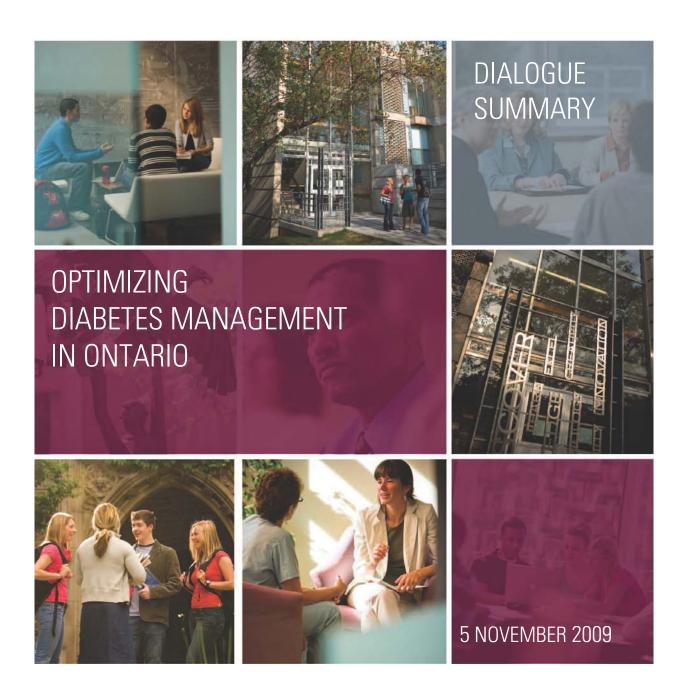


McMaster HEALTH FORUM



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Dialogue Summary: Optimizing Diabetes Management in Ontario

5 November 2009

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 stakeholder dialogue, and the evidence brief that informed it, was funded by the Ontario Ministry of Health and Long-Term Care, as part of a larger project – "Diabetes Tools for Ontario Patients, Clinicians and Policy Makers" – co-ordinated by the Li Ka Shing Knowledge Institute of St. Michael's Hospital. The views expressed in the evidence brief are the views of the authors and should not be taken to represent the views of the Ministry.

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

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

Conflict of interest

The author declares that he has no professional or commercial interests relevant to the dialogue summary. Select staff of the Ministry of Health and Long-Term Care reviewed a draft dialogue summary, but the author had final decision-making authority about what appeared in the dialogue summary.

Acknowledgments

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

Citation

Lavis JN. Dialogue Summary: Optimizing Diabetes Management in Ontario. Hamilton, Canada: McMaster Health Forum, 5 November 2009.

Dialogue

The stakeholder dialogue about optimizing diabetes management in Ontario was held on 5 November 2009 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

Dialogue participants observed that many of the building blocks for an organized system of diabetes care are in place or being put in place. Examples include the emergence of self-management supports for diabetes patients and decision supports for primary healthcare providers, the embedding of multidisciplinary diabetes education and management centres within existing practices/clinics, and the growing interest in supporting diabetes management in primary healthcare practices. However, a number of participants noted that such efforts are characterized by a lack of co-ordination, integration, evaluation, and communication. Several dialogue participants argued that there was a need for the Ministry of Health and Long-Term Care to develop a policy framework to support the optimization of diabetes management in Ontario or, at the very least, a communications strategy to ensure that the full array of stakeholders are familiar with the "pieces" of the plan and how they fit (or are being fit) together.

A number of additional insights emerged during the deliberations:

- A "one-stop shop" for self-management supports could provide significant value, particularly if
 undertaken in partnership with those already well established groups and organizations supporting
 diabetes education and management, and if complemented by peer support programs and reminders and
 prompts at the patient level. Performance measurement and feedback at the primary healthcare
 practice/clinic level, as well as financial incentives, could also provide value. Electronic health records are
 needed to support much of this work.
- A welcome transition is occurring in multidisciplinary diabetes education and management centres which increasingly accommodate a broader array of disciplines and are embedded within existing practices/clinics. Existing centres have a key role to play in nurturing, supporting, and championing efforts to optimize diabetes management in their respective domains. There is a need to address inequitable utilization patterns across centres and to develop a standard curriculum for diabetes educators that encompasses the new focus on patient self-management and cultural diversity.
- One key next step in optimizing diabetes management is to expand nodes of expertise in diabetes management in primary healthcare (and more specifically to facilitate capacity building within Family Health Teams). This can be facilitated by supporting embedded diabetes management and education centres and by creating a pyramid-shaped regional structure that provides secondary and tertiary supports for adults with type 1 diabetes and complex type 2 diabetes.
- A hybrid option that received significant support includes: 1) implementing a model for optimizing diabetes management that expands nodes of expertise in diabetes management in primary healthcare (which can in turn draw on secondary and tertiary care supports), and that supports regional focal points charged with coordination and integration; 2) measuring and providing feedback on performance (and possibly establishing targets along with clear accountabilities and rewards for achieving these targets); 3) disseminating tools and resources to both patients (i.e., self-management supports) and providers (i.e., decision supports); and 4) enhancing communication among those involved in diabetes management.
- Two barriers may come into play with any of the options. First, optimizing diabetes management within
 diverse ethnocultural communities is not just about translating materials into other languages. It can also
 mean dealing with a vast array of lifestyle-related factors, poverty-related factors and other influences.
 Second, diabetes registry implementation needs to be improved because a significant proportion of
 patients with diabetes are currently being missed.
- Several dialogue participants recognized that diabetes is the test case for a disease-based approach to strengthening primary healthcare and observed that the initiative needs to be shown to be successful in helping people live well with diabetes. If it is not, diabetes' "day in the sun" may well be over.

