McMaster University

McMaster HEALTH FORUM

DIALOGUE SUMMARY

ORGANIZING A CARE SYSTEM FOR OLDER ADULTS IN ONTARIO

14 NOVEMBER 2011

EVIDENCE >> INSIGHT >> ACTION

Dialogue Summary:
Organizing a Care System for Older Adults in Ontario

14 November 2011

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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Funding

The funding for the stakeholder dialogue (and the evidence brief that informed it) were both provided by the Labarge Charitable Foundation. The McMaster Health Forum receives both financial and in-kind support from McMaster University. The views expressed in the dialogue summary are the views of the dialogue participants and should not be taken to represent the views of the Labarge Charitable Foundation, McMaster University or the authors of the dialogue summary.

Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the dialogue summary. The funder played no role in deciding what appeared in the dialogue summary.

Acknowledgements

The authors wish to thank Ileana Ciurea and the staff of the McMaster Health Forum for assistance with organizing the stakeholder dialogue.

Citation

Wilson MG, Lavis JN. Dialogue Summary: Organizing a Care System for Older Adults in Ontario. Hamilton, Canada: McMaster Health Forum, 14 November 2011.

Dialogue

The stakeholder dialogue about organizing a care system for older adults in Ontario was held on 14 November 2011 at the McMaster Health Forum in Hamilton, Ontario, Canada.

Product registration numbers

ISSN 1925-2226 (print)
ISSN 1925-2234 (online)

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SUMMARY OF THE DIALOGUE

The deliberations about the problem initially focused on whether the focus should be on frail older adults and/or those living with chronic conditions, as opposed to all of those over the age of 65. Dialogue participants noted that the pressing issue is less about providing care to those aged 65 and older, and more about preventing chronic disease and providing effective chronic care and supports for those who need them. Dialogue participants highlighted six key elements of the problem, including:

1) a care system that consists of 'silos' (e.g., hospitals and community-based supports) that are not integrated and in many cases are driven by a medical model for acute care;
2) a lack of 'system navigators,' which makes it difficult for older adults and their families to access the care and supports they need;
3) a lack of responsiveness to cultural, linguistic, religious and other forms of diversity, as well as to the specific challenges posed by providing care and supports for older adults in rural and remote areas;
4) a lack of preparation for the emerging role of technology in the system;
5) a lack of information and funding that 'follow the patient,' which makes it difficult to identify and address gaps in care and supports, and to ensure continuity and quality of care; and
6) sub-optimal recruitment and training practices for providers who deliver care and supports to older adults.

Dialogue participants identified eight elements of a comprehensive approach to addressing the problem. Three of the eight were long-term priorities:

1) raising awareness and setting expectations about what can and should be done to deliver care at costs that are affordable;
2) recruiting and training of leaders, including CEOs, providers and older adults, to provide leadership throughout the system; and
3) preparing for an increased role for technology.

The remaining were short-to-medium-term priorities:

4) messaging to communicate and emphasize the priorities of supporting physical activity and social engagement, 'home and community first,' and choice within the system based on individuals' needs;
5) promoting supportive health system delivery arrangements, including existing but under-utilized resources such as the 211 information line that helps citizens identify the services that may be available to them, and implementing additional initiatives such as system navigators and hubs that coordinate services that are located within the community sector and that are provided by primary healthcare teams;
6) designing and implementing a risk- and/or outcomes-based funding mechanism for elder care and supports;
7) supporting the engagement of older adults in the governance of the system and of organizations in order to identify and incorporate their expectations (e.g., through enhanced citizen-engagement processes, greater representation on organizational boards, and/or by using providers as advocates); and
8) implementing a dynamic monitoring and correction system that allows for adaptation to emerging issues and to cultural and linguistic needs in different areas of the province.

