from both good and bad experiences and to share these lessons widely.

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

Many dialogue participants agreed that the implementation of these options likely requires moving forward on two parallel tracks: 1) raising awareness about the approaches using easy-to-understand materials that describe: each approach, how to adapt the approach to particular issues and contexts, “alarm bells” that signal a looming problem in its use, and how to evaluate its impact and the factors that influence its impact, and 2) increasing the demand for and supply of relevant and usable research evidence. Regarding the latter, several dialogue participants argued for a phased approach and for promoting success stories in each phase. One dialogue participant identified the necessary phases in relation to civil society organizations as being: 1) identifying pressing health system challenges; 2) setting priorities, promoting the production of research on these priorities, and making use of “one-stop shops” for existing research evidence about these challenges; 3) developing their capacity to make their voice heard and to reinforce arguments with good research evidence – thereby increasing their demand for research evidence (which may need to be preceded by effective organizing in the first place); and 4) organizing deliberative polling and deliberative dialogues (which may need to be preceded by making use of tools and resources to organize them). Such a “bottom-up” approach was argued by the same participant to be the most effective way to create demand for research evidence among policymakers and stakeholders. Another dialogue participant argued that concurrent efforts need to be directed at increasing demand for research evidence among policymakers and stakeholders as well – as had been done by identifying opportunities for improvement in the World Health Organization’s and World Bank’s use of research evidence in their recommendations about health systems. Many participants agreed that success stories need to be shared if the “necessary massive cultural change” is to be introduced, the necessary structures and processes developed or institutionalized at different levels, and the necessary resources made available.

One dialogue participant reminded the group that “introducing innovations in systems is not that easy,” and that the obstacles are particularly great with health systems given their inherent complexity and given that the state of research evidence about health systems is constantly evolving. This participant argued that work should start with the “next generation” of those becoming actively involved in civil society organizations. Another dialogue participant reminded the group that the context for civil society engagement differs dramatically across health systems. This participant suggested beginning with an analysis of barriers and enablers to civil society organizations playing a role in supporting research use in a given health system (and of an analysis of potential “windows of opportunity”), as well as with an explicit discussion of the “non-negotiables” (e.g., a focus on equity). A third dialogue participant argued for developing measures so “we know if we’re improving… and getting more evidence-based [in our] programming and policymaking” (and if so, on what types of issues and in what types of contexts) and so “we know if we’re getting value for money” from our investments in particular approaches to engaging civil society in supporting research use in health systems.

Evidence >> Insight >> Action
DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

Dialogue participants worked in such diverse roles and in such diverse health system contexts that there was tremendous variability in what each saw as important next steps. Some saw value in examining the potential for establishing legal frameworks that support civil society engagement, as Brazil has done. Others saw value in improving the “knowledge infrastructure” within their health system, which includes the role of making research evidence understandable by civil society. Still others wanted: 1) to support existing initiatives like the Evidence-Informed Policy Networks (EVIPNet) to engage civil society more proactively in supporting research use in health systems, 2) to experiment with a particular approach (particularly deliberative dialogues) in their own health system, or 3) to first convince influential health system leaders that civil society engagement is not a threat. One dialogue participant argued that the momentum for civil society engagement that was witnessed at the Global Ministerial Forum on Research for Health (convened in November 2008 in Bamako, Mali) needed to be recaptured. Another dialogue participant expressed interest in donors and research funding agencies finding success stories, uncovering guiding principles and enablers, producing tools, and directing funding to promising approaches.