TRANSFORMING CARE FOR CANADIANS WITH CHRONIC HEALTH CONDITIONS

Put People First, Expect the Best, Manage for Results

Canadian Academy of Health Sciences
Académie canadienne des sciences de la santé

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Report of the Expert Panel appointed by the Canadian Academy of Health Sciences: Nasmith L., Ballem P., Baxter R., Bergman H., Colin-Thomé D., Herbert C., Keating N., Lessard R., Lyons R., McMurchy D., Ratner P., Rosenbaum P., Tamblyn R., Wagner E., & Zimmerman B. (2010).

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EXPERT PANEL MEMBERS

This Expert Panel represents a diverse range of expertise and perspectives, exemplifying the reputation of the Canadian Academy of Health Sciences for objectivity, integrity, and competence:

Louise Nasmith (Co-Chair), University of British Columbia, Canada

Penny Ballem (Co-Chair), City of Vancouver, Canada

Raymond J. Baxter, Kaiser Permanente, United States

Howard Bergman, Fonds de la recherché en santé du Québec, Canada

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Brenda Zimmerman, York University, Canada

Biographies of the Expert Panel members are in Appendix E. All members volunteered their time and expertise to address this critical issue and were required to declare in writing any potential conflicts of interest. These are available for review on request.

Consultants

Catherine Creede, Potential Group, Canada

Sonya Kupka, SJK Services, Canada

External Reviewers

External Reviewers provided candid and constructive comments to assist the Canadian Academy of Health Sciences to ensure that this report meets its standards for objectivity, evidence, and responsiveness to the study charge. The external reviewers were:

Dr Harold S. Luft, Director, Palo Alto Medical Foundation Research Inst, Palo Alto, United States

Professor Martin Roland, General Practice & Primary Care Research Unit, Institute of Public Health, Cambridge, United Kingdom

Dr Ross E.G. Upshur, Director, University of Toronto Joint Centre for Bioethics, Toronto, ON, Canada

External Reviewers were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. Responsibility for the final content of this report rests entirely with the authoring panel and the Canadian Academy of Health Sciences.

ACKNOWLEDGEMENTS

PREFACE: A MESSAGE FROM THE CO-CHAIRS

We were invited to lead this assessment focused on the question:

What will it take to improve outcomes for people with chronic diseases in Canada?

We elaborated the following vision to focus our discussion:

"All Canadians with chronic health conditions have access to healthcare that recognizes and treats them as people with specific needs; where their unique conditions and circumstances are known and accommodated by all of their health providers; and where they are able to act as partners in their own care."

In January 2008, the executive of the Canadian Academy of Health Sciences developed and endorsed a prospectus that committed to examining the evidence related to the burden of chronic disease. The prospectus outlined the importance of this issue to the Canadian public policy agenda.

This major assessment was launched at the fourth annual meeting of the Canadian Academy of Health Sciences in September 2008. This forum further informed the approach to the assessment. Three key themes emerged:

1. Shift from a silo thinking of diseases to a systems-oriented concept of chronicity.

2. There are many good existing chronic disease management models and interventions. It is important to synthesize the learning from these models to identify key elements of a sustainable strategy for healthcare system transformation in Canada.

3. How do we mobilize transformative action across Canada?

    a. Identify a few key points of leverage (strategic interventions to move forward, including primary prevention).

    b. Be bold—explore all possibilities and learn from other countries.

An Expert Panel was carefully selected and charged with creating a strategy to improve health outcomes for patients with chronic disease through reorientation of Canadian health services and better utilization of system resources from policy to point-of-care within the next five years.

Approach

The strategy for action outlined in this report is the result of an extensive, highly iterative process. Our approach can best be described as a blend of evidence, emerging ideas, and consensus.

As we began this work, we realized that the body of evidence on our overarching question is simultaneously overabundant and insufficient. There is a boundless amount of research on individual aspects of how to improve care for people with chronic conditions and at the same time some of the ideas that are most compelling—such as multimorbidity, how to improve interfaces between the different aspects of the care continuum, or the right mix of reimbursement and incentives for healthcare providers in a publicly funded system—are still emerging.

To arrive at our recommendations, we began by identifying key questions and emerging ideas from among the Expert Panel's broad experience, as well as developing guiding principles for our work. At this point, we determined that our recommendations would be:

- **Population-based as well as focused on the person and their family or friend caregiver:** We will provide recommendations directed at optimizing the health outcomes of the population while recognizing and responding to the diversity of individuals and their changing needs (e.g., aging, health, functional, and socio-economic status).

- **Equitable:** We will ensure that population-wide recommendations will not create new or exacerbate existing health inequities and may consider targeted recommendations to decrease existing inequities.

- **Feasible:** We will seek opportunities to shape and optimize the investments that are already planned and focus on recommendations that will demonstrate results within five years and that are sustainable.

- **Accountable:** We will establish reasonable expectations of the system and clearly articulate who is responsible for implementation of the recommendations.

- **Evidence informed:** We will build on our strengths as experts and our access to global evidence to draw upon hints of what might work and ensure that all recommendations are achievable.

- **Innovative:** We are prepared to challenge the status quo and not be limited to enhancing what already exists.

- **Generalizable across diseases:** We will argue that a noncategorical approach better meets the needs of people living with a range of chronic diseases.

Based on our initial questions, we examined the peer-reviewed and grey literature related to the question of healthcare system transformation and chronic conditions. Rather than risk limiting our review through the use of formal criteria in evaluating the literature, we used an iterative approach to identifying existing and emerging evidence in this complex field of study.

We realized that the evidence on the value of comprehensive models was strong and rising. We then expanded our exploration to specific aspects of what is required for comprehensive care, which included:

- case studies of healthcare system transformation in other countries;

- principles of complex system change;

- emerging reforms and research findings about the value of primary care as the core "home base" for people with chronic conditions, including commissioning a paper from Barbara Starfield; and

- emerging best practices and on-the-ground innovations for key enablers, including new models of care and scope of practice, remuneration, continuous learning for healthcare providers, people as partners in their own care, quality and accountability frameworks, and the use of electronic and virtual forms of interaction and information exchange.

The final recommendations were the result of the Expert Panel's many in-person and teleconference conversations over 18 months to review, interpret, and build on the evidence and emerging practices based on their profound breadth of experience in system change, research, health leadership, education, and practice. We are confident that this report encompasses a meaningful, actionable, enthusiastically endorsed consensus of thought leadership on highly complex questions.

During the course of our review, we were heartened to encounter numerous efforts across the country leading us in the same direction, both in terms of innovative actions and thoughtful studies by bodies such as the Health Council of Canada. In a decentralized country like Canada, we believe firmly that action from many sources is needed to achieve a "tipping point."

Making the changes that will move us forward requires widespread support and collaborative action. This means that clinicians can incorporate some of the local innovations and basic principles of integrated care into their practices and ongoing learning, and can influence their professional bodies to achieve some of the key system enablers, such as changes to remuneration models. Policymakers, researchers, funders, administrators, and educators need to take leadership on other aspects of the recommendations, in collaboration and partnership with each other, with clinicians, people with chronic conditions, and their caregivers. Collectively, we will move forward.

Fundamentally, this assessment is about the design and delivery of healthcare in Canada. We recognize the healthcare system is only one contributor to the health of the population and it is also necessary to address the powerful social determinants of health to fully reduce health disparities (as demonstrated by the confluence of reports pointing in the same direction—for example, from the World Health Organization and the Conference Board of Canada). At the same time, the healthcare system is the largest economic investment in our country, and the increasing proportionate costs risk the erosion of other social programs. Immediate action is essential.

We thank the Canadian Academy of Health Sciences for its financial support, guidance, and approach, with particular thanks to their outstanding executive: their Past President and primary author of the Prospectus, Dr. Martin Schechter; their Standing Committee on Assessments and its Chair, Dr. John Cairns; and the current President, Dr. Catharine Whiteside. We acknowledge the support provided by our sponsors and thank experts in various fields who contributed to our assessment by sharing their thoughts on chronic disease management and healthcare system transformation with us.
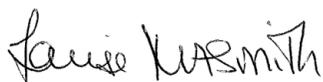
Louise Nasmith
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TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

EXECUTIVE SUMMARY

An estimated 16 million Canadians—roughly half the population—live with some chronic condition. These Canadians and the families and friends who care for them need a healthcare system that meets all of their needs. Some people's needs are relatively simple, involving the management of a single chronic condition, while other people's needs are increasingly complex, requiring the management of several chronic conditions concurrently. At the same time, there are huge demands on our healthcare system for greater sustainability.

The Canadian Academy of Health Sciences initiated a major assessment to address the question:

What will it take to improve outcomes for people with chronic diseases in Canada?

The Academy appointed an international Expert Panel of leading thinkers and researchers who volunteered their time to conduct an 18-month review, assessing the needs of people with chronic conditions, examining existing evidence and the state of the Canadian healthcare system, and contributing their expert opinions on emerging ideas about the appropriate care and support for these people. This comprehensive process led them to a consensus on a vision:

"All Canadians with chronic health conditions have access to healthcare that recognizes and treats them as people with specific needs; where their unique conditions and circumstances are known and accommodated by all of their healthcare providers; and where they are able to act as partners in their own care."

To achieve this vision, the Expert Panel appointed by the Canadian Academy of Health Sciences identified the following overarching recommendation that will be enacted through six enabling recommendations and an implementation recommendation. All are equally essential and require actions that need to be integrated.

Enable all people with chronic health conditions to have access to a system of care with a specific clinician or team of clinicians who are responsible for providing their primary care and for coordinating care with acute, specialty, and community services throughout their life spans by:

1. **aligning system funding and provider remuneration with desired health outcomes;**
2. **ensuring that quality drives system performance;**
3. **creating a culture of lifelong education and learning for healthcare providers;**
4. **supporting self-management as part of everyone's care;**
5. **using health information effectively and efficiently; and**
6. **conducting research that supports optimal care and improved outcomes.**

Federal, provincial, and territorial ministers of health should review these recommendations with a view to making them part of the 2014 renewal of the federal-provincial-territorial accord on healthcare.

A summary of what needs to happen for each recommendation is outlined in Table 1.

Table 1: Strategy to Transform Care for Canadians with Chronic Health Conditions

PUT PEOPLE FIRST – EXPECT THE BEST – MANAGE FOR RESULTS					
Enable all people with chronic health conditions to have access to a system of care with a specific clinician or team of clinicians who are responsible for providing their primary care and for coordinating care with acute, specialty, and community services throughout their life spans by:					
Aligning system funding and provider remuneration with desired health outcomes	**Ensuring that quality drives system performance**	**Creating a culture of lifelong education and learning for healthcare providers**	**Supporting self-management as part of everyone's care**	**Using health information effectively and efficiently**	**Conducting research that supports optimal care and improved outcomes**
Provide sufficient funding for homecare and chronic care services…	Create an overall pan-Canadian quality improvement strategy…	Strengthen pre-licensure education and training of health professionals and managers across all health professions to ensure that they have the core competencies needed to improve outcomes for people with chronic conditions…	Assure that all primary care practices have the appropriate mix of trained staff to provide effective self-management supports…	Establish national unified standards for electronic health records…	Build consensus on a limited number of key performance indicators…
Ensure that all provinces and territories provide equal access to essential medications…	Develop and strengthen regional structures and processes to engage specialty physician and primary care practices in examining their performance to improve health outcomes…		Empower people to share and manage their own health information and contribute to emerging knowledge through web-based technology…	Develop mechanisms for easy and secure transfer of information between all sectors in the healthcare system…	Develop reliable, rapid-cycle evaluations of the implementation of health policy interventions…
Shift remuneration of family physicians away from exclusive fee-for-service…	Develop quality improvement programs focusing on population-based outcomes that include leadership development of health professionals to drive the redesign of primary and specialty care practices…	Increase access to skills development for practitioners and managers across all health professions to shift the nature of the relationship between clinicians and people with chronic conditions to person-focused care by developing interprofessional modules in key areas…	Help people and their family and friend caregivers to identify and access all the community-based health and social services they need to improve their health…	Shift funding away from development of new software to providing technical assistance for specialty physician and primary care practices to implement and maintain…	Ensure that research is relevant and inclusive of people with chronic conditions…
Provide greater flexibility in specialty physician remuneration…				Provide clinical decision supports to optimize care, especially in the context of multimorbidity…	Build capacity so that primary care practitioners, administrators, and all health professionals involved are partners and participants in research…
Create incentives for primary care practices to provide comprehensive care for people with chronic conditions who currently rely on acute or multiple specialty care services…				Use health information systems to facilitate population-based analysis at the individual practice level…	Conduct on-going comparative evaluation studies of new models of primary care across jurisdictions…
Construct a remuneration system for healthcare professionals who are not physicians so that they can be part of the primary care system…				Ensure easy and secure Internet access for people to use and contribute to their own health records…	Articulate knowledge gaps in the provision of chronic care…

The vision and recommendations for improving health outcomes for people with chronic conditions through healthcare system transformation are detailed in Chapter 6. Chapter 7 identifies the key stakeholders and change leaders with existing accountabilities and, for each recommendation, presents promising existing models and suggests potential action points. It recognizes that, while government is not solely responsible for implementing all the recommendations, federal, provincial, and territorial governments have the unique capacity to provide direction, offer leadership, and demand accountability for coherent action across all the recommendations.

The vision and recommendations were informed by complex adaptive system theory. Chapter 5 describes how this theory was used to identify approaches for creating effective change throughout the Canadian healthcare system. It concludes that change in such a complex system is best achieved by building on existing infrastructures and natural networks and that enhancing the Canadian healthcare system through low-cost and feasible actions is best achieved by building on, linking, and learning from existing innovations. Three interrelated and mutually dependent perspectives are presented to form the **core direction for healthcare system transformation in Canada: put people first, expect the best, and manage for results.**

The context for this assessment is provided in the first four chapters, beginning in Chapter 1 with a brief description of the current and the desired experience of individual Canadians as they encounter the healthcare system. Chapter 2 outlines the scope of chronic conditions considered in this assessment—what is known about their magnitude, cost, and impact on communities and the lives of Canadians, and why it is necessary to take a renewed, integrated approach to the way we deal with them. Chapter 3 reviews the emerging approaches to addressing chronic conditions and presents the argument in favour of person-focused, integrated approaches to care delivery for people living with chronic conditions, centred in primary care, with strong interfaces across the continuum of care. Chapter 4 highlights Canada's current performance and experience caring for people with chronic conditions and concludes that despite our cultural and financial commitment to healthcare, Canada is lagging behind other countries in performance and infrastructure to support people living with multiple chronic conditions, particularly in the critical primary care sector. At the same time, across the country, there are many promising and sometimes isolated initiatives or "islands of innovation" that move in the direction of integrated, comprehensive care.