Dialogue participants identified two barriers to implementing the key elements of a more effective care system for older adults in Ontario: 1) the lack of a mechanism to identify pilot projects that should be scaled up and to support this scaling up throughout the province; and 2) the legislative and regulatory barriers to scaling up given that many pilot projects can require approvals and coordination across government departments, and sometimes across levels of government and levels within the delivery system. Dialogue participants identified several implementation strategies for a more effective care system for older adults in Ontario: 1) transition to a governance model that facilitates decision-making within and across governments and that engages key stakeholders; 2) introduce a process for re-organizing, scaling back or discontinuing less effective programs and services so that more effective ones can be introduced while the province goes through such a difficult economic period; and 3) adopt a flexible approach to implementation that allows for course corrections as lessons are learned.

SUMMARIES OF THE FOUR DELIBERATIONS

DELIBERATION ABOUT THE PROBLEM

The deliberations about the problem initially focused on whether the focus should be on older adults in general (defined as those aged 65 years and older) or on frail older adults and/or those living with chronic conditions. One dialogue participant noted that being elderly is no longer defined in relation to the age of 65, and that the population served by the participant's organization is typically 80 years of age and older. The same dialogue participant highlighted that the issue is less about providing 'elder care' and more about providing effective chronic care for those who need it. Echoing data presented in the evidence brief, another dialogue participant similarly argued that the underlying problem is more that people with one or more chronic diseases (particularly those with multiple conditions) generally need more services. Another participant suggested that by removing the focus on age, the discussion could be more about those who require complex supports.

While one dialogue participant labeled the overarching problem (or cause of the problem) as one of poverty and another labeled it as complexity, all other dialogue participants adopted a narrower frame for the problem. These dialogue participants focused on the challenge of organizing a care system for older adults in Ontario and highlighted six features of this more narrowly framed problem.

First, one participant argued that the care system consists of silos (e.g., hospitals and community-based supports) that are not integrated (in large part because funding is not integrated across these silos), and that many of these silos are driven by a medical model for acute care. Several dialogue participants concurred, noting that many types of care and supports are needed for older adults to stay healthy (e.g., through physical activity and social engagement), address health issues when they arise, and remain living at home or in the community for as long as possible, but that it is difficult to access the full range of care and supports given the system's many 'silos.' One dialogue participant highlighted the importance of working across silos and increasing the emphasis placed on providing community and home supports to prevent people from entering an already over-burdened long-term care system in Ontario. Several other dialogue participants observed that a medical model for acute care neither provides the types of care and

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 Ontario;
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 evidence 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.

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.

supports needed by those with multiple chronic conditions, nor addresses the 'upstream' factors needed to prevent chronic conditions in the first place. The same dialogue participant who initially noted the silos and the reliance on a medical model for acute care in many of these silos, argued that the care system for older adults in Ontario will remain as it is now until funding is integrated across these silos and shifted to provide more supports in the community and at home using a social-determinants-of-health model for chronic disease prevention, care and supports.

Second, a number of dialogue participants noted that the lack of 'system navigators' is another key element of the problem. They noted that the fragmentation in the healthcare and community supports systems makes it difficult for older adults and their families to access the care and supports they need regardless of whether the silos and the medical model for acute care continue their dominance. One dialogue participant remarked that if you don't know the system then it is very difficult to access what you need. As a result, many older adults and their families need a 'system navigator' to help them make informed choices, advocate for themselves, and transition among levels of care and types of providers.

Third, a lack of responsiveness to cultural, linguistic, religious and other forms of diversity, as well as to the specific challenges posed by providing care and supports for older adults in rural and remote areas of the province, was noted as an additional element of the problem. One dialogue participant highlighted the general lack of culturally appropriate care within the system. A second dialogue participant noted that not addressing cultural and other forms of diversity can create significant barriers to accessing and receiving appropriate care and supports for a significant proportion of the population in a very multi-cultural province like Ontario. A third dialogue participant emphasized the need to address the gaps in care and supports available in rural and remote areas, given the substantial distances involved in travelling to obtain them in other communities.

