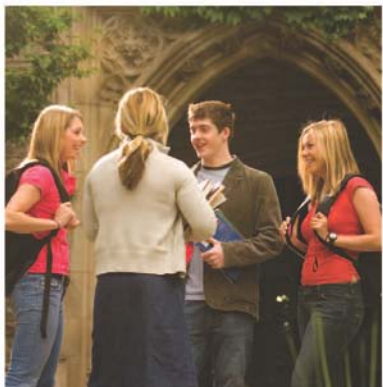




ISSUE BRIEF



ENGAGING CIVIL SOCIETY IN
SUPPORTING
RESEARCH USE IN
HEALTH SYSTEMS



23 NOVEMBER 2009

EVIDENCE >> INSIGHT >> ACTION

Issue Brief:
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.

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The issue brief was reviewed by a small number of researchers, policymakers, and stakeholders in order to ensure its scientific rigour and global relevance.

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KEY MESSAGES

What's the problem?

- The overall problem is a general lack of civil society engagement in supporting research use in health systems.
 - Research evidence is often not used in health systems.
 - Civil society is typically not engaged in supporting research use in health systems.
 - There are few enablers of civil society engagement in supporting research use in health systems.
 - Some policies that call for civil society engagement (and for initiatives to enable such engagement) have not been implemented.

What do we know (from systematic reviews) about three viable options to address the problem?

- Option 1 – Employ deliberative polling to inform health system policymaking
 - No reviews were identified that addressed the benefits, harms, and costs of deliberative polling to inform policymaking. Turning to civil society engagement more generally, a low-quality review found that using credible, relevant, and accessible evidence effectively can be critical to the success of civil society organizations aiming to influence policy agenda-setting, formulation, implementation, and monitoring and evaluation.
- Option 2 – Convene deliberative dialogues to inform and influence health system policymaking
 - A low-quality review found that there is little evidence that identifies the most effective deliberative processes. The same review found some studies suggesting promising design parameters for deliberative processes, namely consultation with all parties affected by the outcome, fair representation of scientists and stakeholders, high-quality syntheses of the scientific evidence, and skillful chairing.
- Option 3 – Use new media to influence health system policymaking
 - No reviews were identified that addressed the benefits, harms, and costs of using new media to influence policymaking. A high-quality but old review found that planned mass media campaigns and unplanned mass media coverage can have a positive influence on the utilization of health services.

What implementation considerations need to be kept in mind?

- While no systematic review was identified about the barriers to implementing these options, many conceptual frameworks and empirical studies can be drawn upon to identify barriers to civil society engagement in general and, by extrapolation, to identify potential barriers to the three options in particular. Further research would be required to establish the benefits, harms, and costs of implementation strategies that might address these barriers.

Key concepts

Civil society can be considered to be any voluntary organization apart from those under the direct control of governments or for-profit firms. Examples include registered charities, community groups, women's organizations, professional associations, social movements, and advocacy groups.

Engagement could take the form of consultation (i.e., seeking the input of civil society), co-operation (i.e., working in partnership with civil society) or control (i.e. giving direct influence to civil society).

Research evidence could be used: 1) to clarify and prioritize problems in health systems; 2) to frame policy and program options to address the problems and describe their benefits, harms, and costs; 3) to identify barriers to implementing preferred options and describe the benefits, harms, and costs of implementation strategies that address these barriers; and 4) to design monitoring and evaluation plans.

REPORT

Civil society can be considered to be any voluntary organization apart from those under the direct control of governments or for-profit firms. Two more detailed definitions are as follows:

- “Civil society is composed of the totality of voluntary civic and social organizations and institutions that form the basis of a functioning society as opposed to the force-backed structures of a state (regardless of that state’s political system) and commercial institutions of the market.”
(www.wikipedia.org/wiki/civil_society; Accessed 18 May 2009)
- “Civil society refers to the arena of uncoerced collective action around shared interests, purposes and values. In theory, its institutional forms are distinct from those of the state, family and market, though in practice, the boundaries between state, civil society, family and market are often complex, blurred and negotiated. Civil society commonly embraces a diversity of spaces, actors and institutional forms, varying in their degree of formality, autonomy and power. Civil societies are often populated by organizations such as registered charities, development non-governmental organizations, community groups, women’s organizations, faith-based organizations, professional associations, trade unions, self-help groups, social movements, business associations, coalitions and advocacy groups.”
(www.lse.ac.uk/collections/CCS/what_is_civil_society.htm; Accessed 18 May 2009)

While the term “civil society” is in widespread use in many countries, particularly in low- and middle-income countries, in some countries (such as Canada) the terms “voluntary organization,” “non-governmental organization,” and “advocacy group” are much more commonly used.⁽¹⁾ The term “stakeholder” typically means something broader than civil society, whereas the term “interest group” tends to be associated with private, not public, interests, and more accurately can be considered to include both civil society and organizations under the direct control of for-profit firms. Similarly, quasi non-governmental organizations (QUANGOs), which are financed by government yet operate independently of them, can be considered a hybrid.