SUMMARIES OF THE FOUR DELIBERATIONS

DELIBERATION ABOUT THE PROBLEM

Dialogue participants focused more on problems associated with the health system arrangements that determine access to and use of effective diabetes programs, services, drugs and devices, and less on: 1) the nature and burden of diabetes that the health system must manage (which were very familiar to all of them); 2) effective (and cost-effective) programs, services and drugs that are not being provided within the health system to meet the needs of those living with diabetes (which many saw as an effect of health system arrangements rather than a cause of problems in its own right); and 3) limitations in the degree of implementation of the current diabetes strategy. That said, within the broad category of health system arrangements, participants' views of the problem ranged from many primary healthcare physicians not working in teams or clinics to the general lack of an organized system of diabetes care.

A number of dialogue participants pointed to the lack of reminders and recalls for patients and of reminders and prompts for healthcare providers. They also observed that there is a lack of some forms of structured/protocolized care (especially for type 2 diabetes, where much of the care can be provided by nurses, as compared to type 1 diabetes where diabetologists find they cannot get primary healthcare practices/clinics to "take their patients back"). One dialogue participant noted that "there is real cynicism with guidelines" among some healthcare providers, and many do not know which guidelines to believe or use. However, the same dialogue participant noted that such healthcare providers may use guidelines if they help them achieve targets.

Dialogue participants differed in the extent to which they saw the primary healthcare system as the most important place to look for problems in diabetes management. One dialogue participant argued that "diabetes is diabetes, it's not a [generic] chronic

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:

- it addressed an issue currently being faced in Ontario;
- it focused on different features of the problem, including (where possible) how it affects particular groups;
- it focused on three options (among many) for addressing the policy issue;
- 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;
- 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;
- 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.

disease" and that most primary healthcare practices/clinics are not focused on diabetes. Other dialogue participants noted that there were many centres of excellence in primary healthcare for diabetes, however, these practices/clinics tend to function more as secondary referral centres than as true primary healthcare practices/clinics. Still others pointed to challenges (and opportunities) involving diabetes educators, who sometimes lack the full knowledge and skills needed to support self-management by patients and to address cultural diversity.

Several dialogue participants pointed to challenges with existing financial arrangements. For example, rostered patients cannot access a primary healthcare practice/clinic providing secondary diabetes care. Also, optometry has been de-listed and many patients cannot afford diabetic retinopathy testing. Moreover, many patients do not have prescription drug coverage and some of the newer diabetes medications can be quite expensive.

A number of dialogue participants noted the lack of performance measurement in primary healthcare and in the system more generally (especially performance measurement focused on what is working, what is not working, and what is missing), and, more importantly, the lack of performance expectations/accountability backed up by "carrots and sticks" (e.g., lack of feedback to support quality improvement at the practice/clinic, local, regional and system level). The lack of performance expectations/accountability, some dialogue participants argued, extends to secondary and tertiary referral centres. For example, these referral centres do not face performance expectations/accountability related to supporting primary healthcare practices/clinics in their communities.

Dialogue participants observed that many of the building blocks for an organized system of diabetes care are in place or being put in place. For example, many patients are integrated into alternative levels of care (and most regions have a number of strong clinical groups at secondary and tertiary care levels), fee-for-service remuneration is much less common than in the past (although one participant challenged this view), a number of diabetes educator programs exist in Ontario (one of which includes a certification program), and some Local Health Integration Networks have a diabetes steering committee in place. However, a number of participants noted that such efforts are characterized by a lack of coordination, integration, evaluation and communication. The dialogue participant who challenged the view about a reorientation in primary healthcare argued that most primary healthcare physicians are still not working in Family Health Teams, are still operating as solo practitioners (even if they are working in "administrative" groups for remuneration purposes), do not work with other types of healthcare providers, and are not seeking out collaborations with diabetes specialists.