This assessment provides the argument, social context, and evidence that led to the development of this vision, along with a strategy and recommendations that will enable us to reach this vision through reorientation of Canadian health services and better utilization of system resources.

When the vision is achieved, Canada's healthcare system will be integrated, person-focused, and population-based, with primary care practices as the hub for coordination and continuity of care with specialty and acute care and community-based services. This integrated healthcare system will:

- have primary care practices that are responsible for a defined population;
- be person focused (and family or friend caregiver focused);
- provide comprehensive services through interprofessional teams;
- link with other sectors in health and social care; and
- be accountable for outcomes.

Plans for implementation must begin immediately and can occur concurrently—across all recommendations and at local, regional, provincial, and pan-Canadian levels.

Figure 1 illustrates how people with chronic conditions and their family and friend caregivers are at the centre of this strategy and will be supported by a healthcare system with three core directions: put people first, expect the best, and manage for results. Throughout the healthcare system there will be movement with concurrent connected activity related to the six enabling recommendations. Stakeholders are connected and engaged and work in collaboration to ensure the full strategy is implemented.

This strategy encapsulates the best of today's research and thinking about the needs of people with chronic conditions. The Expert Panel appointed by the Canadian Academy of Health Sciences does not underestimate the challenge of implementing changes, while continuing to deliver health services. Transforming the Canadian healthcare system will require a tremendous commitment and effort from all levels. However, maintaining the current Canadian healthcare system in the future will be equally or perhaps even more challenging.
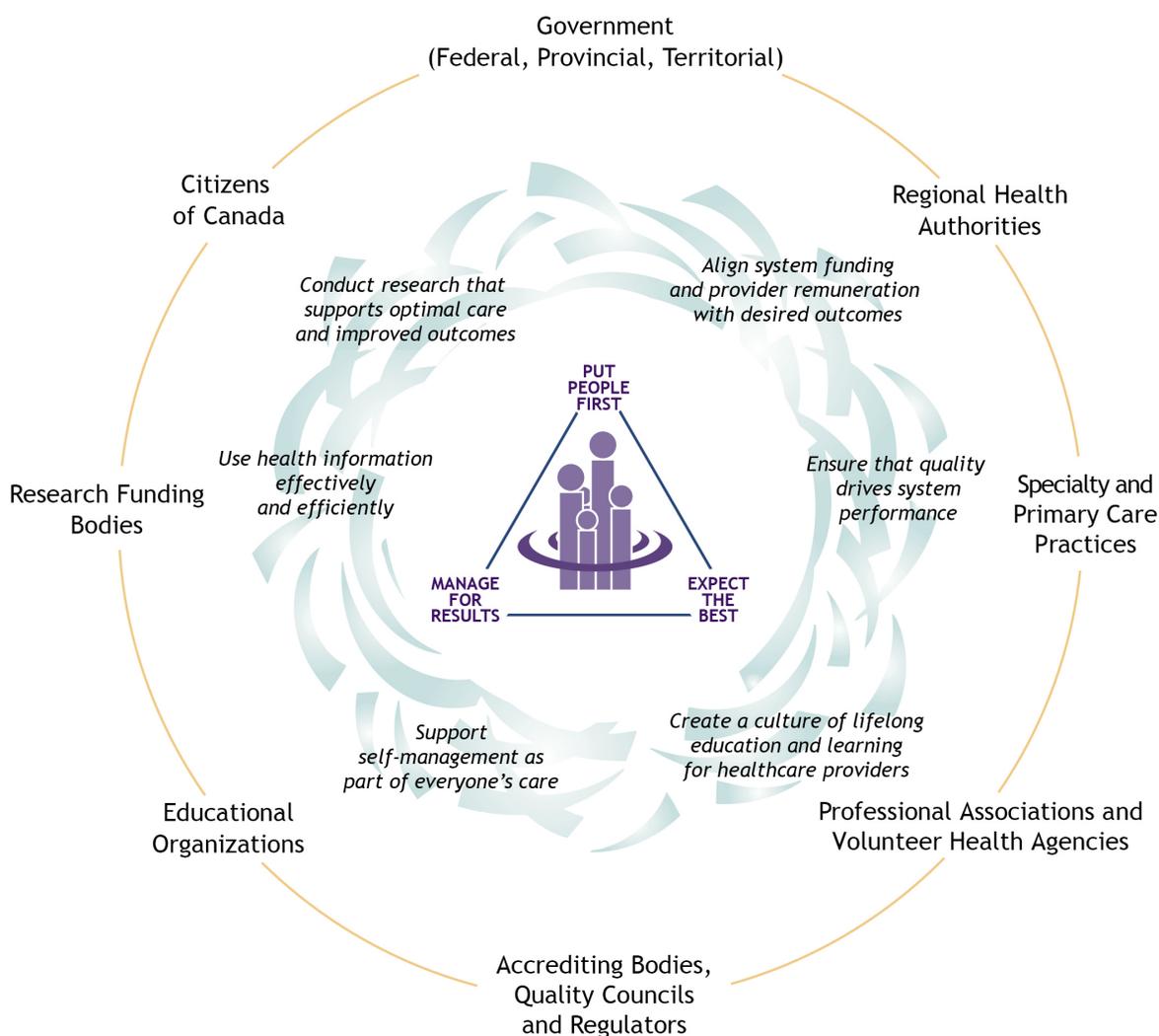
Figure 1: Strategy for Transforming Care for Canadians with Chronic Health Conditions

The burden of chronic conditions is growing: people with chronic conditions are suffering; the healthcare system and providers are stretched beyond capacity. It is time to challenge the status quo in the interest of improving outcomes for people with chronic conditions in Canada.

PART ONE:
BUILDING THE CASE FOR CHANGE

CHAPTER 1
THE HEALTHCARE CANADIANS NEED

> *Mr. E recently celebrated his 80th birthday at home with his wife. Over the years he has been diagnosed with hypertension, diabetes, arthritis, and most recently Alzheimer's. His long-time family doctor retired, and since then he has been unable to find a replacement. Mrs. E is becoming increasingly overwhelmed with the mounting responsibilities, including needing to sort through the advice from the many health professionals they see and to make healthcare decisions on her husband's behalf.*

While there is no one typical Canadian living with multiple chronic conditions, Mr. E's experience is common. There is no preset care approach that meets Mr. E's specific needs. He and his wife cobble together his care in a piecemeal way, attempting to manage his long list of medications and the progression of his conditions through the services of walk-in clinics and the help of their adult daughter. There is no integration of decisions, no oversight of his care, no explicit goals, and no support for his wife or for the challenge of navigating the many aspects of the health and social system they need to connect with.

Variations on Mr. E's situation affect Canadians of all ages across the country. Canadians are living longer, often with severe chronic conditions, and some with diseases diagnosed in their infancy. As more people are diagnosed with multiple chronic conditions, it has become increasingly clear that the Canadian healthcare system does not meet their needs and must be transformed.

This report provides a comprehensive assessment of the needs of people with chronic conditions, the best research evidence, emerging ideas about the appropriate care and support for these people, and an analysis of the state of the Canadian healthcare system. Implementation of the recommendations in this report will lead to the changes needed to ensure people living with chronic conditions receive the healthcare they need and deserve.

> *Mr. E and his family will no longer be struggling to navigate a fragmented system. He will be part of a primary care practice where the interprofessional team has electronic knowledge of his history and his family experience. Mr. E and his wife will have relationships with many members of the team who will be able to spend time in meaningful conversations with them. This may include the team pharmacist supporting Mrs. E in managing her husband's medications and monitoring potential drug interactions; the physician and nurse practitioner monitoring symptoms and disease progression; and the nurse, social worker, and dietitian focusing on prevention, self-management, and the available supports in Mr. E's community. If they find it useful, Mr. and Mrs. E may also have access to peer-support groups or other resources where they can learn from, receive support from, and provide support to other people. His family members will be supported to ensure that Mr. E's quality of life and well-being remains as high as possible. If Mr. E requires hospital admission, rehabilitation, or a move to a long-term care facility, the primary care team will be able to work with the other providers to ensure that his care is integrated and based on his needs.*

Mr. E's healthcare providers will have essential system supports for running the integrated practice. The healthcare providers will be remunerated for all of the roles in the practice as well as for the critical time spent educating, counselling, and partnering with Mr. and Mrs. E to enable them to experience the best quality of life possible. Healthcare providers will have strong relationships with hospitals, community, long-term and specialist care providers, and will be compensated for the time they spend partnering with these groups to create integrated care for Mr. E. Healthcare providers will have electronic health information technology that will allow them to know the number of people they serve in their practices who have some of the same needs as Mr. E and will have the ability to design programs and establish expertise accordingly. Healthcare providers will have integrated scheduling and billing data and will be able to guide patients in making their own appointments or accessing their own lab results and medical records. Healthcare providers will have electronic access to treatment guidelines and other decision supports that address the multiple conditions Mr. E is living with, and they will have access to data that show how they are performing as a practice relative to practices with similar populations so that they can determine where to keep improving. Across this comprehensive service delivery, healthcare providers will have options for continual learning as well as the ability to contribute to and learn from other practitioners across the country who are discovering the best models for care for people with chronic conditions.

Today, there are pockets of innovation in Canada that are moving in this direction and that show hints of what is possible to achieve for people with chronic conditions. However, this is not the standard of care, and the system is not currently designed to enable a system-integrated, population-based, and person-focused healthcare system.

Context for Transformation of the Canadian Healthcare System

Any attempt to change the Canadian healthcare system is necessarily complex because the system consists of a decentralized, interlocking set of 10 provincial and three territorial health insurance plans, with many service and delivery decisions made at the regional or local level. The system is publicly funded and provides all Canadians with universal, comprehensive coverage for medically necessary hospital and physician services. The *Canada Health Act* (1985) frames this coverage, which has five governing principles: public administration, universality, comprehensiveness, portability, and accessibility. However, the administration and delivery of healthcare services is the responsibility of each province or territory, which fund these services with assistance from the federal government in the form of fiscal transfers.

There is no centralized decision-making body. The *Canada Health Act* (1985) specifies conditions and criteria that must be satisfied by the provincial and territorial healthcare insurance plans in order for them to qualify for their full share of the federal cash contribution. Two federal bodies, Health Canada and the Public Health Agency of Canada, provide overarching guidance to the system. Health Canada's mandate is to help Canadians maintain and improve their health, which includes setting and administering national principles for the healthcare system through the *Canada Health Act* and delivering healthcare services to specific groups (e.g., First Nations and Inuit). Working in partnership with provinces and territories, Health Canada also supports the healthcare system through initiatives in areas such as health human resources planning, adoption of new technologies, and primary healthcare delivery. The Public Health Agency of Canada performs a parallel role for health promotion and prevention.

The 10 provincial and three territorial governments are the key providers of healthcare, with the constitutional responsibility for planning, financing, and evaluating the provision of hospital care, negotiating salaries of health professionals, and negotiating fees for physician services. The result is that each provincial insurance plan differs slightly. In most provinces, regional health authorities are responsible for some or all of healthcare delivery.

Canada has always based its system on a strong primary care foundation with half of physicians being family practitioners. Key characteristics of the Canadian healthcare system are provincial, regional, and local control of services and health delivery, physician autonomy, and consumer choice of provider. The end result is that at the level of care delivery, many family physicians operate in isolation from each other, with only loose links to either community services or the providers of specialty care. This isolation is now shifting due to the increased focus on team-based primary care in several provinces, but a basic fragmentation still exists.

Canadians' Expectations of the Healthcare System

Canadians deeply value the publicly funded healthcare system, and they expect it to meet their needs. Canadians have repeatedly reinforced a commitment to a healthcare system that reflects our values of equity, compassion, collective responsibility, individual responsibility, respect for others, efficiency, and effectiveness (National Forum on Health, 1997a, 1997b). At the same time, there are growing concerns about the sustainability of our healthcare system and a recognition that we need to preserve and enhance it for our families, their children, and their children's children. Strategic investments will lead to better health outcomes and to a more cost-effective system.

Most Canadians believe that a compassionate, effective healthcare system is part of what it means to be Canadian. Likewise, most Canadians believe that a strong healthcare system is an essential part of a thriving community and, although the vast majority of people using the Canadian healthcare system report that the quality of care they personally receive is good to excellent, half believe that our healthcare system requires fundamental change to improve it (Health Council of Canada, 2009b).

The strategy and recommendations in this report are based on the values Canadians have long espoused about healthcare. Both were derived from an 18-month review of research findings, empirical evidence, and emerging practices, and with the consensus of an Expert Panel with vast experience in all aspects of healthcare systems in Canada as well as internationally. As the strategy was being created, the Expert Panel developed a guiding description of Canadians' expectations of the healthcare system, expressed in the voice of the users of the system.

This framework informed and served as a test for the final recommendations:

We expect that:

- **Each of us has a primary care practice that we recognize as our "home base" and the hub for all of our care.**

- **Our healthcare providers help us and our family or friend caregivers live a high quality life.** Our health providers give advice and provide care that takes into account the full picture of our lives, including all our health conditions, how our needs will change over time, and the resources and support we have at home and in our community.

- **We, including our family or friend caregivers, are treated as partners in our care.** We have the information we need and are supported in making decisions about how to best manage our health. We have opportunities to connect with our peers who are also managing their own care and wellness. Our questions are answered and our input is respected.

- **We are not the only ones who know our entire "health story."** All of the healthcare providers we see will be able to access the information needed to understand the full picture of our health.

- **The healthcare system encourages our healthcare providers to spend the time they need with us.** Financial incentives are aligned with the goal of providing comprehensive, integrated care for our chronic conditions.

- **Our primary care provider works with other healthcare providers.** They make sure that they understand our priorities and ensure that our care is coordinated and based on the best current evidence.

- **Our healthcare providers are supported to maintain their knowledge and skills.** They continuously strive to improve their practices based on best current evidence, and there are mechanisms in place to ensure this happens.

- **We, together with our family or friend caregivers, can easily identify and access the services we need.** The location, hours, and availability of our healthcare providers meet our day-to-day needs.

- **There is a system within healthcare that connects the different services we will need over time.** There is a network that ensures smooth transition between publicly funded services such as primary care, specialty care, hospitals, residential care, and social and community programs.

- **Healthcare is guided by constant quality improvement.** There are systems in place to gather and make use of good population health information and good measurement indicators. This includes information and perceptions from us, as well as our family and friend caregivers, on our treatments and satisfaction with our care. This information is widely shared in a timely way so that it can be used to make changes and improve care.

- **Government and healthcare providers share knowledge and resources across the country.** Every community has access to the best approaches to healthcare, and we make the best use of public funding.

Summary

Canadians deeply value their publicly funded healthcare system, and they expect it to meet their needs. The current Canadian healthcare system could make changes to better meet the needs of many people with chronic conditions.

