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Dialogue Summary: Strengthening Chronic Disease Management in Ontario

19 October 2009

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# **Table of Contents**

SUMMARY OF THE DIALOGUE	4
SUMMARIES OF THE FOUR DELIBERATIONS	5
DELIBERATION ABOUT THE PROBLEM	5
DELIBERATION ABOUT POLICY AND PROGRAM OPTIONS	6
Option 1 - Enhance support for self-management	6
Option 2 - Co-ordinate (at the provincial level) continuing professional developm providers that enables team-based, process-oriented, just-in-time learning	
Option 3 - Support co-ordinated and proactive chronic disease management mod settings	
Considering the full array of options	9
DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS	10
DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCE	CIES10

# SUMMARY OF THE DIALOGUE

A number of dialogue participants concluded that the underlying policy issue needed to be reframed. Having originally begun the dialogue with a focus on strengthening chronic disease management in Ontario, they concluded that the real challenge lay in "supporting people to live well with chronic conditions." Also, some dialogue participants argued that a concrete goal (e.g., saving 100,000 lives or adding one year to Ontarians' life expectancy) was needed in order to mobilize support for addressing this challenge and to monitor progress in addressing it.

Drawing on the input from the evidence brief, their own knowledge and experiences, and the insights from the deliberations, a number of dialogue participants concluded:

- the healthcare system is underperforming relative to its potential and to the healthcare systems in some of the jurisdictions to which Ontario is commonly compared;
- the province needs a patient-centered system that supports people to live well with chronic conditions;
- achieving a patient-centered system requires a long-term (20- to 25-year) strategy of enhancing and coordinating all of the features of such a system – self-management support, provider decision support such as continuing professional development, delivery system design, clinical information systems, health system changes, and community resources – while simultaneously developing and committing to successive medium-term (3- to 5-year) strategies of enhancing and co-ordinating those system features that will also achieve near-term impacts;
- different "levels" within the health system (e.g., rostered patient populations / clinical practices, regions / Local Health Integration Networks, and provincial collaboratives and organizations) can each play key roles in operationalizing medium-term strategies and should be provided the necessary incentives to do so and entrusted with corresponding accountabilities;
- a broad-based provincial coalition of stakeholders could lead the push for purposeful efforts to deliver early successes in achieving a concrete goal through either:
  - o a focus on addressing a risk factor (e.g., overweight or obesity) or disease (e.g., diabetes) through enhancing and co-ordinating the full range of supportive health system features, and then moving on to other risk factors and diseases; or
  - o a focus on enhancing and co-ordinating a key health system feature (e.g., provider decision supports such as continuing professional development) across the full range of risk factors and diseases, and then moving on to other health system features; and
- the provincial government could, in its role as a steward for the health system, establish the mediumand long-term strategies and the framework within which these and other efforts can be promoted, understood, and supported.

# SUMMARIES OF THE FOUR DELIBERATIONS

# **DELIBERATION ABOUT THE PROBLEM**

Dialogue participants generally agreed with the three take-home messages about the problem as they were summarized in the evidence brief:

- chronic diseases are a significant and growing challenge in the province;
- cost-effective programs, services, and drugs are not always getting to those living with chronic disease; and
- a variety of gaps in existing delivery arrangements (e.g., a lack of self-management supports for patients and provider decision supports for healthcare teams, including continuing professional development), financial arrangements (e.g., a lack of financial incentives for rewarding co-ordinated and proactive chronic disease management) and governance arrangements (e.g., a lack of consumer and citizen voice in healthcare practices) may contribute to the lack of co-ordinated and proactive chronic disease management (CDM) in the province, even if their relative importance is poorly understood.

In a nutshell, dialogue participants generally agreed that the Ontario healthcare system is underperforming relative to its potential and to the healthcare systems in some of the jurisdictions to which Ontario is commonly compared.