Civil society can be engaged in a variety of activities at the population or collective level, including policymaking

Box 1: Background to the issue brief

This issue brief mobilizes both global and local research evidence about a problem, three options for addressing the problem, and key implementation considerations. Whenever possible, the issue brief summarizes research evidence drawn from systematic reviews of the research literature and occasionally from single research studies. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select, and appraise research studies and to synthesize data from the included studies. The issue brief does not contain recommendations.

The preparation of the issue brief involved five steps:

- 1) convening a Steering Committee comprised of representatives from the partner organizations and the McMaster Health Forum;
- 2) developing and refining the terms of reference for an issue brief, particularly the framing of the problem and three viable options for addressing it, in consultation with the Steering Committee and with the aid of several conceptual frameworks that organize thinking about ways to approach the issue;
- 3) identifying, selecting, appraising, and synthesizing relevant research evidence about the problem, options, and implementation considerations;
- 4) drafting the issue brief in such a way as to present concisely and in accessible language the global and local research evidence; and
- 5) finalizing the issue brief based on the input of several merit reviewers.

The three options for addressing the problem were not designed to be mutually exclusive. They could be pursued simultaneously or elements could be drawn from each option to create a new (fourth) option.

Unlike a Forum evidence brief, a Forum issue brief is not informed by key-informant interviews and does not involve as comprehensive an evidence review.

The issue brief was prepared to inform a stakeholder dialogue at which research evidence is one of many considerations. Participants’ views and experiences and the tacit knowledge they bring to the issues at hand are also important inputs to the dialogue. One goal of the stakeholder dialogue is 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. A second goal of the stakeholder dialogue is 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.

about health systems.(2) Such policymaking can range from setting disease and other health-related priorities; choosing among the possible programs, services, and drugs needed to prevent or treat these diseases; establishing or changing the health system arrangements that determine whether programs, services, and drugs get to those who need them; and selecting implementation strategies for these health system arrangements.(3) The goals for such civil society engagement may be “better” decisions, improved or more equitably distributed outcomes (in terms of access, use, quality, efficiency, and satisfaction, among others), or more accountable governments and for-profit firms. Civil society can also be engaged in service delivery within health systems. Engagement may either encourage or discourage particular actions.

One set of complementary civil society activities at the population or collective level includes activities related to the funding, conduct, synthesis, packaging, and dissemination of research to inform policymaking about health systems.(4;5) Here the goals might include research evidence (or guidance based on research evidence) that is more relevant, understandable, and usable from the perspective of diverse groups (e.g., ethnocultural and linguistic groups). Another set of complementary civil society activities relate to supporting the use of research evidence in policymaking about health systems. Here the goals might include a climate that supports research use, research evidence that can be easily found, assessed, and used just at the time it is needed, and policymaking processes that give an explicit role for research evidence among other inputs.(6)

The engagement of civil society in these activities can involve:

- consultation, whereby the receivers of the consultation are not committed to following the advice offered by civil society;
- collaboration, whereby civil society plays a more active role in a variety of activities at the population or collective level; and
- control, whereby civil society exerts an active and direct influence in these activities.(7)

Globally, there has been renewed interest in civil society engagement in the health sector. For example, the reinvigoration of the Alma Ata vision for primary healthcare gives significant attention to civil society engagement.(8;9) Similarly, a statement submitted as an input to the Global Ministerial Forum on Research for Health in 2008 highlighted the importance of civil society engagement in research for health.(4) Even a country like Canada, which has historically not made civil society engagement a highly visible priority, has witnessed both the development of mandated

Box 2: Equity considerations

A problem may disproportionately affect some groups in society. The benefits, harms, and costs of options to address the problem may vary across groups. Implementation considerations may also vary across groups.

One way to identify groups warranting particular attention is to use “PROGRESS,” which is an acronym formed by the first letters of the following eight ways that can be used to describe groups†:

- place of residence (e.g., rural and remote populations);
- race/ethnicity/culture (e.g., First Nations and Inuit populations, immigrant populations, and linguistic minority populations);
- occupation or labour-market experiences more generally (e.g., those in “precarious work” arrangements);
- gender;
- religion;
- educational level (e.g., health literacy); and
- socio-economic status (e.g., economically disadvantaged populations); and social capital / social exclusion.

This issue brief strives to address all people, but (where possible) it also gives particular attention to two groups:

- people with low levels of health literacy; and
- people with no access to information and communication technology (e.g., mobile phones, computers with an internet connection).

Many other groups (such as women or hard-to-reach ethnocultural groups) warrant serious consideration as well, and a similar approach could be adopted for any of them.