The lack of preparation for the emerging role of technology in the system was discussed by several participants as a fourth key element of the problem. One participant argued that the expectations of those who will be elderly in the future (particularly those in the baby-boom generation) are much different than those who are currently elderly, with the former being more informed about and sophisticated in their use of technology. As a result, older adults will be increasingly inclined and likely to expect to use technology in more expansive ways as part of their care. A second dialogue participant noted that individuals will increasingly want to manage their own care and supports up to the point where they can no longer do so, and that an integral part of such management will be done through the use of technology. A third dialogue participant observed that people contacting healthcare and community-based organizations are 'hungry' for information, and that technology can often better and more efficiently provide this information. Building on this, a fourth dialogue participant emphasized that there is a need to embrace a wider range of approaches for using technology in care and supports, such as using it to help keep people connected to their community, be entertained, and stay healthy and fit. A fifth dialogue participant said that the lack of preparation for the role of technology also extends to existing technology, particularly how information captured using technology can be integrated into the system (i.e., across settings, providers and consumers), which also links to the next element.

The lack of information and funding that 'follow the patient' from one setting and provider to the next was the fifth key element of the problem, because it makes it difficult to identify and address gaps in care and supports and to ensure continuity and quality of care. A number of dialogue participants noted that choices among the available care and supports should be based on the preferences of older adults themselves whenever possible, but that doing so means that information about patients' preferences and health conditions need to be immediately available, and that these choices need not be constrained inappropriately by the form of public funding for care (which is often based on specific services provided in particular settings or by particular providers, as opposed to the holistic management of a number of concurrent chronic conditions regardless of setting or provider).

Sub-optimal recruitment and training practices for providers who deliver care and supports to older adults was highlighted as the sixth key element of the problem. One dialogue participant suggested that part of the problem may be that recruitment of the providers of tomorrow does not involve identifying qualified applicants who are specifically interested in providing care to older adults as well as to working in integrated systems and using a social-determinants-of-health model for chronic disease prevention, care and supports. A second dialogue participant noted that the training of those providing care and supports is largely focused on episodic interventions (as opposed to long-term care and supports across the continuum of care) delivered by individuals, and less on thinking holistically (as opposed to by disease) as members of a team. As a third dialogue participant summed it up, 'those providing care and supports are critical to ensuring that people receive the full range of care and supports they need, and this starts with how we train the providers working in the system.' Building on this, a fourth dialogue participant noted that there is a lack of training for how to provide care and supports to the frail elderly specifically. Several participants argued that medical schools need to focus on generating more interest among students about providing care and supports for older adults, and about managing chronic conditions well at the primary care level. Commenting on this, one dialogue participant highlighted that part of the challenge with generating interest is that providing care and supports to older adults is not seen as a 'sexy' part of medicine.

DELIBERATION ABOUT POLICY AND PROGRAMMATIC ELEMENTS

The deliberation focused primarily on what should be emphasized within each bundle of components within the three elements that were described in the evidence brief, including the relative importance or priority accorded to each element (or their components) and whether some elements (or their components) can be sequenced in a way that achieves near-term wins in a difficult economic climate, while paving the way for longer-term wins as economic conditions improve. That said, one dialogue participant noted that the framing of the elements reinforced a silo-based approach rather than encouraging moving beyond silos.

Element 1 - Support older adults and their families in ways that support healthy aging

Much of the deliberation about the first element focused on the need for clarification about what is included within the domain of 'self-management.' Many dialogue participants emphasized that the concept of self-management could be interpreted differently by providers and by those receiving care and supports. One dialogue participant cautioned that care should be taken to not assign responsibilities to older adults and their families that they either don't want or cannot assume on their own. Another dialogue participant cautioned that care should be taken not to assume that older adults are a homogeneous group.

As part of this discussion about supporting older adults and their families both in general and through supports for self-management, dialogue participants emphasized the importance of taking into account their preferences (and not adopting a standardized approach to supporting self-management), the difficulties associated with separating the components of this element from those components described as part of the third element, and the value of using technology effectively.

Several dialogue participants noted that approaches for supporting self-management should not be standardized, and that supports for self-management should accommodate older adults' preferences, needs and circumstances, and, where appropriate, the preferences of their families. As one dialogue participant noted, asking older adults and their families what they want and expect from the health system will help to steer the system in the right direction and to avoid over-promising and under-delivering. Similarly, another dialogue participant emphasized the need for a governance model that includes older adults and that allows for their preferences and expectations to be more consistently taken into account when making decisions.