The Canadian healthcare system consists of a decentralized, interlocking set of 10 provincial and three territorial health insurance plans, with many service and delivery decisions made at the regional or local level. The system is publicly funded and provides all Canadians with universal, comprehensive coverage for medically necessary hospital and physician services.

Canada has always based its system on a strong primary care foundation with half of physicians being family practitioners. At the level of care delivery, many family physicians operate in isolation from each other, with only loose links to either community services or the providers of specialty care.

Canadians deserve a system that is inherently person-focused and integrated across the continuum of care and different sectors. The following chapters provide an overview of the evidence and argument that supports the expectations of Canadians as described in this chapter.

CHAPTER **2**
THE IMPACT OF CHRONIC HEALTH CONDITIONS

> **While the global disease burden has been shifting towards chronic conditions, health systems have not evolved to meet this changing demand. Care is fragmented, focused on acute and emergent symptoms, and often provided without the benefit of complete medical information.**
>
> (World Health Organization, 2003, p. 1)

Why Focus on Chronic Health Conditions?

In the past decade, the question of how to care most effectively for people with chronic disease has become increasingly significant. Globally and in Canada, an increasing concern about chronic disease is well documented (Daar et al., 2007). An estimated 16 million Canadians—roughly half the population—live with some chronic disease (Advisory Committee on Population Health, 2002).

Globally, chronic conditions have a profound economic impact on the functioning of healthcare systems and in people's day-to-day lives. When poorly managed, chronic conditions carry high costs for healthcare systems, have a deleterious impact on quality of life, and lead to reduced productivity of those with chronic conditions and their caregivers. Many people with chronic conditions have socio-economic factors, disabilities, and comorbid conditions that "make it harder for practitioners and practice systems to help them" (Wagner, 2001, p. 945). For all of these reasons, change needs to happen.

This chapter outlines the scope of chronic conditions considered in this assessment, what is known about their magnitude, cost, and impact on communities and the lives of Canadians, and why it is necessary to take a renewed, integrated approach to the way we deal with them.

What Do We Mean by Chronic Conditions?

The definition of chronic disease is not entirely straightforward. The term chronic disease most commonly refers to noninfectious diseases, such as cardiovascular conditions, cancer, respiratory conditions, and type 2 diabetes; however, it now also includes infectious diseases such as hepatitis and HIV/AIDS that persist and require care over time. In recent years, claims have been made that these conditions are at "epidemic proportions" (Daar et al., 2007, p. 2).

The definition of people living with chronic illness, however, is complex, and classifying chronic health conditions in terms of disease is inadequate. Diseases do not exist in isolation from each other, and focusing on individual diseases directs us away from "manifestations of ill health. . . [such as] discomfort, disability and limitation of normal activity" (Starfield, 2009a, p. 3; see also Appendix A).

The more we study chronic disease as a whole, the more we see it as a systemic issue. Boundaries and linear relationships between cause and effect have become increasingly blurred, and observers are reframing basic concepts. For example, Furler (2008) observed that depression was once conceptualized as arising from a troubled life, while diabetes was framed primarily as a physiological problem—but now we understand that there are physiological elements to depression and that diabetes has multiple socio-economic factors.

In addition, we are experiencing an increase in the number of people living with multiple chronic conditions due to an aging population living with both the effects of disease and aging (Institute of Medicine, 2001) and due to conditions such as HIV, kidney failure, and certain cancers, which were once seen as acute and are now redefined as chronic.

As people live longer with chronic conditions, sometimes from childhood onward, the concepts of comorbidity and multimorbidity have become increasingly important. Caring for people with chronic conditions involves supporting some people with a single condition, others with comorbidities (issues related to an initial condition, such as diabetes and renal failure), and still others with multimorbidities (multiple conditions, some related to each other, some complicating each other, and some that are unrelated but coexisting). A common example of multimorbidity is a person with diabetes, hypertension, and asthma who develops arthritis or dementia.

Comorbidities and multimorbidity "have become the rule rather than an exception" (van Weel & Hartman, 2009, para. 2), but clinical guidelines are not structured and outcomes are rarely studied from the perspective of multimorbidity. Measuring the impact of chronic illness based simply on the prevalence of individual diseases is clearly inadequate.

In this context, it is useful to consider the question of chronic conditions in terms of the goals for people's care. Chronic conditions are with people for the remainder of their lives. Grumbach (2003) argued that the goals of chronic care are generally not to cure, but to enhance quality of life and physical, cognitive, and social functionality, prevent secondary conditions, and minimize distressing symptoms.

Nolte and McKee (2008) define chronic disease as:

> **Conditions that require a complex response over an extended time period that involves coordinated inputs from a wide range of health professionals and access to essential medicines and monitoring systems, all of which need to be optimally embedded within a system that promotes patient empowerment.** (p. 1)

This complex response requires the attention not only of health professionals but also of caregivers and family members (Haveman, van Berkum, Reijinders, & Heller, 1997; Marks, 1998).

The focus of this report is on chronic conditions in the broader sense—conditions that require ongoing care or management over years or decades, by both health providers and family members, which "persist over time regardless of treatment" (Starfield, 2010, p. 4). This includes conditions that we think of as disabilities as well as mental health issues, which have been highlighted in Canada in recent years as "both like and unlike" (Kirby & Keon, 2006, p. 41) physical illness, but requiring treatment of "equal seriousness, and people who are living with mental and physical illnesses must be accorded equal respect and consideration" (p. 57).

The trajectory of these conditions varies significantly over time, as context, age, life situations, and other factors shift. Strategizing around chronic conditions requires care approaches that include primary and secondary prevention, acute episodic interventions, expansion of the care circle to recognize the role of family and friend caregivers, and persistent adaptability.

For all of the reasons outlined above, the subject of this report is *people* with chronic conditions. With this in mind, we are referring to people with one or more chronic conditions, encompassing people with a

diagnosis of a single disease such as diabetes or osteoarthritis, people living with comorbidities or multiple diseases or other forms of illness, and people living with disabilities or mental health issues.

Who is Living With Chronic Conditions?

There is no "typical" Canadian living with chronic conditions. Many people are leading "normal" lives with conditions that would have never have allowed them to survive just a few years ago. Many others have multiple conditions that are sometimes acute, sometimes manageable, and sometimes reversible, but collectively make a significant impact on their lives. Like Mr. E, introduced in Chapter 1, many Canadians are facing the conditions associated with aging, while longstanding issues flare up anew. People living with chronic conditions have diverse and changing experiences, and they all need care and support, inside and outside the formal healthcare system.

Chronic health conditions affect all Canadians, in terms of their own health and also as caregivers, coworkers, family members, neighbours, and friends. Over 40 per cent of Canadian adults reported that they had at least one of seven common chronic conditions—arthritis, cancer, emphysema or chronic obstructive pulmonary disease, diabetes, heart disease, high blood pressure, and mood disorders, not including depression (Canadian Institute for Health Information, 2009). In two independent 2007 surveys of Canadian adults, half (51–53 per cent) of the respondents said they take at least one prescription drug, while approximately 15 per cent said they take four or more (Health Council of Canada, 2009a).

There have been increases in life expectancy and changing mortality patterns as those aged 65 years and over constitute an increasingly large number and proportion of the population. One consequence of the aging of the population is an increase in the incidence and prevalence of chronic conditions including Alzheimer's disease and related disorders (Institute of Medicine, 2001). Alzheimer's disease is not part of normal aging, but its prevalence increases with age: 33 per cent of people aged 80 and over have the disease (Canadian Study of Health and Aging Working Group, 2000). Close to 20 per cent of baby boomers will develop Alzheimer's disease in their lifetime (Alzheimer Association, 2009). Up to 80 per cent of people with Alzheimer's have at least one other chronic disease such as diabetes, hypertension, cancer, depression, or heart or lung disease (Schubert et al., 2006).

The impact of living with chronic conditions is far beyond narrowly defined physical effects. In 2002, there were over 2 million caregivers aged 45 years and older (Hollander, Liu, & Chappell, 2009). The health of one family member affects the entire family; simultaneously, family and community support has a significant impact on a person's ability to manage his or her health. Some people living with chronic diseases require important but minimal intervention. Others, especially those living with multiple chronic conditions that shift as they age or acquire acute illnesses, require formal social and healthcare resources. The same person who can readily manage her own care for a chronic condition may be unable to navigate the healthcare system or continue her self-care when suddenly faced with an acute diagnosis. Social context matters for the ability to manage care, and the psychosocial effects of illness are complex.

The Community and Quality of Life Impact of Chronic Conditions

It is widely recognized that the well-being of any individual stems both from health and from the environment. Senator Pépin, Deputy Chair of the Senate Subcommittee on Population Health (as cited in Parliament of Canada, 2009), stated,

> **Even if well integrated, healthcare services alone do not make a community healthy. Governments at all level should support an overall, community-based approach to health and human development and assist with the integration of health and social services, wherever possible, and where it makes sense for the users.** (para. 4)

The World Health Organization (2001) *International Classification of Functioning, Disability and Health*, for example, classifies health and health-related domains as including body functions as well as activity and participation. Improving life for people with chronic conditions is inextricably linked with sustaining healthy communities and a vibrant population able to engage in meaningful work and relationships.

People with multiple chronic conditions are likely to have a much poorer quality of life compared to others' (Walker, 2007). Better primary and secondary prevention, care, and support can delay the beginning of decline and can enable people with chronic conditions to more fully participate in all of the aspects of life that they most care about, from supporting their families to contributing to the work world.

Delaying the onset of decline is particularly critical to enable independence for seniors, whose need for assistance is closely associated with chronic conditions (Statistics Canada, 2006; Walker, 2007). This will become an increasingly important issue as seniors comprise a larger portion of the population; a recent Statistics Canada (2010) report found that within five years the number of people at least 65 years old will outnumber children under 15, and by 2036 there will be between 9.9 and 10.9 million people over the age of 65 in Canada, more than double the number in 2009.

The impact of chronic conditions on quality of life is most pronounced for the poorest Canadians. A recent report in Ontario, for example, found that rates of 38 chronic diseases were highest among people on social assistance (Community Social Planning Council of Toronto, University of Toronto's Social Assistance in the New Economy Project, & Wellesley Institute, 2009). Similarly, Fang, Kmetic, Millar, and Drasic (2009) found that, across Canada, the "lower people are in the socio-economic hierarchy, the shorter their life expectancy and the higher their risk of developing chronic diseases" (Introduction section, para. 1). In addition, these differences in life expectancies reflect provincial inequities in health across the nation (Fang et al., 2009). This inequity is reciprocal: some people are poor because of their disabilities, while others are ill because of their socio-economic conditions, and both cases reinforce each other.

These health inequities are particularly striking for Aboriginal people in Canada. A recent study by Loppie Reading and Wien (2009) noted:

> **According to the United Nations Human Development Index, which measures health through longevity, educational achievement, and adult literacy, First Nations people in Canada rank 63rd in the world. Likewise, the Community Well Being (CWB) scale for First Nations, developed by Indian and Northern Affairs Canada, which measures education, labour force participation, income and housing, indicates that Aboriginal communities represent 65 of the 100 unhealthiest Canadian communities.** (p. 5)

The Economic Impact of Chronic Conditions

The economic impact of chronic conditions is profound, both in terms of productivity losses and direct healthcare costs. Researchers have found that the most common chronic diseases, such as cardiovascular conditions, cancer, respiratory conditions, and type 2 diabetes, account for 60 per cent of all deaths and 44 per cent of premature deaths worldwide (Coleman, Austin, Brach, & Wagner, 2009; Daar et al., 2007; Ebrahim, 2008; Yach, Hawkes, Gould, & Hofman, 2004). Chronic illness has been positioned as a global development issue, and there have been many calls to action in the past several years (Daar et al., 2007; Ebrahim, 2008). In 2005, the World Health Organization (2005) declared a global goal of reducing the prevalence of chronic disease by 2 per cent every year between 2005 and 2015.

Improving the ability to care for people with chronic conditions is a significant part of developing a sustainable healthcare system. The cost of healthcare in Canada is high and is continuing to rise, and researchers are attempting to account for the role of chronic conditions in this increased cost. Canada's total expenditures on health for 2007 were estimated to be 10.1 per cent of the gross domestic product, up from 8.8 per cent in 1997 (Organization for Economic Co-operation and Development, 2009); this is among the highest of the industrialized countries (see Figure 2 for a graphic representation of these data). In per person terms, total expenditure is $3,895 USD, up from $2,152 USD in 1997 (Organization for Economic Co-operation and Development, 2009).

A significant and rising element of the cost of healthcare is pharmaceuticals. The money spent on pharmaceuticals is consuming an increasing size and proportion of healthcare dollars, and the costs are escalating faster than the rate of inflation. Spending on prescription medication in Canada grew at an average annual rate of 10.6 per cent between 1985 and 2005, compared with total health spending that grew at an average annual rate of 6.5 per cent. Spending on prescription drugs in Canada was estimated at roughly $25.4 billion in 2009 (Canadian Institute for Health Information, 2010). Governments pay approximately 40 per cent of these costs through government drug plans, while individual Canadians and private insurers pay the remaining 60 per cent (Health Council of Canada, 2009a).

A large proportion of healthcare expenditures are due to chronic conditions. In the United Kingdom (U.K.), data from the Department of Health (2008) *Raising the Profile of Long Term Conditions Care* report indicated that over 30 per cent of people report that they have a chronic condition, accounting for 52 per cent of all appointments with general practitioners, 65 per cent of all hospital outpatient appointments, and 72 per cent of hospital bed days. The Department of Health has estimated that the treatment and care of those with chronic diseases account for 69 per cent of the total health and social care expenditure in England, or almost £7 of every £10 spent.
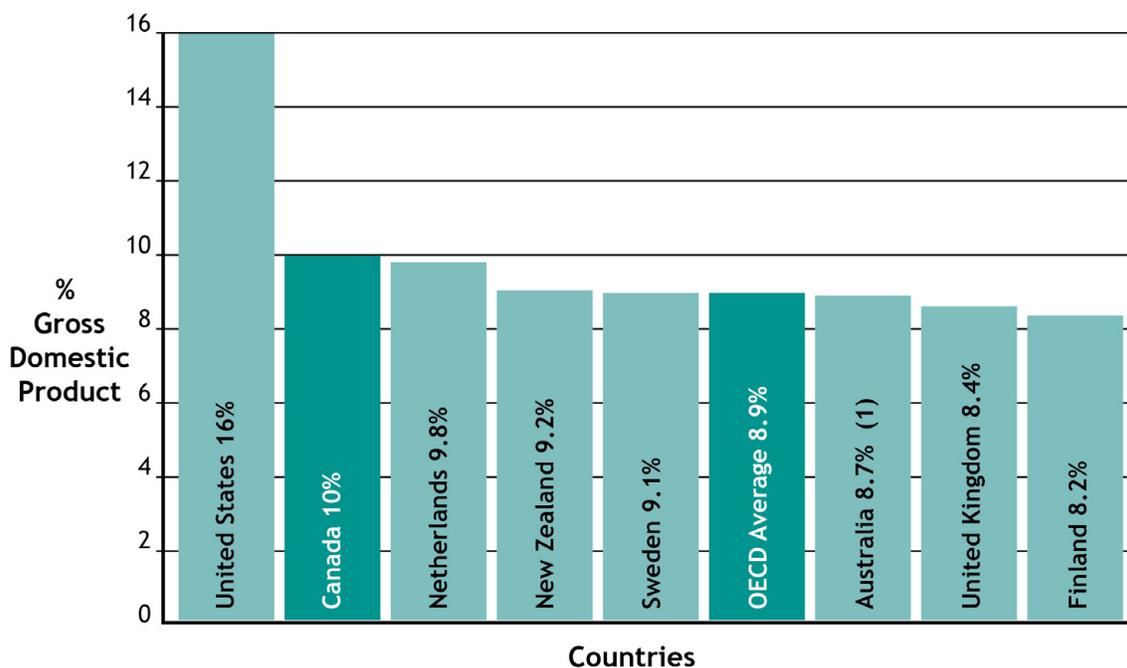
(1) data obtained in 2006.