† The PROGRESS framework was developed by Tim Evans and Hilary Brown (Evans T, Brown H. Road traffic crashes: operationalizing equity in the context of health sector reform. *Injury Control and Safety Promotion* 2003;10(1-2): 11–12). It is being tested by the Cochrane Collaboration Health Equity Field as a means of evaluating the impact of interventions on health equity.

engagement processes within regional health authorities in some provinces and increased discussion about these processes.(1)

Although civil society engagement is re-emerging on the health agenda, there is still much to be done. The purpose of this issue brief is to review: 1) the research evidence about problems underlying the current lack of engagement of civil society in supporting research use in health systems; 2) three options for addressing the problems that might enhance what is currently being done; and 3) key implementation considerations for moving any of the options forward.

We have chosen to define the scope of this brief in three ways in order to spark insights about civil society engagement. First, this issue brief does not consider individuals' involvement in personal health decision-making (e.g., increasing their physical activity and self-managing their chronic conditions), but instead focuses on civil society engagement at the population or collective level. Second, this issue brief only focuses on engaging civil society in supporting the use of research evidence in health systems. This focus does not mean that other types of information, as well as values, interests, institutional constraints, and external factors (e.g., economic conditions and donor pressure), are not critical inputs to policymaking about health systems.(10) To the contrary, it is because these other inputs are so critical that research evidence can sometimes provide the common ground on which these competing influences can be acknowledged and discussed. Civil society has typically not been engaged in supporting the use of research evidence. Third, this issue brief focuses on both Canada (where great attention has been given to supporting research use) and low- and middle-income countries (where great attention has been given to civil society engagement) in order to foster learning within and across these contexts.

Further to the last point, the health system context for civil society engagement differs dramatically across countries. On the one hand, countries like Canada have historically not given a large role to civil society in health systems and lack much of the infrastructure needed to support such engagement. On the other hand, countries like Brazil have long-standing traditions of civil society engagement, well established structures and processes to support engagement, and well organized “peak associations” that provide established channels for representation and that avoid “capture” by private for-profit interests.(11) However, such countries have often not focused specifically on engaging civil society to support research use.

THE PROBLEM

Problems underlying the current lack of engagement of civil society in supporting research use can be understood by considering: 1) the use of research evidence in health systems; 2) the engagement of civil society in supporting research use in health systems; 3) the supports available to enable civil society engagement in supporting research use in health systems; and 4) the degree of implementation of policies that call for civil society engagement.

Research evidence is often not used in health systems

Many countries rely heavily on recommendations about health systems from both the World Health Organization (WHO) and the World Bank.

Interviews and documentary analyses have shown that systematic reviews and concise summaries of findings are rarely used by WHO for developing recommendations.⁽¹²⁾ Instead, processes usually rely heavily on experts in a particular specialty, rather than representatives of people directly affected by these recommendations or on experts in particular methodological areas.⁽¹²⁾ A review of select WHO and World Bank recommendations has also shown that only five of 14 WHO recommendations and two of seven World Bank recommendations were consistent with both the direction and nature of effect claims from systematic reviews.⁽¹³⁾ What is more, four of 14 WHO and two of seven World Bank recommendations were not even consistent with the *direction* of effect claims.⁽¹³⁾ Research evidence cannot easily be used in health systems when prominent international organizations do not use (or at least report using) syntheses of research evidence.

Many governments' decisions about health systems also appear not to have been informed by research evidence. For example, a study of Canadian provincial policymaking about health systems found that in four of eight policies no citable research was used in any stage of the policymaking process.⁽¹⁰⁾ Moreover, citable research was a major influence in the prioritization stage of the policymaking process for only two of the eight policies, and in the policy development stage for only one of the eight policies.⁽¹⁰⁾ Similar findings have been observed in many other settings.⁽¹⁴⁾

Civil society is typically not engaged in supporting research use in health systems

Data about civil society engagement in supporting research use in health systems are scarce. One survey of units that directly support the use of research evidence in developing health policy on an international, national, and state or provincial level (which were labeled "government support units") found that 26% of the units reported not involving "consumers" (identified as patients or the general public) in product development or service delivery.⁽¹⁵⁾ These units were drawn from both high- and low- and middle-income countries. Calls for a greater role for civil society in research, which typically include some mention of supporting research use, suggest that such a finding is not atypical.⁽⁴⁾

Box 3: Mobilizing research evidence about the problem

The available research evidence about the problem was sought from a range of published and "grey" research literature sources. Published literature that provided insights into alternative ways of framing the problem was sought using the qualitative research "hedge" in MedLine. Grey literature was sought by reviewing the websites of a number of Canadian and international organizations.

Priority was given to research evidence that was published more recently, that was locally applicable (in the sense of having been conducted in Canada or in a low- and middle-income country), and that took equity considerations into account.