Many dialogue participants considered it difficult to separate the components of this element from those components described as part of the third element, because many community resources are needed to support older adults and their families in ways that support healthy aging. For instance, one dialogue participant highlighted that central access points for community care are important for supporting self-management (by helping older adults and their families know where to go to access self-management supports), and for coordination of the supports needed by each individual (a component of the third element). In response to this, another dialogue participant suggested that the more appropriate framing of this bundle of elements could be *enabling* older adults and their families in ways that support healthy aging, which would include enablers outside of the medical model of acute care, such as physical activity and social engagement, accessible transportation, and access to the internet and other types of technology.

The effective use of technology was highlighted by several dialogue participants as being a critical component of this element (as well as both of the other elements). As one dialogue participant noted, older adults are increasingly going to be able to and will want to use technology, such as smart phones and tablets, which could be a very effective tool for supporting self-management and for building a circle of care that includes healthcare providers, caregivers and those receiving care. However, one participant cautioned that promoting patient access to electronic health records risks off-loading the responsibility for managing these records to the patients, which could place too much burden on individuals and be risky in terms of ensuring information accuracy.

Element 2 - Coordinate integrated healthcare services that are built around the needs of older adults and support healthy aging

Dialogue participants emphasized the need to coordinate services across the full continuum of care, make better use of technology, modify funding and remuneration models, and provide training to better equip healthcare providers to deliver the types of care needed by older adults.

Several dialogue participants noted that the key question about coordinating services across the full continuum of care (and not just within silos in the existing healthcare and community support system) is *how* to coordinate, however, they sometimes differed in their response to this question. Several dialogue participants argued for providing assistance with system navigation to identify and access needed care and supports, while one dialogue participant argued for identifying a 'hub' for coordination, and another argued for creating an independent assessment mechanism through which individuals are assessed for the level and mix of services they need. One dialogue participant specifically noted that a plan is needed for coordinating access to local healthcare and community support services in rural and remote areas. Several dialogue participants highlighted making better use of technology as being important for element 2, given technology can provide a mechanism for facilitating coordinated follow-up and for linking interprofessional care and support teams.

The need to modify existing funding and remuneration models in ways that allow for better management of complex and chronic conditions was highlighted as another key component of this bundle of elements. Many dialogue participants supported a risk- or outcomes-based model for funding organizations and remunerating providers combined with incentives for providing specific types of care and support. In addition, one dialogue participant highlighted the need to fund bundles of the care and community supports that would help older adults to live at home or in the community for as long as possible. The same participant suggested adopting a primary healthcare fund-holding model whereby primary healthcare providers are given discretion to allocate funds towards customized bundles of services that meet the needs of their patients. Several dialogue participants noted that there is a need to move away from a focus on paying organizations and providers and towards a system in which the funding 'follows the patient' from one setting and provider to the next.

Several dialogue participants emphasized the importance of providing appropriate training for healthcare providers to better equip them to deliver the types of care needed by older adults. Participants noted that healthcare providers do not typically receive training related to providing care to older adults, and that in the future there will be a need to have more physicians qualified to provide geriatric care. However, one dialogue participant cautioned that we don't need 'specialized specialists' because family physicians will likely be responsible for providing most of the primary healthcare for older adults, but they still need training to perform this role effectively.

Element 3 - Coordinate integrated community resources that are built around the needs of older adults and support healthy aging

Dialogue participants gave particular attention in their deliberation about this element to the need for better coordination of community resources, a broader spectrum of community resources than currently exists, and a governance model that ensures that older adults can and do access the resources they need to stay healthy and live at home or in the community.

Many dialogue participants focused on the need for better coordination of community resources as one of the key components of this element. Several dialogue participants noted that when community supports are delivered through coordinated models, different organizations can come together to determine how they can collectively provide an appropriate mix of services given each individual's needs. One dialogue participant noted that system navigators such as case managers can also support coordinated care and supports, including liaising with primary healthcare providers. A second dialogue participant argued that coordination also needed to involve early intervention to prevent the more intensive care and supports required once needs had become more complex.