Figure 2: Health Expenditures as a Share of Gross Domestic Product for Organization for Economic Co-operation and Development Countries in 2007[1]

A Canadian study of 980 adults keeping appointments with family practitioners in Québec found that 90 per cent had more than one chronic condition, rising from 68 per cent of women aged 16–44 years, to 95 per cent of women aged 45–64 years, to 99 per cent of women aged 65 and over (Fortin, Bravo, Hudon, Vanasse, & Lapointe, 2005). In men, the comparable percentages were 72 per cent, 89 per cent, and 97 per cent, respectively (Fortin et al., 2005).

Beyond the impact on the healthcare system, researchers have also examined the impact of chronic conditions on productivity, for both those with health conditions and their caregivers. In British Columbia alone, three risk factors (smoking, physical inactivity, and obesity) contributing to several chronic health conditions were estimated to cost the British Columbia economy $3.8 billion in 2004 (Krueger, Williams, Kaminsky, & McLean, 2007). To put this in perspective, the provincial government budgeted $4.9 billion for all primary and secondary education in the province this same year (Krueger et al., 2007).

Productivity losses are related not only to people with ill health, but also to their caregivers and families. Family members and friends provide much of the care for and support to people with chronic conditions. In 2007, nearly one in four Canadians reported caring for a family member or friend with a serious health problem in the previous year (Hollander et al., 2009). Many have taken leave from work or have left jobs, at some economic cost as a result of lost wages and benefits, and often with serious repercussions for their personal health.

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[1] [1] From *OECD Health Data 2009: How Does Canada Compare* (p. 1), by the Organization for Economic Co-operation and Development, 2009, Paris, France: Author. Copyright 2009 by the Organization for Economic Co-operation and Development. Adapted with permission.

A reasonably conservative estimate of the imputed economic contribution of unpaid caregivers in Canada for 2009 is $25 billion to $26 billion (Hollander et al., 2009). This does not include the opportunity costs (lost wages) of people with chronic conditions and caregivers, the cost of health impacts on caregivers due to the stress of care giving, the implications of tax and social welfare costs, and other such factors. Moreover, this estimate does not account for the fact that care is often shared by those beyond the person immediately identified as a caregiver, i.e., that there are other, hidden caregivers whose costs are not visible (Fast, Keating, Otfinowski, & Derksen, 2004; Keating, Otfinowski, Wenger, Fast, & Derksen, 2003). Rather, the estimate reflects what it would cost to substitute paid care for unpaid care for seniors alone by caregivers aged 45 years of age or older (Hollander et al., 2009).

Sustainability for all Publicly Funded Programs

According to the Canadian Institute of Wellbeing, in 2009, Canadians' top priorities for quality of life were: primary and secondary education, healthcare access, a healthy environment, clean air and water, social programs, responsible taxation, public safety and security, job security, employment opportunities, a living wage, balanced time use, and civic participation. These common themes cut across regions, social backgrounds, and various demographic characteristics.

The healthcare system is the largest economic investment in Canada, and chronic conditions affect both healthcare expenditures and the effective deployment of healthcare providers. If healthcare spending continues to rise disproportionate to gross domestic product, we risk eroding other publicly funded programs. The increase in the provincial healthcare budgets is at the expense of other ministries, many of which contribute to the health of the population. Projections have shown that without any new actions to promote health and prevent disease by 2017, the Government of British Columbia, Ministry of Health Services would require 71.3 per cent of the total budget of the government, an increase from 41.6 per cent in 2005/2006 (Public Health Agency of Canada & World Health Organization, 2009). A recent study found that Ontario government spending on healthcare increases more than healthcare revenues every year, and as a result the amount available for other government spending decreases. The report found that

> **If current trends prevail, health care expenditures would make up 80 per cent of total program spending by 2030, up from 46 per cent today. All other programs, such as education, would be funded out of the remaining 20 per cent.** (Drummond & Burleton, 2010)

Equitable Access to Affordable Treatment for Chronic Conditions

The *Canada Health Act* (1985) did not anticipate community-based management of chronic disease, and thus only services, care aides, technologies, many health professional consultations, and prescription medications provided within hospital settings are considered to be part of the essential health service basket (Tamblyn, 2005).

Consider the following notional example:

> *Mr. Jones, a 56-year-old man, is admitted to hospital with an acute myocardial infarction, undergoes emergency angioplasty, is started on a calcium channel blocker, betablocker, lipid-reducing drug, and aspirin, and is discharged three days later as part of a state-of-the-art early discharge follow-up program. In the hospital they measured his blood sugar on a regular basis and he had a consultation with a dietitian. The total cost for emergency and hospital care is $15,000: $5,000 for the angioplasty, $10,000 for hospital stay and services, including $900 for three days of intravenous and oral drug therapy.*

The cost paid by the patients in hospitals is zero in each and every Canadian province—the *Canada Health Act* (1985) requires equitable access to medically necessary hospital-based care from sea to sea. However, when Mr. Jones is discharged and goes home, the annual cost for the same medically necessary prescription drug treatment started in hospital will cost him $1,400 if he lives in New Brunswick, $800 in Saskatchewan, and $200 in British Columbia. Why? Because each province has instituted different levels of coverage for prescription drugs. This inconsistency in policy creates "daily paradoxes in care delivery that systematically undermine efforts to evolve our hospital-centric system into ambulatory and home-care environments" (Tamblyn, 2005, p. 1343).

The same inconsistencies in access apply to professional consultations through home care services, care aides such as glucose measuring sticks, and appliances such walking devices for people with mobility impairments. This patchwork of programs varies in comprehensiveness, eligibility, and access, and as a result there are considerable differences in out-of-pocket expenses for patients with the same health problem (Bell, Griller, Lawson, & Lovren, 2010; Schoen & Doty, 2004).

These out-of-pocket expenses make it difficult for some people to manage their chronic conditions, which contribute to increasing inequities in health. The cost of medication is a major barrier that prevents optimal adherence to medical treatment (Lexchin & Grootendorst, 2004; Osterberg & Blaschke, 2005) and results in avoidable morbidity (Lexchin & Grootendorst, 2004; Tamblyn et al., 2001). Access to needed medications is especially challenging for people with fixed incomes. In 2007, Canadians spent $19 billion on prescription drugs, with adults 65 years of age and older spending $1,778 per person, three times the amount of the average Canadian (Morgan, McMahon, Lam, Mooney, & Raymond, 2005).

Family and Friend Caregivers

Chronic conditions affect the community beyond those immediately affected, particularly caregivers. There is a constellation of unpaid, informal caregivers connected to the people with chronic conditions, all with unique needs, who need to be considered in public policy and other resource and support planning (Keating & Dosman, 2009).

In addition to the economic effects noted above, caring for people with chronic conditions carries physical impacts. A broad set of physical costs of caregiving has been documented, on both systemic and injury-related health outcomes. These include: lowered immune system functioning, altered response to influenza vaccination, slower wound healing, and higher blood pressure (Haley, 2003; Tsukasaki et al., 2006). Brehaut et al. (2004) reported that parents of children with cerebral palsy had a higher prevalence of a variety of physical problems, including migraine headaches, ulcers, arthritis pain, and chronic health conditions compared with other parents. Compared with non-caregivers, caregivers are more likely to experience inadequate time for sleep, self-care, and exercise (Connell, Janevic, & Gallant, 2001). These physical symptoms can combine to increase the risk of premature death. Haley (2003) found that caregivers who were highly stressed had a 63 per cent higher mortality rate over a four-year period compared with noncaregivers or caregivers who did not report being highly stressed. In some cases, this stress has been implicated in extreme outcomes such as clinical depression and greater use of prescription drugs and alcohol (Fast, Williamson, & Keating, 1999). Caregivers also experience social isolation and reduced capacity to participate in basic social activities (Haley, 2003; Kuuppelomäki, Sasaki, Yamada, Asakawa, & Shimanouchi, 2004).

Bédard, Koivuranta, and Stuckey (2004) noted that rural caregivers have higher caregiving demands than urban caregivers and, thus, are at risk for poorer health status. Limited services also mean that rural- and northern-based caregivers may have less formal assistance (Dobbs, Swindle, Keating, Eales, & Keefe, 2004) and difficulty accessing services, either for the person they are caring for or their own respite (Varga-Toth, 2006).

Summary and Scope of the Review

The human, societal, and economic impact of living with chronic conditions is irrefutable and compelling. While it is difficult to fully assess the magnitude and the cost, chronic conditions place pressure on the healthcare system and the social fabric for Canadians. Improving the systemic care and quality of life for Canadians with chronic conditions is a necessity.

Keon and Pépin (2009) acknowledged that health is determined as much or more by social, economic, environmental, and cultural factors than it is by genetic or medical factors. They cited evidence from the Canadian literature that suggests that while the healthcare system is an important contributor to population health, "it only accounts for 25 per cent of health outcomes regardless of the level of funding it receives" (Keon & Pépin, 2009, p.7).

Canada's total expenditures on health are increasing and are among the highest of the industrialized countries. This assessment focuses on how to optimize the estimated 25 per cent contribution of the healthcare system to population health by improving health outcomes of people with chronic conditions.

In addition to transforming the healthcare system to enable person-focused care, policy-makers and allocators of resources must work to reduce health disparities and address all the determinants of health, including factors such as income, level of education, occupation, social hierarchy, and housing.

CHAPTER 3
THE PREFERRED APPROACH TO CARE FOR PEOPLE WITH CHRONIC CONDITIONS

There is an emerging international consensus that improving care for people with chronic conditions requires a more comprehensive approach. Stange (2009b) phrased this as, "The need to raise the gaze of health care from the disease to the person and the population" (p. 465). Wagner (1998) emphasized the need for "planned, regular interactions with caregivers. . . [including] systematic assessments, attention to treatment guidelines, and behaviourally sophisticated support for the patient's role as self-manager" (p. 2).

In the past decade, integrated chronic care models that take a population approach assume the critical role of primary care with strong interfaces to the community and other aspects of the healthcare system. These integrated chronic care models, which advocate for activated patients through supported self-management and prevention, have started to become internationally established as the preferred approach to care for people with chronic conditions.

Wagner and his colleagues developed one of the most comprehensive chronic care models (Wagner, 1998; see also Bodenheimer, Wagner, & Grumbach, 2002; Wagner, Austin, & Von Korff, 1996). The Wagner model, as it is known familiarly, was developed in response to the realization that comprehensive management of chronic conditions was not the norm in healthcare; it advocated a multifaceted, guideline-based approach for primary care teams (see Figure B1 in Appendix B). As this model has been enacted and adapted in different contexts, other related approaches have been developed and implemented, such as Kaiser Permanente's risk stratification model (Lieu, Quesenberry, Sorel, Mendoza, & Leong, 1998) and the expanded chronic care model (Barr et al., 2003). Similar models are in use in several countries, including Australia, Denmark, Egypt, England, and Germany (Colin-Thomé & Hindmarsh, 2010; Improving Chronic Illness Care, 2007; Nolte & McKee, 2008). Emerging concepts such as the "medical home" (Berenson, Hammons, Gans, & Zuckerman, 2008, p. 1219) also incorporate comprehensive, integrated approaches to primary care (see Appendix B for a more detailed overview of these models). The concept, first introduced in 1967 by the American Academy of Pediatrics, has evolved to an approach or model that allows for better access to healthcare, improved satisfaction with care, and improved health outcomes through the use of evidence, clinical decision support tools, health information technology, performance feedback, and payment reform (Barr & Ginsburg, 2006; Goroll, Berenson, Schoenbaum, & Gardner, 2007; Sia, Tonniges, Osterhus, & Taba, 2004).

These chronic care models have several themes in common that are linked with improving outcomes and satisfaction: a shift from reactive to proactive care; population-based care, including delivering levels of care based on risk-stratification; recognizing primary care as the hub for prevention and care support, with strong interfaces with the rest of the healthcare system; providing care that focuses on the individual needs of the person, in his or her specific social context; meaningful health information systems; leveraging community partnerships; supporting self-management and caregivers; using clinical practice guidelines in a way that acknowledges multiple conditions; and continued practice redesign and improvement.

The College of Family Physicians of Canada (2009) recently defined the primary care "medical home" (p. 3), which brings together most of these elements in the context of the Canadian healthcare system.

This chapter provides an overview of the current evidence about the key elements of comprehensive, integrated care. It provides a base for assessing Canada's current performance and indicating where change needs to occur. These elements are clustered as: primacy of primary care grounded in a population approach; interprofessional collaboration and team-based care; person-focused care; interfaces between primary care and other aspects of the system; self-management by people with chronic conditions and caregivers; electronic health information systems; practice redesign (guidelines, performance assessment, and remuneration); and continued practice redesign, improvement, and learning.

Primacy of Primary Care Grounded in a Population Approach

"The well known but underappreciated secret of the value of primary care is its person and population, rather than disease, focus" (Starfield, 2009a, p. 12).

Care for people with chronic conditions requires not only ongoing knowledge of the person but also time for providers to have meaningful conversations with people with chronic conditions and their family and friend caregivers to provide information, guidance, and counselling about prevention, self-management, and available support (E. H. Wagner, personal communication, August 19, 2009). The individual relationship between the person with chronic conditions and healthcare providers needs to be grounded in the context of a population perspective, to understand risk factors, demographics, and needs of the practice to design effective services, along with awareness of and relationships with community services and specialty care.