Few supports enable civil society engagement in supporting research use in health systems

Data are also hard to find about the extent of capacity building and financial and infrastructure supports available to enable civil society engagement in supporting research use in health systems. Capacity-building supports can include training workshops and mentoring, financial supports can include the costs of mobilization (incurred by organizers) and participation (incurred by citizens), and infrastructure supports can include mobile phones and computers with internet connections.(16) Again, calls for a greater role for civil society in research and in health systems suggest that such supports are typically lacking.(4)

Some policies that call for civil society engagement (and for supports to enable such engagement) have not been implemented

While the Alma Ata declaration noted that “[t]he people have the right and duty to participate individually and collectively in the planning and implementation of their health care” and the Bamako statement noted that it was necessary to “[m]obilize all partners and players (public, private, civil society) to work together in effective and equitable partnership to find needed solutions,” arguably these policies have been implemented only to some extent and only in some settings.(8;17)

Additional equity-related observations about the problem

The available data and research evidence about the problem often does not address specifically the two prioritized groups: people with low levels of health literacy and people with no access to information and communication technology (e.g., mobile phone, computer with internet connection). Yet it is likely that problems are more pronounced for these groups compared to many others.

THREE OPTIONS FOR ADDRESSING THE PROBLEM

Many options could be selected to address the problems underlying the current lack of civil society engagement in supporting research use in health systems. To promote discussion about the pros and cons of potentially viable options, three have been selected as examples for more in-depth review. They include: 1) employing deliberative polling to inform health system policymaking; 2) convening deliberative dialogues to inform and influence health system policymaking; and 3) using new media to influence health system policymaking. Option 1 can be described as a form of consultation (which is why the focus is informing policymaking, not influencing it actively), Option 2 as a form of collaboration, and Option 3 is a form of control (which is why the focus is on influencing policymaking). Option 2 could both inform and influence policymaking.

The focus in this section is on what is known about these options. In the next section the focus turns to the barriers to adopting and implementing these options and to possible implementation strategies to address the barriers.

Option 1 – Employ deliberative polling to inform health system policymaking

This option can be understood both narrowly in the sense of a very particular civil society engagement strategy (deliberative polling) and more broadly in the sense of civil society engagement as a general approach. With deliberative polling, one key question is about its effectiveness. With civil society engagement more generally, effectiveness is a key question, but so too is the comparative effectiveness of deliberative polling and alternative engagement strategies.⁽⁷⁾

Deliberative polling involves a sequencing of opinion polling, exposure to balanced information (including research evidence), small-group discussions, and repeated opinion polling in order to obtain informed public opinion on a specific issue.⁽¹⁸⁾ The balanced information may be presented in the form of a brief that mobilizes both global and local research evidence about the issue and supports a full discussion of relevant considerations about the issue.

Stratified random samples of citizens can be chosen to participate in deliberative polling, with the strata chosen to ensure that the voices of prioritized communities are heard. For example, to inform a major review of Canada's health system, deliberative polling was undertaken with 40 stratified random samples of

Box 4: Mobilizing research evidence about options for addressing the problem

The available research evidence about options for addressing the problem was sought primarily from a continuously updated database containing more than 900 systematic reviews of delivery, financial, and governance arrangements within health systems: the Program in Policy Decision-Making (PPD) / Canadian Cochrane Network and Centre (CCNC) database. The reviews were identified by first searching the database for reviews within the sub-category of consumer and stakeholder involvement. Additional reviews were identified by searching the database for reviews addressing features of the options that were not identified within this sub-category.

The authors' conclusions were extracted from the reviews whenever possible. Some reviews contained no studies despite an exhaustive search (i.e., they were "empty" reviews), while others concluded that there was substantial uncertainty about the option based on the identified studies. Where relevant, caveats were introduced about these authors' conclusions based on assessments of the reviews' quality, the local applicability of the reviews' findings, equity considerations, and relevancy to the issue. (See Appendices for a complete description of these assessments.)

Being aware of what is not known can be as important as being aware of what is known. When faced with an empty review, substantial uncertainty or concerns about quality and local applicability, or a lack of attention to equity considerations, primary research could be commissioned or an option could be pursued and a monitoring and evaluation plan designed as part of its implementation. When faced with a review that was published many years ago, an updating of the review could be commissioned if time allows.

No additional research evidence was sought beyond what was included in the systematic review. Those interested in pursuing a particular option may want to search for a more detailed description of the option or for additional research evidence about the option.

Canadians, with the strata chosen to ensure that voices from across the country and from both major linguistic groups were heard.(19)

The proponents of deliberative polling have argued that its benefits include that:

- participants in deliberative polls gain information;
- participants' opinions and vote intentions change (and do not become homogeneous within groups or polarized across groups);
- these changes are interrelated but they are not related to social location; and
- options and vote intentions tend to be more predictable, and to hinge more on normatively desirable criteria, after deliberation than before.(18)

Civil society engagement as a general approach can mean public engagement (where the focus is individual citizens), community engagement (where the focus is communities, not individuals), and service-user engagement (where the focus is individual service users, not all citizens and not communities).(16;20;21) Many different strategies can be chosen to execute this approach, with deliberative polling being just one public-engagement strategy (or service-user-engagement strategy).