Several dialogue participants highlighted the need for a broader spectrum of community resources to be available. For instance, one dialogue participant argued that for community resources to be built around the needs of older adults one needed to consider areas 'outside of the box,' such as building architecture, transportation design and urban planning, to ensure that older adults can easily access resources close to or easily accessible from where they live.

Lastly, dialogue participants re-emphasized the need to adopt a governance model that ensures that older adults can and do access the resources they need. One dialogue participant suggested that all community care and supports should be placed under the purview of the Ministry of Community Services, to provide more control over planning and decisions in this sector. Another dialogue participant agreed with this suggestion and further highlighted that until community resources are separated from healthcare services the former will continue to be forced to provide care within a medical model for acute care. However, another dialogue participant cautioned against such a transition in authority, noting that the community sector may resist such a move for fear of being marginalized outside of the healthcare system as opposed to being more integrated with it.

Considering the full array of elements

As was described in the preceding sub-sections of the dialogue summary, dialogue participants identified a number of elements of a comprehensive approach to addressing the challenge of organizing a care system for older adults in Ontario, which were summarized at this point in the deliberation (and before initiating the deliberation about implementation considerations). At this juncture no new elements were identified for consideration. The way in which these key elements are framed and nuances in how they are discussed were then re-visited after the deliberation about implementation considerations.

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

Dialogue participants identified two barriers to implementing the key elements of a more effective care system for older adults in Ontario: 1) the lack of a mechanism to identify pilot projects that should be scaled up and to support this scaling up throughout the province; and 2) the legislative and regulatory barriers to scaling up given that many pilot projects can require approvals and coordination across government departments and sometimes across levels of government and levels within the delivery system.

Regarding the first barrier, several dialogue participants noted that there are many innovative pilot projects (including many focused on models of care and supports) at the local level that have shown promising results, including the many that received funding from the Aging at Home Strategy, and that no individuals or organizations in the health system have the job of identifying these innovations and ensuring they are adopted more broadly in the province.

Turning to the second barrier, a few dialogue participants observed that even when a pilot project has been identified as one that should be scaled up, there are many legislative and regulatory barriers to doing so. For instance, some dialogue participants noted that when an initiative includes a mix of healthcare and social supports, approvals and coordination can be required from two or more government departments and two levels of government, which often requires a long and difficult process of consensus building. One dialogue participant noted that coordination can sometimes also be required across levels within the delivery system, as well as mechanisms to ensure accountability. However, a second dialogue participant cautioned against placing too much emphasis on accountability mechanisms, particularly for rural and remote regions with limited resources. This individual noted that at times it seems as though more money is spent on fulfilling accountability requirements than on delivery of care and supports, and that providers and managers need some level of discretion about the types and mixes of care and supports to deliver to people in their community.

Dialogue participants identified several implementation strategies for a more effective care system for older adults in Ontario: 1) transition to a governance model that facilitates decision-making within and across governments and that engages key stakeholders; 2) introduce a process for re-organizing, scaling back or discontinuing less effective programs and services so that more effective ones can be introduced while the province goes through such a difficult economic period; and 3) adopt a flexible approach to implementation that allows for course corrections as lessons are learned.

Regarding the first proposed implementation strategy – the transition to a new governance model – one participant argued that the model should facilitate decision-making and implementation across government departments and levels of government, which the individual called a model of joined-up governance, and where responsibility for decision-making and accountability for decision-making are clearly delineated. A second dialogue participant argued that the model should also help to build consensus with key stakeholders, including particularly influential stakeholders such as the Ontario Hospital Association and Ontario Medical Association.

The second proposed implementation strategy – the introduction of a process for freeing up funding that can be used to support innovative approaches to care and supports – was suggested in response to many dialogue participants questioning how much a coordinated and integrated system of care and supports would cost, and who would provide any additional funding that might be needed. One dialogue participant noted that reforming or strengthening the care system for older adults is not necessarily always about adding on, but in many instances requires reorganizing, scaling back or discontinuing less effective programs and services so that more effective ones can be introduced. This individual argued that without such an approach during this economic climate, it will not be possible to scale up effective pilot programs.