Regardless of the dialogue participants' perceptions of a reorientation in primary healthcare, there was a widely held view that the building blocks "are all cobbled together." One dialogue participant asked how one could bring the key people together to build on what is working. Another dialogue participant noted the lack of supports for building on local/regional successes and strengths such as teams that move beyond the traditional nurse/dietitian model and mentoring programs (besides a single motivated civil servant who has been playing this role for many years).

Dialogue participants noted three other facets of the problem: 1) lack of standardized education and certification of some professional groups involved in diabetes care; 2) lack of attention to pricing of the products that patients use to manage their diabetes, in particular, glucose-test strips; and 3) lack of a policy framework for diabetes that helps to clarify the elements of a system-wide approach to optimizing diabetes management (and the interrelationships among these features), support the coordination of those elements, monitor their implementation, and evaluate their impact. With regard to pricing, one dialogue participant noted that the price of glucose-test strips varies dramatically by jurisdiction despite the large number of companies producing them, and that the total cost of these strips for the Ontario Drug Benefit program and for patients is significant.

While discussing the lack of a policy framework for diabetes, dialogue participants observed that many diabetes initiatives are being undertaken by the Ontario Ministry of Health and Long-Term Care, and that these are sometimes not linked to existing programs. Moreover, labelling a single set of enhancements as the "diabetes strategy" has caused (and continues to cause) confusion when, in several participants' view, this is not an overarching strategy and needs to be formulated in the context of a broader policy framework. One dialogue participant noted that there once was a comprehensive diabetes strategy, which formed the basis for decisions about requests for funding, but the Ministry did not publish it. Regardless of whether a policy framework is formalized or not, one dialogue participant argued that some attention needs to be given to

economies of scale, given that some things can only be done at the primary healthcare practice/clinic level, whereas other things can be done at the regional or provincial level.

With regard to features of the problem that pertain to the implementation of existing initiatives, one dialogue participant noted that the diabetes registry planners seem to assume that every patient "belongs to someone" (i.e., is rostered), but this is not the case and non-rostered patients are missed. Non-rostered patients include both those seeing primary healthcare physicians who do not maintain a roster and those seeing specialists in academic health science centres.

DELIBERATION ABOUT POLICY AND PROGRAM OPTIONS

Dialogue participants discussed three options that had been "worked up" as concrete examples of what could be done differently.

Option 1 - Provide self-management support to diabetes patients and decision support to primary healthcare providers

A number of dialogue participants endorsed the idea of a "one-stop shop" for self-management tools and resources that would support patients to live well with their diabetes. Several expressed a personal willingness to share tools and resources. One dialogue participant noted that some patients cannot or do not access the internet, so diabetes educators and others need to make particular efforts to reach out to these individuals. Another dialogue participant noted that the development of a patient portal was being funded as part of the same initiative as the dialogue. Several dialogue participants noted the importance of attending to issues related to cultural diversity in setting up such a one-stop shop.

Several dialogue participants identified select elements of this option as warranting more attention. For example, they argued that the challenges in providing supports to healthcare providers are less knowledge-based (although continuing professional development programs suggest – incorrectly in one dialogue participant's view – that this is not the case) and are more social influence- and process-based. They argued that greater attention needs to be placed on: 1) supporting self-management through peer support programs and through reminders and prompts at the patient level (which in turn require an electronic health record); 2) optimizing diabetes management through performance measurement (audit) and feedback at the practice/clinic level, as well as through financial incentives; and 3) providing managerial supports to the practices/clinics doing this work and making linkages between teams to help them model their processes on one another's successes (e.g., printing a report for the patient, their regular primary healthcare provider, and the practice/clinic supporting the patient's diabetes management). With regard to financial incentives, one dialogue participant argued that there are currently only two, and a third for an electronic health record, but there are no incentives for the reminders and prompts that should be built into this system.

Dialogue participants made a number of observations about electronic health records. They observed that such records are needed to support performance measurement and feedback, as well as reminders and prompts. Several lamented the set-backs related to the e-health scandal, but emphasized that the initiative needed to continue. One dialogue participant noted that these electronic health records need to be able to communicate with one another, which is not the case among Family Health Teams even in a mid-sized and collegial professional community like Hamilton. One dialogue participant emphasized that all lab data should be online and with access controlled by patients (i.e., Ontario needs a web-based lab reporting system).