A key issue with this option is whether the use of research evidence in a given civil society engagement approach actually increases the prospects for the option to inform policymaking. In theory, research evidence can inform almost any topic that could be the focus for deliberative polling, including: clarifying and prioritizing problems in health systems; framing policy and program options to address the problems and describing their benefits, harms, and costs; identifying barriers to implementing preferred options and describing the benefits, harms, and costs of implementation strategies that address these barriers; and designing monitoring and evaluation plans.(3) The question is whether research confers legitimacy and other benefits on those who use it as a key part of their engagement approach.

Synthesized research evidence is available about some dimensions of this option. A summary of key findings from this synthesized research evidence is provided in Table 1. In brief, no reviews were identified that addressed the benefits, harms, and costs of deliberative polling to inform policymaking. Turning to civil society engagement more generally, a low-quality review found that using credible, relevant, and accessible evidence effectively can be critical to the success of civil society organizations aiming to influence policy agenda-setting, formulation, implementation, and monitoring and evaluation.(22) The other reviews, which tend to focus on civil society engagement in conducting, packaging, and disseminating research, have much less salience when considering civil society engagement to inform health system policymaking.

For those who want to know more about the systematic reviews contained in Table 1 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 1.

Table 1: Summary of key findings from systematic reviews relevant to Option 1 - Employ deliberative polling to inform health system policymaking

Category of finding	Summary of key findings
Benefits	<ul style="list-style-type: none"> • Public engagement <ul style="list-style-type: none"> ○ A high-quality, relatively recent review found that moderate quality evidence indicates that involving consumers in the development of patient information material results in material that is more relevant, readable, and understandable to patients, without affecting their anxiety. The review also found low quality evidence suggesting that telephone discussions and face-to-face group meetings engage consumers better than mailed surveys to set priorities for community health goals, and result in differing priorities as well.(23) • Community engagement <ul style="list-style-type: none"> ○ A medium-quality, relatively recent review found varying qualities of evidence suggesting that interventions that engage the community improve the dissemination of information and the development of interventions.(24) • Use of research evidence by civil society organizations to influence policymaking processes <ul style="list-style-type: none"> ○ A low-quality review found that using credible, relevant, and accessible evidence effectively can be critical to the success of civil society organizations aiming to influence policy agenda-setting, formulation, implementation, and monitoring and evaluation.(22)
Potential harms	<ul style="list-style-type: none"> • None identified
Costs and/or cost-effectiveness in relation to the status quo	<ul style="list-style-type: none"> • None identified
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	<ul style="list-style-type: none"> • Uncertainty because no systematic reviews were identified <ul style="list-style-type: none"> ○ Deliberative polling <ul style="list-style-type: none"> ▪ No reviews were identified that addressed the core option element • Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review <ul style="list-style-type: none"> ○ Community engagement <ul style="list-style-type: none"> ▪ A medium-quality but relatively old review found no studies on the effects of involving users in the planning of mental health services.(25) ▪ A second medium-quality and relatively old review found no studies on the effects of the involvement of users on accessibility and acceptability of services, or the impact on the satisfaction, health, or quality of life of patients.(26) • No clear message from studies included in a systematic review <ul style="list-style-type: none"> ○ Not applicable
Key elements of the policy option if it was tried elsewhere	<ul style="list-style-type: none"> • None identified
Stakeholders' views and experience	<ul style="list-style-type: none"> • None identified

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

This option can be understood as a strategy that engages civil society as one key (and very diverse) constituency among several. Other constituencies can include government officials and industry representatives (e.g., pharmaceutical and device manufacturers) – that is, the two “poles” in relation to which civil society was earlier defined. Deliberative dialogues bring together individuals from all of these constituencies who would be involved in or affected by future decisions related to an issue.(27-30) (Deliberative dialogues can also limit participants to citizens, however, the focus here is dialogues that involve all key constituencies.)

Dialogues can be used to set agendas, inform policy and program choice, and support implementation.(30) As with this issue brief and the stakeholder dialogue it is meant to inform, dialogues targeting policy and program choice could focus on different features of a problem, three policy and program options (among many), and implementation considerations.(30) As with deliberative polling, a dialogue can be informed by a brief (often pre-circulated and taken as read) that mobilizes both global and local research evidence about the issue and typically supports a full discussion of relevant considerations about the issue (in the case of dialogues, this is typically done in order to inform action to address the issue).(30) Dialogues also typically employ a “safe harbour” rule in order to ensure that comments are not attributed to individuals or their organizations.(30) As well, they avoid aiming for consensus (while embracing it if it emerges spontaneously, which some research suggests can be more likely when deliberations are supported by research evidence).(30)

Unlike deliberative polling, which often engages a stratified random sample of citizens (or service users), deliberative dialogues typically engage a purposive sample of civil society group representatives. For example, the McMaster Health Forum typically uses two criteria to identify and select dialogue participants:

- individual will bring unique views and experiences to bear on a challenge and learn from the research evidence and from others’ views and experiences; and
- individuals will champion within their respective constituencies the actions that will address the challenge creatively.(30)

Also unlike deliberative polling, which focuses on consultation rather than collaboration, deliberative dialogues are often organized with the direct participation of civil society group representatives (through a steering committee, for example).(30) The greater the degree of civil society involvement in this planning process, the more a dialogue can be seen as a collaboration rather than a consultation.