The third proposed implementation strategy – adopt a flexible approach to implementation that allows for course corrections as lessons are learned – is perhaps less a strategy and more an approach to whatever strategy is adopted. One dialogue participant argued for using a flexible, 'course correction' model that could take into account feedback from ongoing evaluations, among other sources. A second dialogue participant used the 'home first' philosophy as an example of a model that is now 'starting to bear fruit' in terms of older adults' acceptance of it and its impacts, but that may require ongoing adaptation to optimize its impacts.

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

Dialogue participants identified eight elements of a comprehensive approach to addressing the problem. Three of the eight were long-term priorities:

1) raising awareness and setting expectations (in collaboration with older adults, their families and communities) about what can and should be done to deliver care at costs that are affordable;
2) recruiting and training of leaders, including CEOs, providers and older adults, to provide leadership throughout the system; and
3) preparing for an increased role of technology, including to support self-management, to build a circle of care among elderly adults, their caregivers and their interprofessional care and support teams, and to enhance coordination among these teams.

Recruitment and training (priority 2) was the focus of the greatest amount of elaboration among these long-term priorities. Beginning with leaders in the health system, one dialogue participant gave equal emphasis to raising awareness among all leaders of the need for integrated systems and for a social-determinants-of-health model for chronic disease prevention, care and supports, and to targeted education to those who will work in long-term care and in the community. Turning to providers, another dialogue participant argued that training about providing care and supports to older adults, particularly the frail elderly, should be compulsory, with one key reason being that such care will likely constitute a significant part of their clinical practice. Another dialogue participant argued that for such training to be successful, it should take place outside acute care settings and instead in the long-term care facilities and in the community where much of the care is provided, and where more of the innovative models of care are being used. For leaders and possibly for providers as well, one dialogue participant argued that incentives would be needed to recruit them to work in environments that specialize in care and supports for older adults and their families.

The remaining elements of a comprehensive approach were short-to-medium-term priorities:

4) messaging to communicate and emphasize the priorities of supporting physical activity and social engagement for all older adults, 'home and community first' for those older adults needing care and supports, and choice within the system based on the specific needs of individuals, as well as to reinforce the idea that, as one dialogue participant noted, 'aging is a normal part of life and not a disease' to be treated medically;
5) promoting supportive health system delivery arrangements, including existing but under-utilized resources such as the 211 information line that helps citizens identify the services that may be available to them, and implementing additional initiatives such as system navigators and hubs that coordinate services that are located within the community sector and provided by primary healthcare teams;
6) designing and later implementing a risk- and/or outcomes-based funding mechanism for elder care;
7) supporting the engagement of older adults in the governance of the system and of organizations in order to identify and incorporate their expectations (e.g., through enhanced citizen-engagement processes, greater representation on organizational boards and/or by using providers as advocates), while avoiding 'tokenism' and ensuring fair representation; and
8) implementing a dynamic monitoring and correction system that allows for adaptation to emerging issues and to cultural and linguistic needs in different areas of the province (and that, as one dialogue participant suggested, could usefully include or draw on a clearinghouse containing descriptions and evaluations of pilot projects).

The 'hubs' (part of priority 5) and funding mechanism (priority 6) were the focus of the greatest amount of deliberation among the short-to-medium term priorities. Beginning with the hub idea, several participants questioned how and where the hub function would be performed, with a few suggesting that the Local Health Integration Networks would be the logical location for this function, given that they don't have a service delivery role that would present a conflict of interest, and that they have an explicit mandate to support integration and coordination across the entire health system. However, one dialogue participant noted that Local Health Integration Networks would need to better connect with providers that are paid by municipal governments in order to execute this function well. A second dialogue participant argued that introducing hubs doesn't need to mean introducing new structures and that we need to avoid further restructuring and ultimately stop 'turf wars.' A third dialogue participant suggested that a logical choice for a hub in many rural areas would be acute care hospitals, while a fourth dialogue participant suggested that long-term care facilities could also play this role. Turning finally to the funding mechanism, one dialogue participant observed that selecting outcomes that can be used for risk- and/or outcomes-based funding would be very challenging, so that it would be better to consider the initiation of a process for designing a new funding mechanism as a short-to-medium-term priority, but that completing the design and then implementing it would be better considered as a long-term priority.