Primary healthcare providers and teams are a critical hub of the comprehensive approach required for person-centred, integrated care that can improve healthcare system efficiency, patient outcomes and satisfaction, and quality of care (Kringos, Boerma, Hutchinson, van der Zee, & Groenewegen, 2010; Scobie, MacKinnon, Higgins, Etchegary, & Church, 2009). This may imply that the traditional solo family physician is not a viable model for the future and that team-based, interprofessional care is the only way to provide the comprehensive services needed.

Primary care is the most appropriate system for providing prevention and screening, enhanced relationships between providers and patients and families, and a vehicle for patient and family participation in decision making and care (Health Council of Canada, 2010b). One study found that practices that had "a multispecialty physician and staff dietitians, decision support in the form of point-of-care reminders and clinical staff meetings, and clinical information systems such as electronic health records" (Hung et al., 2007, p. 69) were much more likely to recommend primary and secondary prevention services such as health risk assessment, behavioural counselling, and referral to community-based programs. Primary care also offers the possibility of acting as a focal point for comprehensive care by providing a central interface with specialists and community services (Lewis, 2009; Murray, Bodenheimer, Rittenhouse, & Grumbach, 2003; Scobie et al., 2009; Starfield, 2009a; see also Appendix A).

Starfield (2004) defined the core characteristics of primary care as "first contact, person-focused care over time, comprehensiveness and coordination" (p. 4). There is growing evidence that this type of care is most effective if it is enacted through a "population-oriented set of primary care services in the context of other levels and types of services" (Starfield, 2004, p. 5; see also Starfield, Shi, & Macinko, 2005).

Effective primary care, Scobie et al. (2009) argued, is practice that focuses on the person's needs (where the patient is known and comfortable and where health providers can spend time addressing assessment, support, and education) and which is strongly connected to all other aspects of the care network. In an assessment of person-oriented interventions within primary care, O'Connor (2008) showed that such interventions improve "knowledge, patients' experience, service use, [and] behaviour, if [they are] personalized, combined with support and extended duration" (p. 2).

While providing a locus for continuity of patient relationships and knowledge, effective primary care also plays an important role in ensuring that people have access to the right care at the right time, including acting as a navigation point for an increasingly complex system and providing the site for patients to take on a context-appropriate role in their own health maintenance and decision making (Health Council of Canada, 2010b; Kirby, 2002).

Primary care does not supplant specialist, acute, community, or long-term care or public health functions. Østbye et al. (2005), for example, argued that community-based resources, including neighbourhood health educators and social workers, are also effective resources for chronic disease management. Primary care is, however, increasingly positioned as a critical hub between all of those functions. In the U.K., a system-wide restructuring over the past two decades elevated the significance of primary care as more than general practice, but rather, a strategic locus for the wider public health and bioclinical-specialized care (Colin-Thomé & Hindmarsh, 2010). A 2010 Health Council of Canada paper on primary care reform made a call to "connect the dots" (Health Council of Canada, 2010a, p. 4), to emphasize the fundamental value of primary care and then to put "appropriate management structures" (p. 6) in place between "health ministries and primary health care delivery at the [provincial/]regional/community level in order to steer and support the process of strengthening primary health care" (p. 6).

To address broader population health needs, there is resurgence in considering community-oriented primary healthcare as an effective approach (Mullan & Epstein, 2002, p. 1748). This approach is aligned with the focus of the comprehensive chronic care models to recognize the critical community context for both practice design and care for individual people. Community-oriented primary healthcare takes a population health approach, structuring itself around the specific needs of its community, systemically drawing on principles derived from epidemiology, preventive medicine, and health promotion (Goel, 2010). Community, in this context, may refer to a geographic area and, increasingly, to different constituencies such as socio-economic, cultural, or demographic groups. With adequate information and analytical tools, a defined population provides opportunities for targeted prevention, programs geared specifically to the needs of the community, innovative approaches to care, such as peer support and group medical appointments, and data for quality improvement. Appendix B provides a detailed example of how Kaiser Permanente does this through its HealthConnect program (Kaiser Permanente Institute for Health Policy, 2008). Practices that structure services around the needs of the community also act as attractors, increasingly drawing in patients who need these specific services.

This community-focused approach is consistent with the conclusions of researchers who have examined the role of healthcare in addressing ethnic and socio-economic health inequalities (Tobias & Yeh, 2009) and have recommended the integration of population health practices into primary healthcare (Neuwelt et al., 2009). There are various ways to approach population health, including either geographic analysis of community needs and services or a demographic and needs analysis of a practice's patient base. The latter requires some form of registering or rostering of patients, which has generated fears that patient choice of health primary care provider may be reduced or that utilization data may be skewed where multiple registrations are permitted.

A Canadian study of patients with access to primary care practices analogous to the medical home (i.e., with all of the key features of integrated, person-focused care) found these practices associated with "improved self-reported access to healthcare services, coordination of and confidence in services received, and provider knowledge and fewer medical errors" (Scobie et al., 2009, p. 47).

Interprofessional Collaboration and Team-Based Care

Research has also expanded the notion of primary care beyond the traditional physician-led model, particularly in interprofessional team-based care. In 2002, the Romanow Report argued that good primary healthcare is based on interdisciplinary teamwork with care available to all, 24 hours a day, 7 days a week. Studies are beginning to demonstrate that interprofessional primary care teams improve patient outcomes, provider outcomes and organizational outcomes (Barrett, Curran, Glynn, & Godwin, 2007).

In many contexts, the physician is still seen as the centre of the practice, with physician assistants, nurse practitioners, and professional health educators taking on education, follow-up of protocols and guidelines, counselling, and guidance to free up time for the physicians (Østbye et al., 2005). There are also emerging models for primary care that expand leadership beyond physicians, particularly as the scope of practice of other health professionals is expanding. The rise in interprofessional collaboration across Canada is challenging the assumption that all primary care practices must be physician led. In some Canadian jurisdictions, for example, nurse practitioners have been situated in primary care as independent practitioners with wide scopes of practice, prescribing privileges, and ordering of diagnostic, lab, and imaging services. In some jurisdictions, nurse practitioners also have the authority to make direct requests for consultation with or referral to specialists (College of Registered Nurses of British Columbia, 2010). In Ontario, nurse practitioners are seeking to be authorized to admit, treat, transfer, and discharge patients to and from inpatient settings (Fucile & Grinspun, 2010).

The potential to expand the scope of practice for other health professions has been suggested as a way to reduce pressure on the system and to provide more opportunities for person-focused care. For example, a recent Health Council of Canada paper suggested expanding the role of the pharmacist to include the provision of paid services such as blood tests, diabetes care, smoking cessation, vaccinations, initial treatment for minor ailments, cholesterol control consultations, and some prescribing privileges (Bell et al., 2010).

The emerging consensus is that interprofessional collaboration is not a substitution model (i.e., not "nurse instead of physician") but rather one that allows for a group of health professionals to work in a complementary way to improve access to comprehensive person-focused services and care.

Person-Focused Care

At a primary care conference in Toronto in January 2010, a young woman described the problems she was having with managing her diabetes:

> *"My doctor had a flexible mindset—she started throwing out ideas of what other people had done, and that wasn't helpful, but when we started talking about my life and my experiences, and the things I care about outside my diabetes, we came up with great ideas for me to most effectively manage my diabetes."*

Integrated models require person-focused care (also known as patient-centred and patient-focused care), which approaches healthcare system integration from the perspective of the patient experience (Lewis, 2009). Person-focused care also acknowledges that the role of family and friends as caregivers is critical for all ages (Rosenbaum, King, Law, King, & Evans, 1998). Stange (2009a) described this approach as "the ability to prioritize and integrate care based on an inclusive view and personal knowledge" (p. 390) and called it a "crucial primary care function that is only beginning to be recognized" (p. 390).

Other descriptions of person-focused care highlight the exploration of both the "disease and the patient's illness experience" (Stewart et al., 2003, p. 49). Ontario's externally informed *Annual Health Systems Trends Report* (as cited in Stewart, 2010), for example, defined person-centred care as including: "respect for people's values, preferences, and expressed needs; coordination and integration of care; information, communication, education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of family and friends; and transition and continuity" (p. 8).

Person-focused care has been described in terms of a continuing relationship between a patient and a practice, where the providers in the practice know the patient and the patient has a regular source of care (McMurchy, 2009). Some core elements of this approach to care include: comprehensive care, coordination of care, timeliness, functioning e-health, clear and reliable communication, convenience, respect, empathy and understanding, time, continuity and stability, and fairness (Lewis, 2009). Fundamentally, person-focused care acknowledges that patients' health problems are not synonymous with their diagnoses and that the health problems of people and populations are not the same as the sum of their individual diseases (Starfield, 2009a). Person-focused care takes different forms, with the core principle of offering diverse care that fits people, not their diseases or single parts of their bodies.

There is emerging interest in the effectiveness and benefits of person-focused care. Care that takes person-focused principles into account is associated with benefits such as: more timely care, appropriate preventive care, greater likelihood of recognition of health problems, fewer diagnostic tests and prescriptions, more accurate diagnoses, lower costs, reduced emergency department and hospital use for ambulatory care sensitive conditions, and reduced health disparities associated with socio-economic status (McMurchy, 2009).

Person-focused approaches have been introduced globally in various forms, including in the acute and primary care sectors. Person-focused approaches have led to improved patient satisfaction scores (Commonwealth Fund, 2009) and improved indicators of safety, patient and provider satisfaction, promotion of self-care, reduced length of stay, and other measures (Charmel & Frampton, 2008; Cooper et al., 2009; King, Teplicky, King, & Rosenbaum, 2004; Sidani, 2008).

Interfaces Between Primary Care and Other Aspects of the System

A critical element of person-focused care is that people with chronic conditions experience care that is as seamless as possible as they move between primary, acute, specialty, and community care. This requires rethinking the interfaces between the home base of primary care and other aspects of the system. One simple way of expressing this is: people should not need to completely repeat their "health stories" with every encounter nor should they need to be the only keeper of their health information. Rather, history, diagnoses, treatments, test results, home situations, and other relevant information need to move with the person across the system.

Beyond information sharing, person-focused care requires that people with chronic conditions are not moved sequentially through the system; instead, providers of primary and specialty care need to look for opportunities to collaborate on decisions about diagnoses and care. This is particularly important during transitions, such as life stages from childhood to adulthood and adulthood to the greater needs of aging and end-of-life care as well as transitions between parts of the healthcare system.

A common example illustrates the imperative for this kind of coordination. Seniors are likely to experience a need for acute care, either in the emergency room or extended hospitalization, as well as community and long-term care. While the home base may be primary care, people are frequently moving in and out of different parts of the system.

The implications of this movement within the realm of medications, alone, are profound. An Ontario review found that physicians in primary care practices write 85 per cent of the prescriptions for seniors (Jaakkimainen et al., 2006). At the same time, the average number of medication classes an individual takes is also increasing. There is a lack of coordination of medication records between admission to hospital-based acute care and discharge to community care. The resultant polypharmacy is believed to lead to situations where the medications may be appropriate on an individual basis, but are not appropriate collectively. Currently, neither the healthcare system nor research about medication interactions and the effects of particular drugs on people with multiple conditions can begin to adequately consider these complexities.

Supported Self-Management

One of the most highly developed aspects of person-focused care within the context of the chronic disease model is self-management. Self-care of some kind is an inherent requirement of living with chronic conditions, since "healthcare professionals may only interact with people with a chronic disease a few hours a year—the rest of the time patients care for themselves" (Ham, 2010, p. 8). Obviously, the scope of self-care is highly dependent on the capacity of individuals and their circumstances. At the same time, both the chronic care model and some definitions of person-centred care highlight a desire to "increase their capacity to self-manage and otherwise participate in their health" (Lewis, 2009, p. 9).

The goal is collaboration between informed, respected persons and their families and a coordinated healthcare team (Canadian Institutes of Health Research, 2007). There are two sides to this: what is the person with chronic conditions doing to be more engaged, and what are providers doing to help people be more engaged? This form of engagement is what the Wagner model refers to as the "activated patient" (Wagner, 1998, p. 3).

The focus on self-management is to shift to a frame of person-professional partnership involving collaborative care and supports for self-management in ways that are appropriate for people's conditions. Frail older adults, or people with cognitive impairment, for example, would have different possibilities for self-management than would a 16-year-old girl with type 1 diabetes.

Improved Health Outcomes

Bodenheimer, Lorig, Holman, and Grumbach (2002) found that helping people to apply and enhance their problem-solving skills for their chronic conditions was key, and that bringing together people with a variety of conditions improved outcomes. Lorig, Ritter, Plant, Laurent, and Mcneil (2008) had similar findings in a study of a peer-led, online self-management program for patients—a 6-week program, studied over one year, led to decreased symptoms, improved health behaviour and self-efficacy, and better healthcare utilization. An early study of a self-management program involving 800 participants in the United States (U.S.) found that participants experienced improvements in health status, fewer distressing symptoms, and fewer emergency room and outpatient visits (Lorig et al., 2001). A U.K. study involving patients with inflammatory bowel disease indicated the value of training healthcare providers to support patients in guided self-management (Kennedy, Gask, & Rogers, 2005).

Virtual Interactivity: Health 2.0

Health 2.0 offers multiple opportunities for creative and revolutionary ways to develop and share knowledge, self-manage, and support peers, as well as novel ways of interacting to provide different kinds of conversations between people with chronic conditions and healthcare providers, and among peer communities. The *Wall Street Journal* described the consumer aspect of this kind of connectivity in terms of patient empowerment:

> **Patients who once connected mainly through email discussion groups and chat rooms are building more sophisticated virtual communities that enable them to share information about treatment and coping and build a personal network of friends. At the same time, traditional Web sites that once offered cumbersome pages of static data are developing blogs, podcasts, and customized search engines to deliver the most relevant and timely information on health topics.** (Landro, 2006, para. 2)

Examples of these kinds of sites include dailystrength.org and curetogether.com, where people with chronic conditions share information, contribute to the body of knowledge about symptoms and treatments for common conditions, and create online communities for peer support. Healthcare providers are integrated into these communities in various ways.

While some consumers are engaging in their own healthcare virtually, some providers are using electronic means to connect to each other and to consumers. For example, the concept of "eConsultation" is emerging as a potential means of simplifying and accelerating access to the expertise of providers of specialty care by primary care providers in order to improve delivery of care to the patients (Liddy et al., 2010). Other providers are using opportunities like the virtual community Second Life, where avatars interact in real time, for health promotion and peer support.

Inherent in the phrase "person-focused" is the acknowledgement that needs vary from person to person and from circumstance to circumstance. This includes recognizing that individuals participating in their own health will vary according to their resources and capacity. People who are frail or experience high levels of

cognitive impairment, intellectual disabilities, language barriers, or other barriers to access may require additional supports to navigate the healthcare system. Self-management is not a one-size-fits-all goal (Cheraghi-Sohi et al., 2008; Nápoles, Gregorich, Santoyo-Olsson, O'Brien, & Stewart, 2009).