The proponents of deliberative dialogues have argued that their benefits include that:

- insights are sparked, and specifically 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; and
- action is generated among the full range of those who participate in the dialogue and by those who review a summary of the dialogue and other outputs, and not just by a single constituency.(30)

With deliberative dialogues, key questions include their effectiveness and how the design features of these dialogues can be matched to particular issues and contexts. A “safe harbour” rule, for example, may work well for highly politicized issues and in countries without a tradition of civil society engagement in policymaking. Such a rule may not work as well for other issues and in other countries.

Synthesized research evidence is available about deliberative dialogues that involve all constituencies. A summary of key findings from this synthesized research evidence is provided in Table 2. In brief, a low-quality review found that there is little evidence that identifies the most effective deliberative processes.(27;28) The same review found some studies suggesting that promising design parameters for deliberative processes include consultation with all parties affected by the outcome, fair representation of scientists and stakeholders, high-quality syntheses of the scientific evidence, and skillful chairing.(27) For those who want to know more about the systematic review contained in Table 2 (or obtain a citation for the review), a fuller description of the systematic review is provided in Appendix 2.

Table 2: Summary of key findings from systematic reviews relevant to Option 2 - Convene deliberative dialogues to inform and influence health system policymaking

Category of finding	Summary of key findings
Benefits	<ul style="list-style-type: none"> • None identified
Potential harms	<ul style="list-style-type: none"> • None identified
Costs and/or cost-effectiveness in relation to the status quo	<ul style="list-style-type: none"> • None identified
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	<ul style="list-style-type: none"> • Uncertainty because no systematic reviews were identified <ul style="list-style-type: none"> ○ Not applicable • Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review <ul style="list-style-type: none"> ○ Not applicable (i.e., no “empty” reviews were identified) • No clear message from studies included in a systematic review <ul style="list-style-type: none"> ○ A low-quality review found that there is little evidence that identifies the most effective deliberative processes.(27)
Key elements of the policy option if it was tried elsewhere	<ul style="list-style-type: none"> • A low-quality review found some studies suggesting promising design parameters include consultation with all parties affected by the outcome, fair representation of scientists and stakeholders, high-quality syntheses of the scientific evidence, and skillful chairing.(27)
Stakeholders’ views and experience	<ul style="list-style-type: none"> • None identified

Option 3 – Use new media to influence health system policymaking

New media, such as mass-short-messages (MSMs) and other mobile-phone based strategies, as well as online petitions and other internet-based approaches, constitute a third option for consideration. New media involve direct civil society control (not consultation or collaboration) and offer the potential to actively influence health system policymaking (not just inform it). New media can hold policymakers accountable for poorly informed health system policymaking and encourage better informed health system policymaking. It achieves this by bringing citizens to the streets or to the polls and by showing the breadth of public opposition when citizens cannot take to the streets, among other ways. MSM campaigns have brought citizens to the streets for the World Trade Organization meeting protests in Seattle in 1999 and for the “Orange revolution” in the Ukraine in 2004 and 2005.(31) MSM campaigns have also brought citizens to the polls to oust presidents in the Philippines in 2001 and in South Korea in 2004.(31) News and photos from Burma have brought latent (or pacifist) public opposition to the attention of the rest of the world.(31) Online petitions and other internet-based strategies have been used by organizations like Avaaz.org to articulate for policymakers and others widespread public concerns over the environment and many other global issues. Values, not research evidence, have typically been the motivator for those using new media. The question here is whether research evidence can be a similarly powerful motivator.

As the “new” in its title might foreshadow, this strategy is sufficiently new that its effectiveness has not been well studied. In brief, no reviews were identified that addressed the benefits, harms, and costs of using new media to influence policymaking. Synthesized research evidence is available about mass media, not new media. A summary of key findings from this synthesized research evidence about the mass media is provided in Table 3. A high-quality but old review found that planned mass media campaigns and unplanned mass media coverage can have a positive influence on the utilization of health services.(32) For those who want to know more about the systematic review contained in Table 3 (or obtain a citation for the review), a fuller description of the systematic review is provided in Appendix 3.