Single dialogue participants made a number of other observations about Option 1: 1) some of the Canadian Diabetes Association's chapters support self-management (and food and religion are often the common denominator in gatherings of chapter members); 2) industry wants to support the development of guidelines

for diabetes management, but there is a push to keep this function within the public domain; 3) simple protocols need to be distilled from high-quality guidelines to support primary healthcare; 4) decision support can make optimal diabetes management easy for family physicians who are "time poor"; and 5) the Quality Improvement and Innovation Partnership is organizing learning collaboratives as one approach to decision support. One dialogue participant observed that there may be (at least some) performance measurement and feedback in the system, but there is no accountability for performance at this time.

Option 2 - Expand multidisciplinary diabetes education and management centres

A number of dialogue participants recognized that a welcome transition is already occuring in multidisciplinary diabetes education and management centres. Several dialogue participants argued that the "old" model – the "1950s model that got institutionalized," as one dialogue participant put it – was built around a nurse and a dietitian and operated in a stand-alone fashion, which meant that diabetes education was typically disconnected from the diabetes management being provided by physicians. One dialogue participant noted that under this model "diabetes management and education centres" would more accurately be called "diabetes education centres." The emerging new model accommodates a broader array of disciplines and is embedded within existing practices/clinics, which means that diabetes education and management are interconnected within a multidisciplinary team environment. Even the limitation that community-based centres needed to have medical directives in order to serve patients outside their roster has now been solved.

Additional changes still needed as part of the transition to a new model were noted by two participants. One pointed out that the threshold for accessing diabetes education and management centres (which, strictly speaking, are no longer called centres) is different in different communities, and mobility and access barriers result in inequitable utilization patterns. A second participant commented that many diabetes educators need additional knowledge and skills to support the new focus on patient self-management and to address cultural diversity. This participant argued that many diabetes educators are now working with a "deficit" model and are not using innovations like group visits and local networks that are likely to be both more effective and more sustainable. Another dialogue participant observed that a standard curriculum is being developed for diabetes educators, which should begin to address the need for building capacity within this group.

Two notes of caution were offered, each by a different dialogue participant. First, there is always the risk that diabetes will get lost amidst primary healthcare practices'/clinics' other priorities. Second, multidisciplinary education that emphasizes self-management and decision supports still needs to be accommodated in at least some existing fee-for-service practices/clinics, otherwise "silos will continue to be perpetuated."

Option 3 - Support primary healthcare practices in using an integrated model of chronic disease management

Several dialogue participants noted that the next step in optimizing diabetes management is to expand nodes of expertise in diabetes management in primary healthcare (and more specifically to facilitate capacity building within Family Health Teams). This can be facilitated by supporting embedded diabetes management and education centres and by creating a pyramid-shaped regional structure that provides secondary and tertiary supports for adults with type 1 diabetes and complex type 2 diabetes. Several dialogue participants emphasized the potential of mentoring. One participant gave the example of the Ontario College of Family Physicians' "insulin preceptorships" (i.e., supervised opportunities to develop skills in managing patients' insulin treatments), which are supported by unrestricted educational grants.

While generally supporting this approach, dialogue participants suggested potential enhancements to it, and offered one warning. Several dialogue participants emphasized the importance of moving beyond just having nurses and dietitians (diads) located in or supporting primary healthcare practices/clinics, and including

additional health professionals such as foot-care professionals and optometrists. One participant emphasized the importance of helping primary healthcare practices/clinics deal with diverse ethnocultural communities, and with others facing access barriers such as people with disabilities Another participant noted that primary healthcare diabetes specialists can provide a helpful intermediate level of care, and that in the United Kingdom such clinicians are formally designated as community diabetes specialists. One participant warned that if a pyramid-shaped regional structure is operationalized by moving secondary and tertiary supports from academic health sciences centres into community settings, a key economy of scale will be lost.

Participants had mixed views on the helpfulness of framing diabetes management within an integrated model of chronic disease management. (One dialogue participant noted that this and other similar reactions may have been because the dialogue did not have many participants who could speak to the realities of routine primary healthcare. Even the primary healthcare physicians present functioned more like specialists than primary healthcare physicians.) One dialogue participant dismissed the Chronic Care Model as "motherhood and fluff," and something that "every practice should have." Others pointed out that the elements of the Chronic Care Model are quite far from what every primary healthcare practice/clinic in Ontario currently has. Another participant argued that it's all "theoretical... the practical commitments aren't there." This concern was reinforced by another participant's observation that the diabetes strategy, while billed as using a chronic disease management model, is not funding system changes of the types envisioned by the Chronic Care Model. Rather, the strategy is funding pieces of systems. One dialogue participant noted the importance of partnerships with organizations like the Quality Improvement and Innovation Partnership to enhance the decision support element of the Chronic Care Model, and another noted the importance of engaging and leveraging community resources, such as the YMCA, which is another element of the model.