Several participants described the problem in different terms, namely as the structural, cultural, and economic realities that needed to be addressed or accommodated. A key structural reality is that different "levels" within the health system do not face any expectations that they will play a specific role in supporting chronic disease management, or any incentives to do so. These levels include: patients and their families, rostered patient populations/primary healthcare practices (and networks of these practices), specialty clinics, regions/Local Health Integration Networks, and provincial collaboratives and organizations. One dialogue participant noted that "co-ordinated care

# 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;
- 3) 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.

requires co-ordination, and this must be done regardless of when and to whom any benefits accrue." A key economic reality is that economies and diseconomies of scale operate at these different levels. Some approaches to supporting chronic disease management may be optimally undertaken at the regional or provincial level and not, for example, at the level of primary healthcare practices. A key cultural reality is that there is no sense of shared responsibility among people living with chronic conditions (and their families) and

among the many types of healthcare providers (including allied health providers) involved in the management of these conditions. With no sense of "we're all in this together in support of those living with chronic conditions," patients' (and their families') experiences with the healthcare system can be very fragmented. One dialogue participant noted that in dealing with these structural, economic, and cultural realities, equity is a key consideration. Those who most need support may be least able to benefit from a one-size-fits-all approach.

A number of dialogue participants concluded that the underlying policy issue needed to be reframed. Having originally begun the dialogue with a focus on strengthening chronic disease management in Ontario, they concluded that the real challenge lay in "supporting people to live well with chronic conditions." And they argued that "living well" should be defined by those living with chronic conditions. The phrase "chronic disease management" will not engage people. Being supported to live well with chronic conditions, on the other hand, will engage people.

Some dialogue participants argued that a concrete goal (e.g., saving 100,000 lives or adding one year to Ontarians' life expectancy) was needed in order to mobilize support for addressing this challenge and to monitor progress in addressing it. Other dialogue participants, while not necessarily disagreeing with the need for such a tangible goal, noted that other value propositions may also be needed. For example, one value proposition may be getting greater value for the resources we have, both from the perspective of people living with chronic conditions (and their families) and from the perspective of those paying taxes to support care, treatment, and support. For the former group, greater value may mean that people living with chronic conditions can navigate the system easily, access care from the right healthcare provider when they need it, be proactively offered co-ordinated support to assist them in living well with their chronic conditions, be supported in achieving their goals (such as a particular target for risk factor reduction), and more generally feel that the system is "there for them." For the latter group, greater value may mean ensuring that the "right level does the right thing."

# **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 - Enhance support for self-management

A number of dialogue participants noted that enhancing support for self-management is part of the solution, but that it cannot achieve its potential without pursuing other options simultaneously. For example, enhancing support for self-management will require embracing Option 2 (provider decision support) as well. Healthcare providers need to be engaged in supporting self-management and develop the knowledge and skills to do so. One participant noted that "patient-mediated interventions" may be needed to enlist patients in getting their healthcare providers on board to support self-management. Another participant reminded the group about the lessons learned from healthcare providers' roles in smoking-cessation campaigns, particularly the importance of simple, often-repeated messages in motivating behaviour change. Enhancing support for self-management will also require some form of provincial (or national) knowledge infrastructure that achieves price discounts through its buying power and that makes available tools and resources that either don't need to be locally contextualized or that facilitate local contextualization. These tools and resources include: 1) decision aids and other supports for self-management; and 2) tools and resources to enable healthcare providers to support self-management; and 3) tools and resources to enable healthcare providers to offer effective, co-ordinated, and proactive care. Such an infrastructure is a necessary but not sufficient condition for self-management. Building this infrastructure at the provincial (or national) level could draw upon the contributions of many groups (including the work of disease-based charities) and avoid duplication,

but it would need to be designed to ensure its accessibility to diverse communities and its credibility from their perspectives. One potential risk to those groups contributing to the infrastructure is "scope creep," meaning that over time they find their scope of work being gradually expanded into areas that are beyond their remit or expertise.