Table 3: Summary of key findings from systematic reviews relevant to Option 3 - Use new media to influence health system policymaking

Category of finding	Summary of key findings
Benefits	<ul style="list-style-type: none"> • Mass media <ul style="list-style-type: none"> ○ A high-quality but old review found that all of the studies (which were of variable quality) apart from one concluded that planned mass media campaigns and unplanned mass media coverage can have a positive influence on the utilization of health services.(32)
Potential harms	<ul style="list-style-type: none"> • None identified
Costs and/or cost-effectiveness in relation to the status quo	<ul style="list-style-type: none"> • None identified
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	<ul style="list-style-type: none"> • Uncertainty because no systematic reviews were identified <ul style="list-style-type: none"> ○ New media <ul style="list-style-type: none"> ▪ No reviews were identified that addressed the core option element • Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review <ul style="list-style-type: none"> ○ Not applicable (i.e., no “empty” reviews were identified) • No clear message from studies included in a systematic review <ul style="list-style-type: none"> ○ Not applicable
Key elements of the policy option if it was tried elsewhere	<ul style="list-style-type: none"> • None identified
Stakeholders’ views and experience	<ul style="list-style-type: none"> • None identified

Additional equity-related observations about the three options

The available synthesized research evidence about the three options hardly mentions the two prioritized groups: people with low levels of health literacy and people with no access to information and communication technology (e.g., mobile phone, computer with internet connection). Yet it is highly likely that at least the costs of the first two options will be higher for these groups. But it remains to be seen whether the benefits and harms of these options are bigger or smaller for these groups.

IMPLEMENTATION CONSIDERATIONS

While no systematic review was identified about the barriers to implementing these options, many conceptual frameworks and empirical studies can be drawn upon to identify barriers to civil society engagement in general and, by extrapolation, to identify potential barriers to the three options in particular.(7;16;33-35) A summary of the potential barriers is provided in Table 4.

Table 4: Potential barriers to implementing the options

Levels	Option 1 – Employ deliberative polling to inform health system policymaking	Option 2 - Convene deliberative dialogues to inform and influence health system policymaking	Option 3 – Use new media to influence health system policymaking
Patient/Individual	<p>Difficulty of engaging people with low levels of health literacy and with no access to information and communication technology (ICT), among others, which limits the generalizability of the findings</p> <p>Frustration within civil society if their past efforts to inform health system policymaking were not influential</p>	<p>Difficulty of engaging individuals who can articulate diverse viewpoints, which limits the influence of some communities on health system policymaking and leads to concerns about “tokenism”</p> <p>Frustration within civil society if their past efforts to inform health system policymaking were not influential</p>	<p>Difficulty of engaging people with low levels of health literacy and with no access to ICT, among others, which limits their influence on health system policymaking</p>
Service provider	<p>Concern among service providers that greater visibility of civil society viewpoints may come at the expense of the visibility of their own viewpoints</p>	<p>Concern among service providers that greater visibility of civil society viewpoints may come at the expense of the visibility of their own viewpoints</p>	<p>Concern among service providers that greater civil society influence may come at the expense of their own influence</p>
Organization	<p>Concern among civil society organizations that their representational legitimacy is being called into question when their members are approached directly for input</p>	<p>For-profit firms’ financial support to some civil society organizations may undermine the organizations’ representational legitimacy</p>	<p>For-profit firms’ financial support for new media strategies may undermine the strategies’ legitimacy</p>
System	<p>Lack of sustained funding for deliberative polling undertaken in the public interest</p> <p>Lack of government awareness of, and interest in, deliberative polling</p>	<p>Lack of sustained funding for deliberative dialogues convened in the public</p> <p>Lack of capacity-building, financial and infrastructure supports for civil society engagement in dialogues</p> <p>Lack of government awareness of, and interest in, deliberative dialogues</p>	<p>Lack of ICT infrastructure in some contexts (or at least a lack of harnessing of ICT infrastructure by those seeking to support the use of research evidence in health systems)</p>

While there are notable commonalities in the barriers across the three options, further research would be required to establish the benefits, harms, and costs of implementation strategies that might address these barriers.

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APPENDICES

The following tables provide detailed information about the research evidence identified for each option. Each row in a table corresponds to a particular systematic review, with rows grouped according to the option element that they address. The focus of the review is described in the second column. Key findings from the review that relate to the option element are listed in the third column. The remaining columns provide additional data about each systematic review as identified or assessed by two independent raters. The raters reached consensus on any areas of disagreement.

The fourth column presents the year the literature was searched as part of the systematic review. For each option element, reviews are presented in reverse chronological order, with the review containing the most recent search presented first. The fifth column presents a rating of the overall quality of the review. The quality of each review has been assessed using AMSTAR (A Measurement Tool to Assess Reviews), which rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality.⁽³⁶⁾ It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to delivery, financial, or governance arrangements within health systems. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered “high scores.” A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations.⁽³⁷⁾

The last three columns convey information about the utility of the review in terms of local applicability, equity, and issue applicability.⁽³⁸⁾ The sixth column notes the proportion of studies that were conducted in Canada and (separately) in low- and middle-income countries (LMICs), while the seventh column notes the proportion of studies included in the review that deal explicitly with one of the prioritized groups. The final column indicates the review’s issue applicability in terms of whether or not it focused on supporting research use.