Electronic Health Information

Person-focused, comprehensive care is predicated in relationships and knowledge. One of the key elements that runs through system redesign for effective care is the clear need to exchange information and have conversations virtually and electronically, between people and their clinicians, among peers, between healthcare providers, and to gauge progress and outcomes across the system.

While opportunities are increasing for novel forms of virtual interactivity and new kinds of communities, there is a simultaneous attempt to grapple with the complex need for formal structures related to electronic health information. It is widely recognized that sharing of individual and population-based information is necessary for: clinical care, support, and self-management for individuals; population-health analyses and program planning; tracking and comparing the performance of healthcare practices; and contributing to the development of knowledge. At the same time, attempts to create effective, cost-manageable systems have proven to be difficult and complex.

Technological integration can support shared care, evidence-based decision making, and practice population tools that provide reminders for preventive care and follow-up monitoring—all critical requirements for successful care (see Appendix B for an outline of the Kaiser Permanente health information model as an exemplar of a comprehensive system, as well as research on implementation needs). Electronic decision-support systems improve patient outcomes and practitioner performance (Garg et al., 2005) as well as patient safety (Isaac et al., 2009). However, implementation of commercial systems has been less comprehensive and less successful than those that have been internally developed by leading integrated care institutions (Keshavjee et al., 2006; Mostashari, Tripathi, & Kendall, 2009).

Based on broad experiences with electronic health information over the past decade, the Expert Panel developed a schematic that illustrates how health information can be better used, particularly in primary care, to provide person-focused care for people with chronic conditions as well as for managing the healthcare practice in a population-based way (see Figure 3).

The schematic illustrates that three key types of electronic health information are needed:

- electronic health records;
- administrative information; and
- other data.

Each of these types of health information is described below, along with their unique interrelated functions and suggestions regarding access.

Electronic Health Records [2]

Comprehensive electronic health records capture key information for each individual in a clinical setting (e.g., active problem lists, relevant social history, access to recent investigation results, medications, and so on), with full functionality for registries, alerts, reminders, chronic disease management templates and decision supports, analyses, and report capacity (e.g., trends in blood pressure) for patient and population. The electronic health record also includes self-management tools, appointment scheduling, and bidirectional monitoring and communication capabilities that allow providers and people in the clinical setting to communicate.

Functions of electronic health records:

- The electronic health record fosters a more active role for people with chronic conditions through providing them with access to individual health information, lab test results, and diagnostic information and by providing tools for self-management of chronic conditions.

- Every clinical setting, including solo-physician practices, is nested within regional networks to enable automation of functions such as ordering and retrieval of lab test results, ordering of prescribed and dispensed medications, ordering of diagnostic imaging, emergency room admissions, hospital admissions and e-discharge summaries, and specialty and other health professional consults.

- The electronic health record allows all healthcare providers to access and tailor clinical decision supports to provide evidence-based care for their patients or clients.

- Together with administrative data, the electronic health record allows health providers to plan for and monitor changes and shifts among the practice population by: identifying all people within a clinical practice with chronic conditions and characterizing the practice population by socio-demographic, health conditions, service utilization and outcomes, and identification of providers who seem to achieve the best outcomes to encourage others to learn from them.

- The electronic health record contributes to the capacity to provide comparative analyses of care delivery and outcomes for populations with chronic conditions among practices as well as populations in the same practice over time.

- In aggregate form, the electronic health record contributes to research data and innovation through design, where higher performing practices share experience with moderate to lower performing practices.

Access to electronic health records:

- The electronic health record must be sensitive to people's openness to sharing their personal information; access to this information would need to adhere to the relevant laws and legislation for privacy and protection of information.

- The person and their caregiver have access to their own records and test and diagnostic results (with meaningful explanations as appropriate for the severity of the issue) through secure access over the Internet and can contribute relevant administrative information such as scheduling their appointments online, as well as clinical information needed to monitor important outcomes (e.g., glucose control, adverse effects with new medication), and receive feedback from the treatment team.

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[2] The term electronic medical record (or EMR) is frequently used for office-based systems that track individual histories and care; we have chosen to use electronic health record throughout our discussion for the information that incorporates office-based EMR but also can be shared with and used by other health professionals and other sectors, including hospitals, home care, and so on. This is consistent with Canada Infoway's description of the EMR as a building block for a broader electronic health record. The term "health" also serves to emphasize that primary care practices should consider broader health and not just medical needs.

- All health providers have access to the clinical information necessary to perform their functions.

- All practices provide and have access to their aggregated practice or clinical data (arising from individual electronic health records) to develop population-based knowledge about their practices.

- Practices provide aggregated information arising from electronic health records to researchers and primary care quality networks to improve practices across the system.

Administrative Information

Administrative information includes: (a) practice administration (scheduling, billing, and integrated computer generated decision support reminders); (b) information exchange and communication functions (payers and other stakeholders); and (c) population characteristics, evidence support and practice-based computer-generated decision-support reminders (e.g., due dates for mammography screening) through centrally held data (e.g., billing data, such as Ontario's Institute for Clinical Evaluative Sciences, Québec's Régie de l'assurance maladie du Québéc, BC PharmaNet, or the Manitoba Centre drug utilization database, the Ontario Drug Benefit database, and other information such as the Canadian Institute for Health Information Discharge Abstract database).

Functions of administrative information:

- In addition to functions outlined under the electronic health record, these data contribute to the assessment of practice and system performance by providing comparative data for similar populations.

Access to administrative information:

- Practice-specific administrative data are available only to the individual practice and to the designated regional health or government authorities that evaluate performance assessment.

- Aggregated administrative data should be available for the purposes of research and quality improvement.

Other Data

Other data include treatment guidelines, healthcare provider characteristic data, geographic information systems data, links to health information databases (e.g., patient-reported outcome measures, Canadian Community Health Survey, provider surveys), demographic information about the practice, linkages with other health and social services in the community, and other population-based demographic data.

Functions of other data:

- Other data contribute to health improvement across communities through linkages with other health and social services in the community and employers or private sector initiatives.

Access to other data:

- Practices have access as determined by holders of data, and practices make decisions about which community partners with whom to link with and how linkages will occur.
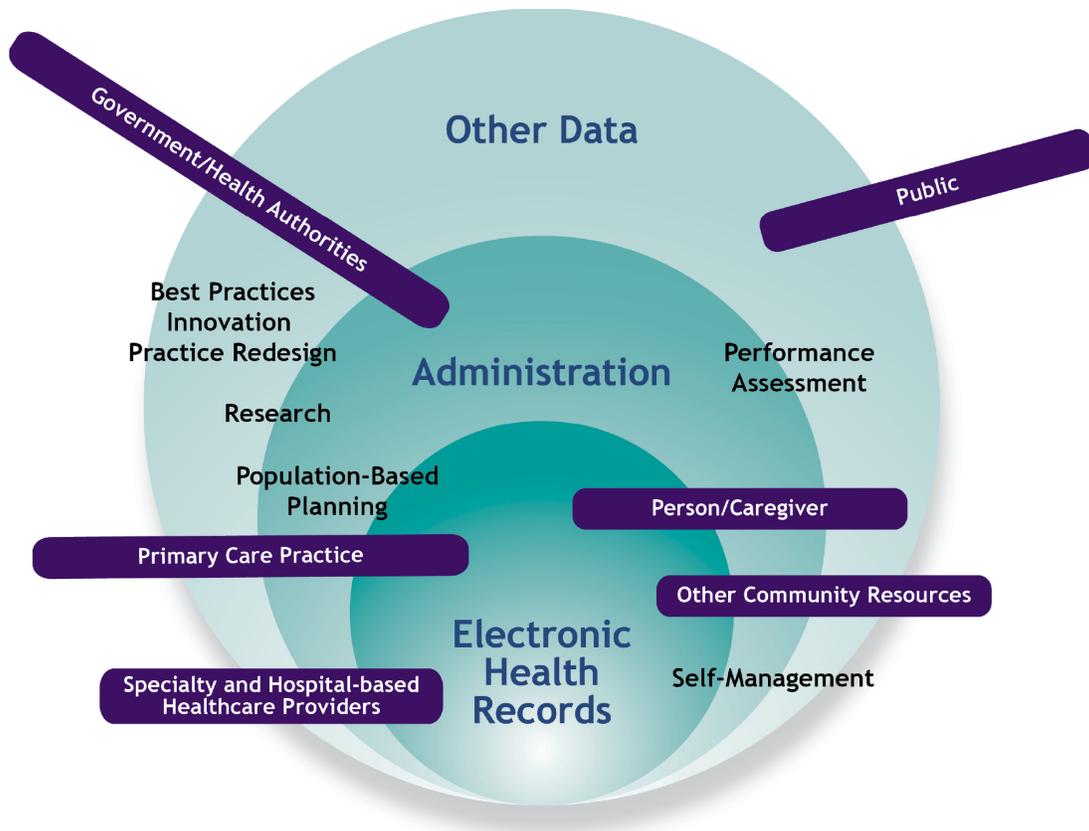
Figure 3: Types of Health Information with Corresponding Functions and Groups Benefiting From Access

Overall, the different pools of information are used to inform population-based planning, individual care plans, performance assessment, practice redesign, and research. In many cases the aggregated results of analyses could be disseminated. For example, aggregated electronic health record, administration and other data could be used for public reporting of particular indices of system performance.

Practice Redesign
(Guidelines, Performance Assessment, and Remuneration)

The chronic care models indicate that changing outcomes requires "fundamental practice change" (Improving Chronic Illness Care, 2007, p. 8) with components in six areas: influencing healthcare provider behaviour, better use of all healthcare team members, enhancements to information systems, planned encounters, modern self-management support, and care management for high-risk patients (Improving Chronic Illness Care, 2007). In addition to the roles for health providers and the critical nature of information systems, there are three other key areas for practice redesign: ensuring that evidence-based treatment guidelines account for multiple conditions, performance assessment, and remuneration.

Evidence-Based Guidelines and Multimorbidity

The comprehensive chronic care models based on Wagner's (1998) model are firmly rooted in evidence-based clinical guidelines, in a context that allows healthcare providers to spend enough time with people with chronic conditions to interpret guidelines for each context and to support people in decision-making and integrating changes into their daily lives.

The development of evidence-based clinical guidelines has contributed to improved quality of care in many contexts. At the same time, the limits of clinical guidelines are increasingly recognized, particularly in the settings of chronic multimorbidities.

The focus on single or comorbid conditions rather than on multimorbidity can lead to contradictions in treatment recommendations and the need for clinicians to try to reconcile this conflicting information. This is challenging when "primary care providers with reasonably sized practices would scarcely have sufficient time in clinic to adhere to [guidelines] for the 10 most common chronic conditions if those conditions were stable" (Upshur, 2010, p. 520) let alone poorly controlled conditions or comorbidities.

Although some interpretation and utilization of clinical guidelines is essential, it is necessary but challenging to capture the full reality of people's lives and experiences with chronic conditions. The "typical patient" developed by Boyd et al. (2005) illustrates the complexities of decision-making for people with multiple conditions. They estimated that for a hypothetical 79-year-old woman with chronic obstructive pulmonary disease, type 2 diabetes, hypertension, osteoarthritis, and osteoporosis, 19 doses of 12 different medications, taken five times throughout a day, every day, would be required.

Stange (2009a) noted that most scientific evidence "explicitly excludes people with comorbid conditions" (p. 390). Partly for this reason, research is often not well translated into practice. There is work underway in the U.S. to expand the "research pipeline" (Kleinman & Mold, 2009, p. 312) model used by the National Institutes of Health to emphasize and enhance funding for and the value of practice- and community-based research and guidelines that would be contextualized and inclusive of people with comorbidities.

Performance Assessment

A culture of accountability is needed in which primary care providers from all health professions recognize the importance of measuring their performance, compare their performance to their peers', and change their behaviour. However, given the nature of primary care and the patients that are followed, there are several challenges inherent in trying to optimize care. These include having access to the right data, being able to analyse and compare between providers and the right outcomes, and ultimately changing practice.

Mangin (2010) and Starfield (2010) noted that what is currently measured does not always lead to meaningful difference in patients' lives, and that patient-centred care includes implied values that may conflict with clinical practice guidelines. Health funders and administrators, these authors argued, often view guidelines as proxies for quality, but guideline-driven care may not always be in the best interests of patients when the broader health context is considered and desired outcomes become more than target laboratory values. Indeed, guideline-driven care may not be fully possible. For example, Yarnall, Pollak, Østbye, Krause, and Michener (2003) estimated that to satisfy the clinical practice guidelines of the U.S. Preventive Services Task Force, a clinician would have to spend 7.4 hours each day providing the recommended preventive services for a practice of 2,500 patients.

Upshur, VanDenKerkhof, and Goel (2001) argued that evidence-based practice tends to focus on the quantitative and the individual, rather than on the more general and qualitative approaches. This paradigm sets up obvious limits around guiding and evaluating population-based knowledge and care that is meaningful to the full person, rather than focused on specific disease states. Starfield (2010) argued that evaluations for the quality of primary care should address achievement of primary care features, such as comprehensiveness, coordination, and longitudinality (see Figure B7 found in Appendix B), and not be limited to diagnosis and management of specific diseases.

The current trend in Canada is to create evidence-based benchmarks or established targets for primary care that are still largely based on single disease indicators. Johnston, Dahrouge, and Hogg (2008) provided examples of performance indicators for primary care such as "proportion of diabetics with a primary care provider. . . with [glycosylated hemoglobin] HbA1c testing in the past 12 [months and]. . . with HbA1c level at below or target value" (p. 1215). Even in this context, however, the need to develop indicators that capture more comprehensive quality is clear since "there are many aspects of day-to-day primary care that are not accurately captured in billing data" (Johnston et al., 2008, p. 1216). For example, Rowan, Hogg, Labrecque, Kristjansson, and Dahrouge (2008) developed a logic model that provides a more comprehensive approach to measuring care for people with chronic conditions within primary care, where the long-term outcomes take into account health of the patient, improvement of the population, function of the practice, and cost. Guidelines, benchmarks, and targets must also take into account patients' life expectancy, the likelihood of achieving any benefit, and patients' preferences.

Realignment of Health Provider Remuneration

Another critical element for practice redesign is to ensure that remuneration for all health professionals permits the time and relationships needed for integrated, person-focused care. Currently, remuneration and funding models in Canada reinforce the fragmentation of the system, particularly through the influence of single disease advocacy groups that support health promotion and research, governance that separates acute and primary care, and the payment system that drives short office visits that limit patients to discussions of one issue only at a visit. Additionally, the continuum of care includes health and healthcare services viewed as being outside the established publicly insured system. These services include public health, home care, long-term care, pharmacare, and mental health services.