Considering the full array of options

Participants discussed the potential for a fourth option, namely to: 1) implement a model for optimizing diabetes management that expands nodes of expertise in diabetes management in primary healthcare (which can in turn draw on secondary and tertiary care supports), and that supports regional focal points charged with coordination and integration (e.g., allocation of scarce resources such as dietitians); 2) measure and provide feedback on performance (and several dialogue participants argued for taking this a step farther to include establishing targets along with clear accountabilities and rewards for achieving these targets); 3) disseminate tools and resources to both patients (i.e., self-management supports) and providers (i.e., decision supports); and 4) enhance communication among those involved in diabetes management (ideally in partnership with Local Health Integration Networks). As one dialogue participant summed up, "with this approach you would be able to say to primary healthcare teams, 'here are the expectations against which you'll be judged... and your success will be rewarded'."

Many dialogue participants saw great value in this model. They offered a number of suggestions for strengthening this option further:

- 1) keep focused on optimizing diabetes management, and not on the bureaucratic elements, and ensure that the work is done with openness and transparency;
- 2) work out an approach to setting priorities in order to capture the "low-hanging fruit" and an approach to establishing what can best be done at the practice/clinic, Local Health Integration Network (LHIN), and provincial levels;
- 3) develop performance measures at the beginning and in a way that allows them to be "rolled up" to the level of the LHIN and the province;
- 4) build capacity to harness existing research evidence to support change at all levels (e.g., ensure that guidelines that address the organization of diabetes care include the full range of relevant systematic reviews about governance, financial and delivery arrangements related to that care) and identify the resources to permit evaluations where little is known ("this is a golden opportunity to figure out what works"); and

5) as the focus shifts to prevention over time (e.g., subsidies to encourage nutritious food purchases, changes to the built environment to encourage physical activity), begin to engage other Ministries like Agriculture, Food and Rural Affairs, Environment, and Transportation.

Dialogue participants had mixed views about co-location of the regional focal points with the LHINs.

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

Dialogue participants acknowledged the many potential barriers to implementing the options that were identified in the evidence brief, but they also identified two barriers that may come into play with any of the options. First, several dialogue participants emphasized that optimizing diabetes management within diverse ethnocultural communities is not just about translating materials into other languages. It can also mean dealing with a vast array of lifestyle-related factors, poverty-related factors (e.g., having no phone and no money for glucose test strips), and other influences. Second, several dialogue participants emphasized that diabetes registry implementation needs to be improved because a significant proportion of patients with diabetes are currently being missed (in part because they are not registered with a rostered primary healthcare practice and in part because they may receive all of their care from a specialist).

Dialogue participants also noted a number of barriers to the implementation of specific options. Regarding Option 3 (supporting primary healthcare practices), dialogue participants noted the lack of management structures to support primary healthcare, and the regulatory barriers to multi-disciplinary care (e.g., scopes of practice and medical directives), although one participant felt that the latter could be addressed relatively easily. Regarding the additional option that was considered (expanded nodes of expertise in diabetes management in primary healthcare and regional focal points to optimize diabetes management), dialogue participants noted the challenges that will emerge with trying to engage already busy people (which is the key to the success of the regional focal points, who are ideally a "public" face who know everyday practice realities) and trying to coordinate existing efforts (which must be done with local flexibility and superb communication skills).

Several dialogue participants recognized that diabetes is the test case for a disease-based approach to strengthening primary healthcare, and observed that the initiative needs to be shown to be successful in helping people live well with diabetes. If it is not, diabetes' "day in the sun" may well be over.

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

A number of dialogue participants emphasized the importance of the Ministry of Health and Long-Term Care developing a policy framework to support the optimization of diabetes management in Ontario or, at the very least, a communications strategy to ensure that the full array of stakeholders are familiar with the "pieces" of the plan and how they fit (or are being fit) together. One dialogue participant noted that researchers developing self-management supports and decision supports need to work in partnership with those already well established groups and organizations supporting diabetes management. Existing centres of diabetes education and management expertise also have a key role to play in nurturing, supporting, and championing efforts to optimize diabetes management in their respective domains.