All of the information provided in the appendix tables was taken into account by the issue brief’s authors in compiling Tables 1-3 in the main text of the brief.

Appendix 1: Systematic reviews relevant to Option 1 - Employ deliberative polling to inform health system policymaking

Option element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada or in LMICs	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on supporting research use
Public engagement	The effects of different methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines, and patient information material(23)	Moderate quality evidence indicates that involving consumers in the development of patient information material results in material that is more relevant, readable, and understandable to patients, without affecting their anxiety. Low quality evidence suggests that telephone discussions and face-to-face group meetings engage consumers better than mailed surveys to set priorities for community health goals, and result in differing priorities as well.	2006	10/11	2/5 (Canada) 0/5 (LMICs)	Not reported	2/5 (both studies focused on the involvement of consumers in research (i.e., patient satisfaction surveys) and as interviewers/ data collectors)
	A review of the literature on when public engagement should be sought, how it should be obtained, or how it might be incorporated by decision-makers into priority setting and resource allocation processes(39)	There is growing interest in ongoing deliberative approaches to public engagement. Formal evaluation of public engagement is rare. The literature provides little guidance on how public views might be integrated with other decision inputs when allocating social resources.	2006	n/a (scoping review, not a full systematic review)	9% (the actual number of studies was not reported) (Canada) Not reported (LMICs)	Not reported	Not reported
Community engagement	The effects and cost-effectiveness of community engagement and community development approaches on improving health and reducing health inequalities(24)	There is little evidence on the effects of specific interventions on health promotion. Varying qualities of evidence suggest that interventions that engage the community improve the dissemination of information and the development of interventions.	2007	7/11	4/21 (Canada) 0/21 (LMICs)	Not reported	0/21

Engaging Civil Society in Supporting Research Use in Health Systems

Option element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada or in LMICs	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on supporting research use
Service-user engagement	The effects of involving users in the delivery and evaluation of mental health services(25)	<p>Involving users with severe mental disorders in the delivery and evaluation of services is feasible.</p> <p>There are no studies on the effects of involving users in the planning of mental health services.</p> <p>Involving users as employees of mental health services led to clients having greater satisfaction with personal circumstances and less hospitalization.</p>	2001	6/11	<p>1/12 (Canada)</p> <p>0/12 (LMICs)</p>	Not reported	0/12
	The effects of involving patients in the planning and development of health care(26)	<p>Involving users has contributed to changes in the provision of health services.</p> <p>There were no studies on the effects of the involvement of users on accessibility and acceptability of services, or the impact on the satisfaction, health, or quality of life of patients.</p>	2000	6/11	<p>2/40 (Canada)</p> <p>0/40 (LMICs)</p>	Not reported	0/40
Use of research evidence by civil society organizations to influence policymaking processes	The impact of the role and use of evidence on the legitimacy and effectiveness of civil society organizations(22)	The literature suggests that using credible, relevant, and accessible evidence effectively can be critical to the success of civil society organizations aiming to influence policy agenda-setting, formulation, implementation, and monitoring and evaluation.	2005	0/11 (no methodology was described)	<p>Not reported (Canada)</p> <p>Not reported (LMICs)</p>	Not reported	Not reported

Appendix 2: Systematic reviews relevant to Option 2 – Convene deliberative dialogues to inform and influence health system policymaking

Option element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada or in LMICs	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on supporting research use
Deliberative dialogues	<p>The role of health sector deliberative processes in combining different forms of evidence to produce guidance⁽²⁷⁾</p> <p>(The concept of “evidence” is treated by those who produce scientific evidence, those who formulate guidance, and those who make decisions.)</p>	<p>There is little evidence that identifies the most effective deliberative processes.</p> <p>Some studies suggest design parameters for deliberative processes that are likely to produce balanced consensus (i.e., guidance that respects scientific integrity and implementability in the healthcare system), namely consultation with all parties affected by the outcome, fair representation of scientists and stakeholders, high-quality syntheses of the scientific evidence, and skillful chairing</p>	2005	3/11	<p>Not reported (Canada)</p> <p>Not reported (LMICs)</p>	Not reported	Not reported

Appendix 3: Systematic reviews relevant to option 3 - Use new media to influence health system policymaking

Option element	Focus of systematic review/cost-effectiveness study	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada or in LMICs	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on supporting research use
Media	The effects of mass media on the utilization of health services(33)	A high-quality but old review found that all of the studies (which were of variable quality) apart from one concluded that planned mass media campaigns and unplanned mass media coverage can have a positive influence on the utilization of health services.	1999	10/11	1/20 (Canada) 1/20 (LMICs)	0/20	0/20