The current remuneration agreements do not acknowledge the comprehensive and coordinated approach to care needed to address the complexity of life and health for people living with chronic conditions. For example, physician payer models that code one disease or issue at a time (i.e., fee for service) neither account for the complexity of most people's conditions nor provide for the conversational and relationship time that comprehensive, person-centred models call for (Canadian Health Services Research Foundation, 2010). These models also create unintended incentives that promote dependency rather than self-management.

Globally, there are several initiatives that can be drawn on for insight into system resource allocation. Australia and the U.K., for example, have introduced funding initiatives that support improved management of chronic disease, including practice incentives and system redesign (Harris & Zwar, 2007; Nolte & McKee, 2008). The U.K., in particular, has undertaken radical healthcare system reforms in the National Health Service, including decreasing control from the centre, giving patients more choice, and creating primary care trusts that encourage the implementation of prevention-oriented investments (Dixon, 2007). In addition, these reforms are expected to release annual savings of up to £2.7 billion by enabling better management of care (Department of Health, 2009).

Common themes to system reform include the revamping of primary care models, incentives that foster proactive behaviour, and coordinated action on multiple diseases. The overarching questions appear to be about how to identify and incent the optimal roles and responsibilities of individuals, health and other practitioners, professional associations, public and private organizations, and governments at different levels (Catford, 2009).

A recent Ontario economic report called for a shift in the way physicians are compensated, away from fee-for-service towards a blended per capita salary and volume structure (Drummond & Burleton, 2010). These authors noted that the shift to collaborative, team-based care is a promising move toward "a more cohesive health care system and would move the system towards aligning the incentives of physicians with those of the rest of the health care system" (pp. 27–28). Drummond and Burleton argued for further incentives to be put in place through payment mechanisms to reward effective practice, increased number of patients, and so on.

An extensive literature review of innovative models for comprehensive primary care delivery suggests that more flexible funding arrangements for family physicians are required, including funding team-based practices rather than individual physicians, and offering a variety of funding mechanisms for general practices, to accommodate variations in physician working styles (Naccarella et al., 2006). Naccarella et al. recommended that new funding arrangements be developed between general practices and regional health authorities (rather than with the provincial or federal government) to allow for local flexibility in service delivery and enhancement of the capacity of the system to directly plan for and effectively address regional needs.

In a subsequent discussion paper, Young, Gunn, and Naccarella (2008) concluded that the international evidence base for economic incentives and payment systems as they relate to preventive healthcare is underdeveloped and limited mostly to descriptive rather than evaluative or experimental studies. Nevertheless, international evidence suggests that healthcare systems oriented towards lower cost primary care, rather than higher cost hospital care, achieve better health and well-being outcomes (Young et al., 2008). Within primary care, there is little empirical evidence to support any particular mix of payment systems in meeting health policy or health outcome objectives. There are a large number of studies of the impact of specific financial incentives on healthcare provider (mostly physician) behaviour, but few of these studies have been done using rigorous methods. However, based on the existing literature, Young et al. recommended that the creation of any new economic incentive and payment system for supporting prevention in primary care should be based on a number of systemic, evidence-based, performance-focused principles. In the context of comprehensive, person-focused care, these principles are inherently limited, in that they focus only on physicians, do not account for the challenges of using single disease clinical guidelines in the context of multiple conditions, and focus on measuring preventive healthcare, not more comprehensive outcomes.

While the research is still emerging, it is clear that a payment system for all healthcare providers—not just physicians—that blends elements of capitation, quality, salary, infrastructure, and fee-for-service promises to drive person-focused care.

Continued Practice Redesign, Improvement, and Learning

Practicing with a complex understanding of chronic conditions requires a paradigm shift of focusing on the person in the context of that person's family or living situation and community. This requires a modification in provider behaviour, values, and beliefs about how providers think about chronic conditions and life course history, in skills at supporting self-management (Lorig et al., 2008), and in skills at case management (Hutt, Rosen, & McCauley, 2004), along with regarding the individual patient in the context of population issues. This reorientation also requires the ability to be comfortable with uncertainty, while still knowing that there are certain givens, such as the next patient arriving soon. While many family practitioners and other providers are already practicing this way, this is still an emerging standard of care.

As the healthcare system is renewed to support people with chronic conditions in Canada, a commensurate shift in both pre- and post-licensure education is required. The Romanow Report (2002) stated:

> **In view of. . . changing trends, corresponding changes must be made in the way health care providers are educated and trained… If health care providers are expected to work together and share expertise in a team environment, it makes sense that their education and training should prepare them for this type of working arrangement.** (p. 109)

In this context, health professional education, both pre- and post-licensure, requires some changes, including developing skills at teamwork, deepening capacity to partner with patients and families to determine the best course of action in their context, and positioning population-based thinking as central. Case management is also beginning to emerge as a key practice.

Two existing and promising approaches to developing practitioners' capacity to work in new ways include the movement toward interprofessional education and care and the emergence of collaboratives to share developing ideas and practices.

Interprofessional pre- and post-licensure education has begun to be established in Canada and the U.S. to build system capacity to work in more flexible, multiperspective ways, by including interprofessional learning in student theory and practice as well as professional development in interprofessional collaboration among practitioners (Reeves et al., 2009).

Collaborative learning models have been established for practitioners to develop new skills in comprehensive care across disciplines and diseases. The MacColl Institute and the Institute for Healthcare Improvement in the U.S. are two of the leaders in this model, where front-line practitioners, researchers, and successful innovators conduct intensive discussion on a focused topic area while practitioners work on improvements within the local organization.

Another innovative aspect of collaborative learning is the ability to spread innovation that developed within practices. One such model follows a pattern where practice innovators are supported to become learning sites and mentors for other practices, such as in Jönköping, Sweden, where the innovative operational leaders in comprehensive care have been established as a formal learning site for the rest of the country (Andersson-Gäre & Neuhauser, 2007; Baker et al., 2008).

The experience in the U.S. with collaboratives shows promise for shared learning and knowledge transfer, as do some of the emerging opportunities in Canada, such as the Canadian Interprofessional Health Collaborative's facilitation of knowledge transfer across the system.

Summary

To create person-focused, comprehensive care for people living with chronic conditions, the healthcare system needs to:

- enable long-term relationships between patients and providers;
- create accessible and meaningful knowledge about both individuals and populations served by individual practices;
- offer opportunities for more interactive types of conversations and community-building, electronic and otherwise;
- develop guidelines for care and compensation that account for multimorbidity;
- remunerate healthcare providers through a blend of capitation, salary, fee-for-service, and compensation for quality; and
- allow for adequate time and skills within provider visits to understand the patient's current life context and capacity for self-management.

A critical factor in enabling these elements is the reshaping and strengthening of team-based primary care as the hub for person-focused care, with strong interfaces across the continuum of care. Practice redesign, including supports for self-management, requires modernization of health information systems and an increasing openness on the part of providers to interact in novel ways. As part of this reshaping, clinical guidelines, quality assurance, evaluation, health professional education, and ongoing learning need to be transformed to enable comprehensive, person-focused care.

This report can be framed as transforming the healthcare system to enable person-focused care for people living with chronic conditions. In the next chapter, we examine the current state of the Canadian healthcare system to determine what needs to be done to incorporate integrated approaches to care for chronic conditions in a meaningful, achievable way.

CHAPTER 4
HOW IS CANADA DOING?

The prevalence of people living with multiple chronic conditions is rising, and the nature of the conditions is increasingly complex. The Canadian healthcare system is designed for acute care focused on a single disease. As such, it does not meet the needs of people with multiple and complex chronic conditions. Global research indicates that Canada is lagging behind other countries in performance and infrastructure to support people living with multiple chronic conditions. This is particularly true in the primary care sector (McMurchy, 2009). A recent survey found that 40 per cent of Canadians with a chronic condition reported not having made a treatment plan with their provider within the last 12 months, and 40 per cent of people with three or more chronic conditions reported that they were rarely or never counselled about what to do to improve their health (Canadian Institute for Health Information, 2009).

> **If we were building a health care system today from scratch, it would be structured much differently from the one we now have and might be less expensive. The system would rely less on hospitals and doctors and would provide a broader range of community-based services, delivered by multidisciplinary teams with a much stronger emphasis on prevention. We would also have much better information linking interventions and health outcomes.** (National Forum on Health, 1997a, Straight Talk About Health Care Reform, para. 8)

Chapter 3 outlined the argument in favour of person-focused, integrated approaches to care delivery for people living with chronic conditions, centred in primary care, with strong interfaces across the continuum of care. The obvious question is: how is Canada doing in relation to this ideal?

This chapter provides a high-level review of Canada's current performance in integrated, person-focused healthcare provision for people with chronic conditions. The emphasis is on innovation and performance in relation to comprehensive, multiple-condition issues, not on single disease outcomes. The focus is also on highlighting some of the pockets where activity already exists that move Canada toward the ideal. This approach is aligned with a complex adaptive systems approach to transformation of identifying existing innovative sites, and then determining how to learn from or expand them, (i.e., "fanning the flames") or linking them together to spread momentum across the country.

Areas Where Canada is Lagging Behind

Despite our cultural and financial commitment to healthcare, Canada is lagging behind other countries in performance and infrastructure needed to support people living with multiple chronic conditions, particularly in the critical primary care sector. In a review of primary care experience in Canada, McMurchy (2009) argued,

> **Canada's primary care sector lags behind other countries with similar wealth and healthcare systems, most notably in after-hours care, wait times, chronic disease management, mental health, quality improvement and electronic medical records. Moreover, Canada's primary care sectors are characterized by fragmentation, ineffective use of providers, and inefficient use of resources.** (p. 1)

As described in Chapter 3, access to effective primary care is a critical element of caring for people with chronic conditions. Effective primary care in this context is the provision of first contact, person-focused, ongoing care over time that meets health-related needs and coordinates care when people receive services at other levels of care.

A recent study by Nie, Wang, Tracy, Moineddin, and Upshur (2008) suggested that seniors in Ontario have about 70 points of contact with the healthcare system every year (i.e., family physician visits, specialist physician visits, emergency department visits, drugs, lab claims, X-rays, inpatient admissions, computed tomography scans, and MRI scans). This translates into some form of health service every five days and does not account for the number of contacts they may need to make to arrange for these points of contacts (e.g., phone calls to schedule and prescription drop off and pick up). Clearly, seniors and other Canadians with a high need for support require access to primary care to help them coordinate the care provided by other aspects of the healthcare system.

As McMurchy (2009) noted, while people living with chronic conditions need frequent access to healthcare, Canadians face limited access to primary care:

- A recent Statistics Canada report (as cited in Scobie et al., 2009) revealed that, in 2007, 15 per cent of Canadians aged 12 or older did not have a regular medical doctor. This translates into 4.3 million Canadians whose health is not being monitored and who apparently do not have a clear place to reach out for healthcare.

- A total of 40 per cent of Canadians do not have access to after-hours care from their regular healthcare provider (Schoen et al., 2007), and 34 per cent of primary care physicians report that they do not provide these services (Schoen, Osborn, Huynh, & Doty, 2006).

- Of the adult population, 16 per cent reported going to the emergency department for a condition that could have been treated by a primary care practice, and 45 per cent of those with a chronic illness reported visiting the emergency department in the past two years, the highest rates among the eight study countries, i.e., Australia, France, Germany, New Zealand, Netherlands, U.S., and the U.K. (Schoen, Osborn, How, Doty, & Peugh, 2008).

- Among the eight Commonwealth Fund countries, wait times for accessing specialists was longest in Canada, New Zealand, and U.K. (Schoen et al., 2008), and 22 per cent of Canadians reported that they were able to schedule an appointment to see their regular doctor on the same day they called, the lowest rate among the countries studied (Schoen et al., 2007). In the same study, Canadians generally reported the greatest delay in getting to see a doctor.

A study of eight Commonwealth Fund countries revealed that Canada's training in quality improvement lags behind several comparable countries:

- Canada reported the lowest rates for training in quality improvement methods and tools among primary care physicians (44 per cent), and was least likely to have set formal targets for clinical performance or to have data available on clinical outcomes (Schoen et al., 2006).

- Of Canadian primary care physicians, 45 per cent had conducted a clinical audit of patient care in the previous two years compared with 76 per cent, 82 per cent, and 96 per cent of those in Australia, New Zealand, and the U.K., respectively, and 11 per cent said that they routinely receive data about patients' experiences and satisfaction, again the lowest rate in the countries studied (Schoen et al., 2006).

Against this backdrop of comparatively lower focus on quality improvement, Canadians are also reporting errors and ineffective practices across the spectrum of primary care. One in five patients in Canada reported a time when pharmacists told them that the drug they were about to fill could be harmful because of medications they were already taking; laboratory and diagnostic test errors were also of concern with higher test-error rates and delays in hearing about abnormal test results (Schoen et al., 2008). In Canada, and in the other countries participating in the Commonwealth Fund study, the majority of patients said that their medication, laboratory, and test-error mistakes occurred outside the hospital—the likelihood of error increased with complexity—and the percentage of reported errors doubled or more among patients seeing four or more physicians compared to only one or two (Schoen et al., 2008). Finally, 17–18 per cent of hospitalized chronically ill patients in Canada said that they were readmitted to the hospital or went to the emergency room as a result of complications—this is double the rate in France and Germany (Schoen et al., 2008).

In 2009, the Health Council of Canada noted, "In recent Canadian research, primary health care that is consistent, accessible, and well coordinated was associated with fewer medical errors" (Health Council of Canada, 2009b, p. 8). The high rate of errors is a strong indicator that primary healthcare in Canada is neither comprehensive nor coordinated. This issue will continue to be compounded as the population ages.

Approximately half of the physicians in Canada work in primary care. Up until very recently, most of these physicians have not been formally connected with each other, nor have they been connected to other aspects of care. Primary care is a critical element in care and support for people living with chronic conditions, and it is a hub for the other critical elements of the system. And yet it is fragmented from most aspects of community, acute, and specialty care.

Community-based health-related services, such as exercise and peer-support programs, are an important part of wellness and self-management for people with chronic conditions. However, there is a general lack of integration between primary care and community medicine. According to a recent study, community medicine providers rarely provide health promotion services when engaged in clinical practice, and family practitioners rarely practice community-oriented primary care, despite their training (Russell & McIntyre, 2009). There are small pockets of movement to create the infrastructure for population-based medicine through rostered group practices in some provinces, but overall this is in its infancy.

As noted earlier, Canadians wait longer than any of the other Commonwealth Fund studied countries for access to specialty care (Schoen et al., 2007). This underlines once more the critical role of generalist primary care, which needs to support patients who are waiting for access to specialty care (College of Family Physicians of Canada & Canadian Medical Association, 2009).

From the patient perspective, there is no such thing as primary care, acute care, specialty care, or community care—there is simply healthcare. A functioning healthcare system needs to operate just as seamlessly.