Several dialogue participants noted the importance of both goal-setting by those living with chronic conditions and attending to equity issues by those involved in supporting them. They observed that goal-setting is critical to behaviour change, including treatment adherence, for those people who choose to play a greater role in the management of their conditions. They also observed that enhancing support for self-management has the potential to increase inequities by supporting those with high levels of health literacy and problem-solving skills, comfort with technology, facility in English or other commonly spoken languages, and comfort with dominant ethnocultural approaches, while leaving behind others.

# Option 2 - Co-ordinate (at the provincial level) continuing professional development for healthcare providers that enables team-based, process-oriented, just-in-time learning

Dialogue participants observed that continuing professional development (CPD) is also part of the solution and that it, too, can only achieve its potential in conjunction with other options. As with enhancing support for self-management, CPD requires some form of provincial (or national) knowledge infrastructure that makes available the guidelines and other tools and resources that support team-based, process-oriented, just-in-time learning. However, many dialogue participants argued that CPD needs to broaden its focus beyond "education" (i.e., addressing perceived knowledge deficits) to address all barriers to behaviour change, align itself with "sister" initiatives that share similar goals (such as quality-improvement initiatives like the Quality Improvement and Innovation Partnership) and with current health system initiatives (such as disease strategies like the diabetes strategy), and organize itself to complement and enhance key system features. These system features include:

- delivery system design, as the option's focus on team-based learning acknowledges (given that healthcare teams are increasingly seen as the centrepiece of efforts to deliver effective, efficient clinical care and selfmanagement support);
- clinical information systems, as the option's focus on process-oriented learning acknowledges (given that effective decision supports also include audit and feedback, as well as prompts, both of which can be operationalized more easily with clinical information systems);
- health system changes, as the option's focus on just-in-time learning implies (given that crises like the H1N1 pandemic illustrate the need for the rapid mobilization of sectors that currently work in "silos" and yet need to work seamlessly together to promote safe, high quality care); and
- community resources, such as those produced or identified by disease-based charities, healthcare organizations, municipalities, and Local Health Integration Networks, among others, which can augment the resources made available through a provincial (or national) knowledge infrastructure.

One dialogue participant noted that these system features have reinforced the need for CPD to address competencies like leadership, management (including quality improvement, performance management, and change management more generally), inter-professional collaboration, and patient-centeredness, not just competencies related to the clinical management of patients living with (often multiple) chronic diseases.

Several dialogue participants noted the importance of CPD planning being sensitive to key realities that have historically meant that CPD is often a "flash in the pan" (in the sense of its focusing on one-off events), while trying to address these realities over time in order to ensure that CPD makes sustained contributions to helping people living well with chronic conditions:

• the structural reality that different levels within the CPD subsystem (e.g., academic health science centres and provincial professional associations) do not face any expectations that they will play a specific role in supporting chronic disease management, or any incentives to do so, and that different levels within the

- healthcare system (e.g., primary healthcare practices, regions / Local Health Integration Networks, and provincial collaboratives and organizations) do not face any expectations that they will participate in CPD that facilitates their specific role in supporting chronic disease management, or any incentives to do so (including the time and other rewards for introducing prompts for proactive care);
- the key economic reality that economies and diseconomies of scale operate at these different levels of the CPD subsystem and broader healthcare system and that the right levels need to assume responsibilities for the right roles, with an organization like Continuing Professional Development Ontario (CPD-O) potentially playing a facilitating role in priority-setting (to ensure a focus on the "low-hanging fruit"), role allocation, standard setting, and possibly resource generation and allocation; and
- the key cultural reality that there is no sense of shared responsibility among the many types of healthcare providers (including allied health providers) involved in the management of chronic diseases, which reinforces and is reinforced by the "silos" within which their respective CPD communities operate and which suggests the need for CPD-O to expand its membership to include non-medical health providers.

Regarding resource generation, dialogue participants voiced mixed views about the role of industry in CPD (with industry conceived of in the broad sense of pharmaceutical companies, device manufacturers, and for-profit firms more generally). Many dialogue participants agreed that ground rules were needed in order to ensure that industry contributions support CPD that addresses system needs, not just sales, but other dialogue participants argued that strict and well-enforced regulation was needed.

# Option 3 - Support co-ordinated and proactive chronic disease management models in healthcare settings

A number of dialogue participants agreed that the six features of the Chronic Care Model – self-management support, provider decision support, delivery system design, clinical information systems, health system changes and community resources – are the essential building blocks of a patient-centered system that supports people to live well with chronic conditions (as well as to cope with acute illnesses and injuries). However, they argued that achieving such a patient-centered system requires a long-term (20- to 25-year) strategy of enhancing and co-ordinating all of the features of such a system while simultaneously developing and committing to successive medium-term (3- to 5-year) strategies of enhancing and co-ordinating those system features that will also achieve near-term impacts. They argued that different levels within the health system (e.g., rostered patient populations / clinical practices, regions / Local Health Integration Networks, and provincial collaboratives and organizations) can each play key roles in operationalizing these medium-term strategies and should be provided the necessary incentives to do so and entrusted with corresponding accountabilities.

Several dialogue participants noted that purposeful efforts to deliver early successes in achieving a concrete goal required two strategic choices. First, a strategic choice needs to be made between:

- a focus on addressing a risk factor (e.g., overweight or obesity) or disease (e.g., diabetes) through enhancing and co-ordinating the full range of supportive health system features, and then moving on to other risk factors and diseases (i.e., moving down a column in Table 1); and/or
- a focus on enhancing and co-ordinating a key health system feature (e.g., provider decision supports such as continuing professional development) across the full range of risk factors and diseases, and then moving on to other health system features (i.e., moving across a row in Table 1).

Second, a strategic choice needs to be made between a focus on one or more regions or the whole province. Many dialogue participants argued that the result of these choices should not be seen as pilot/demonstration projects, which so often are not sustained, but rather as a first step towards achieving a long-term strategy.

Select dialogue participants emphasized different features of a patient-centered system and inter-relationships among these features. For example, one dialogue participant noted the importance of clinical information systems in identifying problems and monitoring progress in addressing problems, while another participant

noted that such systems can accelerate or magnify processes that are not functioning well. Another dialogue participant noted the importance of building on the strength of most patients' relationships with their primary healthcare physician in their community and on the promise of shared-care collaboratives, which combine delivery system design (healthcare teams) with clinical information systems and community resources.

One dialogue participant recommended that each step towards a long-term strategy be subjected to a form of "appreciative inquiry" to ensure that lessons were learned, success stories promoted, and course corrections made.

Table 1: Options for purposeful efforts to deliver early successes in moving towards a patient-centered system

Elements of a patient-centered system	Focus for purposeful efforts to deliver early successes		
,	Risk factor like overweight/obesity	Disease like diabetes	Common combinations of diseases
Self-management support (i.e., empowering and preparing patients to manage their health and healthcare)  Provider decision support (i.e., promoting clinical care that is consistent with scientific evidence and patient preferences through, for example, embedding evidence-based guidelines, as well as related patient decision aids, into daily clinical practice and supporting their implementation through continuing professional development)  Delivery system design (i.e., organizing programs and services to assure the proactive, culturally sensitive delivery of effective, efficient clinical care and self-management support by healthcare teams)  Clinical information systems (i.e., organizing patient and population data to facilitate more efficient care through, for example, an electronic health record that provides reminders for providers and patients and monitors the performance of healthcare teams and the system in which they work)  Health system changes (i.e., creating a culture, organization, and mechanisms that promote safe, high quality care, which can include visibly supporting comprehensive system change that moves beyond "silos" for acute care, primary healthcare, public health, home care, and mental healthcare)  Community resources (i.e., mobilizing community	overweight/obesity		
resources to meet the needs of patients even though these resources are not formally part of healthcare systems)		V	

# Considering the full array of options

A large number of participants supported:

- the idea that the province needs a patient-centered system that supports (a wide range of) people to live well with chronic conditions;
- an approach that integrates a long-term (20- to 25-year) strategy of enhancing and co-ordinating all of the features of a patient-centered system with successive medium-term (3- to 5-year) strategies of enhancing and co-ordinating those system features that will also achieve near-term impacts; and
- an approach that provides the necessary incentives and corresponding accountabilities to different levels within the health system that are best positioned to play different roles (e.g., rostered patient populations

/ clinical practices, regions / Local Health Integration Networks, and provincial collaboratives and organizations).

Some participants expressed reservations about the nature of the accountabilities that may be set at the level of clinical practices and how they may be set.

## **DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS**

One dialogue participant cautioned that a large, centralized healthcare system redesign process was "not in the cards," but that a strategic intervention that would support a shift in this direction (such as allocating healthcare budgets to physicians with an accompanying set of accountabilities and defined risks) might be considered. Another dialogue participant noted that the system was, in fact, being progressively redesigned and that solo-practice physicians and others would need to be the focus of sub-regional efforts so that they and their patients are not left behind.

One dialogue participant also noted the lack of any group or organization that is "responsible for chronic diseases" in the way that, say, Cancer Care Ontario is for cancer. This means that the system lacks a well accepted framework for supporting people living well with chronic conditions, as well as incentives and accountabilities for the practices and organizations allocated to different roles. This also means that there is a great deal of squabbling and jockeying among disease-based groups.

A number of dialogue participants noted a related point: the absence of stakeholder forums in which different levels within the health system can work through strategic choices, operational strategies, and role allocations that would achieve these strategies. One dialogue participant noted how critical it would be to select the right people in convening such forums, and to select the right people for leadership positions in the execution of any strategies developed in the forums. Another dialogue participant noted that physicians are often well suited for leadership positions but are not trained for management positions. Still another dialogue participant noted that disease-based charities and diverse communities are often absent from "single-level" forums. This participant also noted the inherent tension between a focus on single diseases (which facilitates fundraising and community mobilization) and a focus on chronic diseases more generally (which facilitates patient-centeredness and the focus on the "whole person"). While Local Health Integration Networks can convene such forums to support integration and efficiency gains (and some are already doing so), they do not have specific funding to do so or they have only time-limited project funding to do so. Moreover, LHIN-led forums make it difficult to discuss potential roles for provincial collaboratives and organizations.

#### **DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES**

A number of dialogue participants noted that one possible next step is for a broad-based provincial coalition of stakeholders to lead the push for purposeful efforts to deliver early successes in achieving a concrete goal through either:

- a focus on addressing a risk factor or disease through enhancing and co-ordinating the full range of supportive health system features, and then moving on to other risk factors and diseases; or
- a focus on enhancing and co-ordinating a key health system feature across the full range of risk factors and diseases, and then moving on to other health system features.

Several participants recommended focusing on diabetes, which is a current health system priority and a domain in which many self-management supports have been developed or identified, and later moving on to risk factors or other diseases. An alternative to a provincial coalition would be for one or more Local Health Integration Networks to convene a broad-based regional coalition.

Several dialogue participants suggested that another possible next step is for the provincial government, in its role as a steward for the health system, to establish the medium- and long-term strategies for creating a patient-centered system that supports people to live well with chronic conditions and the framework within which these and other efforts can be promoted, understood, and supported. However, a number of dialogue participants noted that such action would be more likely to come about in response to sustained advocacy by disease-based charities, healthcare provider associations, and Local Health Integration Networks, among others. And they also pointed out that in the absence of such action "goodwill will only go so far." That said, several dialogue participants argued that "in the meantime we have to start somewhere."