The current capacity for the Canadian healthcare system to meet the needs of people living with chronic conditions is limited. By and large, the research, education, and delivery systems are structured to support continued action on single disease strategies and approaches. In 2006, Haydon and associates noted that chronic disease prevention in Canada is characterized by "disjuncture in and repetition of activities, with little infrastructure, minimal evaluation, and relatively poor communication of best practices" (Haydon, Roerecke, Giesbrecht, Rehm, & Kobus-Matthews, 2006, p. 18), with "innumerable programs" (p. 18) related to chronic disease prevention. Beyond prevention, our current system does not easily allow for and incorporate the kinds of assessment, support, and education that are sometimes called soft skills and that take time. For example, when asked, 51 per cent of Canadian adults with a chronic condition described a relationship that included knowledge of the patient's medical history, easy phone access, and help in coordinating care (Schoen et al., 2007); this relationship is not easily achieved within the current performance framework.

What Canada Can Build On: Islands of Innovation

The current overall performance of Canada's healthcare system in the key areas outlined in the previous pages needs to be considered in light of the existing points of innovation in Canada. Across the country, there are many promising and sometimes isolated initiatives or "islands of innovation" that move in the direction of integrated, comprehensive care.

For example, in 2004, "governments agreed to 50 per cent of Canadians having 24/7 access to multidisciplinary teams by 2011" (Health Council of Canada, 2009c, p. 51). The largest provinces—Alberta, British Columbia, Ontario, and Québec—have invested in substantial provincial initiatives aimed at integrated, population-based, person-focused, and team-based primary care, but these are not the mainstream for the population. For example, teams now serve 25 per cent of the target population in British Columbia, and 19 per cent of primary care physicians in Ontario work in interdisciplinary models of care (Health Council of Canada, 2009c). Primary care teams are being introduced across the country, but with limited penetration.

These new models for primary care are key areas of some innovation. Other areas where there is innovation include: new comprehensive approaches to care for people with chronic conditions; new models for primary care; improving interfaces across the care continuum; community and health partnerships; expanded scope and roles for professionals; quality improvement and learning networks; new approaches to manage electronic health information and virtual communication; increased support for self-management; and new types of pharmacare programs. This list is by no means comprehensive, but illustrates that there are many areas where there are clusters of initiatives that are striving to improve health outcomes of people with chronic conditions.

Figure 4 illustrates how these areas of innovation across Canada are reaching out to people with chronic conditions and their family and friend caregivers, but are not connected to each other in a concerted effort to move the country toward population-based, person-focused, integrated, interprofessional care.
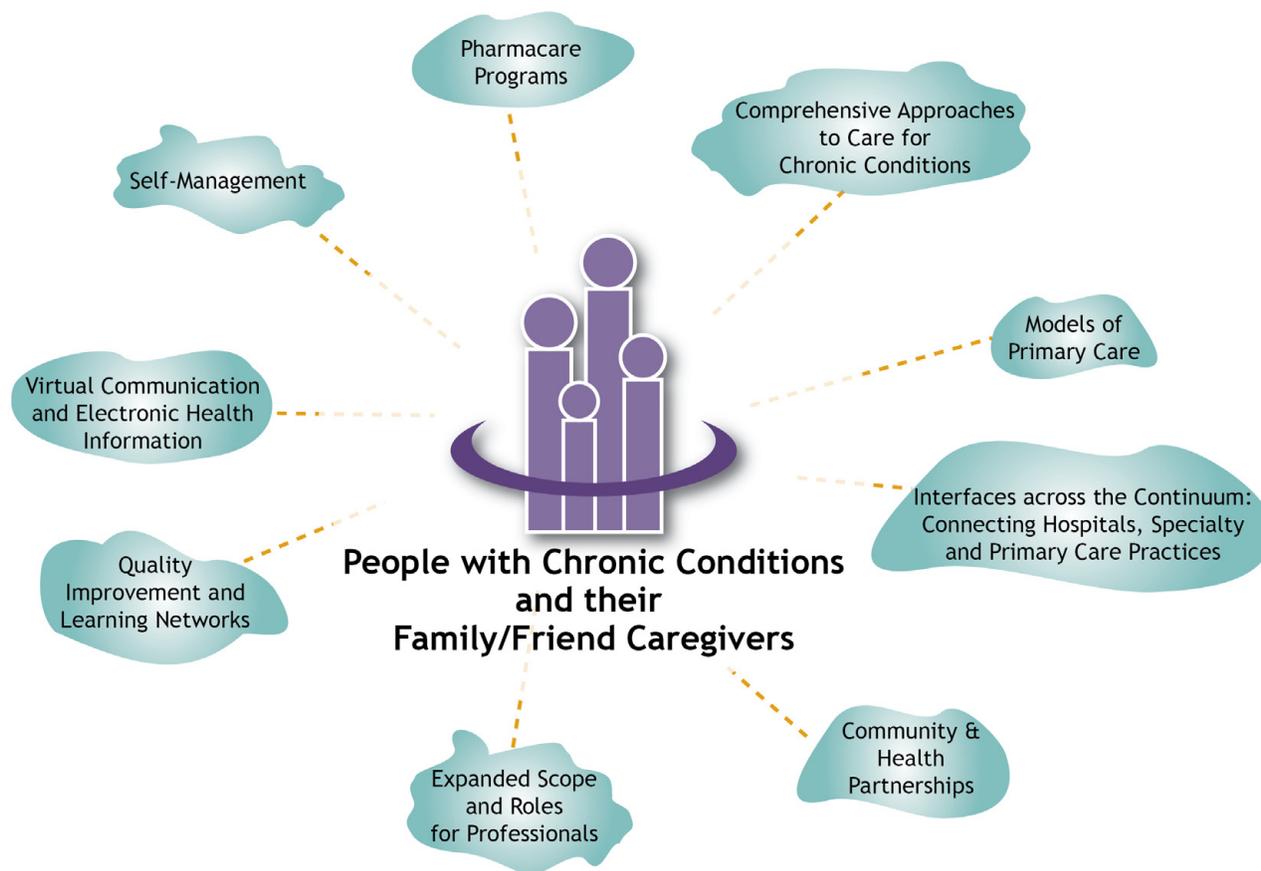
Figure 4: An Opportunity: Building on Areas Where There is Innovation

When contemplating changing the healthcare system, it is important to recognize that healthcare in Canada is a complex adaptive system, achieved not from one central control mechanism, but rather functioning and changing through a complex network of federal, provincial, territorial, regional, and municipal policies and structures, research, and other evidence about improving practice, shared learning across professions and other groups, organizational frameworks, and on-the-ground adaptations. Complex systems, such as in healthcare, change, evolve, and grow through multiple parallel or divergent initiatives, responses, and changes.

Transformation of complex systems is best achieved by building on existing infrastructures and natural networks so that promising ideas and actions will spread (Westley, Zimmerman, & Patton, 2006). Another critical element of transformation is involving providers and people with chronic conditions themselves in system redesign; the involvement of key users (patients and clinicians) in the design and implementation creates greater likelihood of shared ownership and fundamental behaviour changes (Maher, Gustafson, & Evans, 2007).

Based on this understanding, enhancing the Canadian healthcare system through low-cost and feasible actions is best achieved by "fanning the flames" of existing innovations, by building on, linking, and learning from them. Appendix C details many of the innovations in each of these areas that can be used as prototypes, strengthened, and drawn on to expand the impact within their provinces or area of origin or even beyond these boundaries. Chapters 6 and 7 provide concrete recommendations and strategies for building on the areas that are already poised to continue leading the country. To support these recommendations, it is important to first highlight the current state of four key enablers:

- pharmacare;
- electronic health information and communication;
- quality and accountability; and
- learning and education.

Pharmacare Reform

The rising cost of prescription drugs is significantly straining government health budgets, with drug plan expenditure squeezing out other health department priorities, and overall health budget growth crowding out other government priorities including education and public infrastructure (Bell et al., 2010). Many Canadians struggle to pay for their medications, an added stress when they may already be vulnerable because of illness or unemployment.

In 2004, the National Pharmaceuticals Strategy was established as part of the 2004 First Ministers' Health Accord, to "develop nationwide solutions to some of the concerns about the safety and affordability of prescription medications in Canada" (Health Council of Canada, 2009a, p. 1). The strategy was also intended to alleviate the "patchwork of different initiatives across the country" (p. 1).

Highlights of the strategy include:

- developing options for catastrophic drug coverage to ensure that Canadians do not face undue financial hardship to pay for prescription medications they need, regardless of where they live. (*Catastrophic* refers to the impact on a person's finances, not to his or her medical condition);
- finding ways to reduce the costs of prescription medications to governments and individual Canadians;
- improving patient safety by helping healthcare professionals provide the most appropriate and safest prescriptions for their patients and by implementing electronic prescribing to reduce medication errors;
- improving the way medications are monitored after they are released onto the Canadian market to protect patients from unanticipated side effects;
- ensuring that all Canadians have access to the same prescription drugs through their government drug plans, based on a common national drug formulary; and
- providing faster access to new emerging drugs for unmet health needs.

This strategy is a complex one, and the Health Council of Canada (2009a) noted,

> **"Making the necessary changes to our highly complex pharmaceutical system. . . requires exceptional cooperation among the provincial, territorial, and federal governments to resolve complicated issues of regulations, ethics, and financing"** (p. 29).

At the same time, the pharmaceutical strategy offers a promising model for coordinated effort on a critical national question.

As part of this strategy, Bell et al. (2010) conducted a comprehensive review of generic drug pricing that identified six critical success factors that can "improve affordability, accessibility, and sustainability" (p. 5) for pharmacare:

- effective pricing strategies—particularly reimbursement for generics;
- appropriate and efficient use of generics;
- alternative drug distribution channels;
- diverse offering of pharmacy services—including pharmacists working to full scope to provide some nondispensing services, such as diabetes care and smoking cessation;
- high consumer involvement—particularly in drug-purchasing decisions to foster competition on price; and
- optimal government involvement—to balance their multiple roles as regulators, price setters, and purchasers.

Electronic Health Information

Every one of the comprehensive models for care for people with chronic conditions stresses the criticality of being able to capture and share detailed patient information, as well as to foster more opportunities for communication among providers and between providers and people with chronic conditions. Information needs to be available across providers, for population-based service planning, for decision-support with clients, and for clients to be able to assume an active role in their own care.

On the question of availability of health information, Canada again ranks lowest on the list of countries studied by the Commonwealth Fund, with patient records or information either "often" or "sometimes" unavailable to physicians at the time of a scheduled visit 41 per cent of the time (Schoen et al., 2006). Only 37 per cent of primary care physicians in Canada use electronic health records, compared to 95 per cent or more of the primary care physicians in Australia, the Netherlands, New Zealand, and the U.K. (Schoen et al., 2009). Finally, only 15 per cent of patients in Canada can communicate with their physicians online, again the lowest among the eight countries studied by the Commonwealth Fund—others range from 22 per cent in France to 35 per cent in the Netherlands (Schoen et al., 2006).

Across Canada, provincial and territorial governments have made assertive commitments to using electronic health information, but implementation has been problematic. A recent article in the *Canadian Medical Association Journal* observed that "ten years after the federal government agreed to build a national 'infostructure' for electronic health records. . . confusion and disarray appear to be the only form of national standards in operation within health information record-keeping circles" (Webster, 2010, p. 888). The same article noted the Auditor General's concern that the lack of national standards or a single "national marketplace" (p. 888) for health information products have led to a situation where provinces continue to create separate standards that oblige national vendors to conform to local specifics instead of pan-Canadian standards.

In a recent review of the implementation experience of electronic health records in Canada, Keshavjee (2009) found that Canada has "poor" (p. 16) rollout experience, even after 10 years of effort, and has spent "tens of millions" (p. 16) of dollars with "little to show for it" (p. 16). Using an electronic health record implementation policy framework for analysis (Keshavjee et al., 2006), Keshavjee (2009) analyzed the

experiences of Alberta, British Columbia, and Ontario, and found that only Alberta had applied best practices for implementation but then had only implemented half of those practices. The analysis found that, for the most part, implementers had not engaged provider users and none of the provinces had engaged key medical players or patients and patient advocacy groups. While some practice and management implementation funding had been provided in Alberta, it was insufficient, and absent altogether in the other provinces. The only consistent factor of the implementation was training, but other critical change management support was largely missing.

The experience to date with electronic health records strongly points to the fact that the focus for future work needs to be coordinated with forward-thinking implementation in mind, rather than developing new technologies.

Despite the overall low penetration of electronic health information, there are a few "bright lights" in Canada where electronic health records have been successfully implemented. Three of the most innovative include MyOSCAR, the Mydoctor.ca health portal, and MiHealth in the Bluesky family health team in Ontario (see Appendix C for details). These are enhancements to existing electronic health records that demonstrate the opportunities for an activated population (i.e., people with chronic conditions and their caregivers who are able to access information and make decisions about their own care and to act as real partners with their healthcare providers).

These types of technology and other innovations also streamline practice management for providers. Ultimately, the goals of these patient-focused types of electronic health records are for appointment scheduling and feedback about test results using the technology, and for augmenting decision-support systems when providers can effectively alert patients about a need for follow-up on an abnormal test result or screening (e.g., Papanicolaou test, mammograms, fecal occult blood). Additionally, providers have an audit trail and legal record showing exactly what was said (e.g., when an e-mail was opened).

Quality and Accountability

There is general agreement that improving the experience for people living with chronic conditions requires a healthcare system that incorporates clinical practice guidelines that can be used and speak to the comorbidity and multimorbidity issues, health indicators that are relevant to primary care, and accountability across sectors. Clearly information systems and a defined patient population for which the primary care practice is responsible are a core part of being able to track information and monitor movement and performance. Chapter 3 outlined some of the suggested frameworks for quality assurance in a person-focused, integrated approach to care for chronic conditions that would need to be built into any information management and clinical guidelines systems, as well as some possible logic models for more comprehensive assessment of the performance of primary care practices.

One of the significant enablers for improving quality on any of these factors is to improve the accountability system. A recent Ontario White Paper (Ontario Health Quality Council & Ontario Joint Policy and Planning Committee, 2008) suggested the implementation of an "indicator cascade" (p. 15) to align accountability across different levels of the system (see Appendix C for details).

Like the integrated models for care for people with chronic conditions, integrated approaches to plan, evaluate, and learn what works are beginning to emerge in other pockets of healthcare management. These approaches underline that measuring performance needs to be primarily about viewing the full system, how it works together, and how it serves Canadians in a holistic way.

Learning, Education, and Training

As the healthcare system is renewed to support people with chronic conditions in Canada, we require a commensurate shift in both pre- and post-licensure education. Health professionals need to be able to practice in an interprofessional way; plan and deliver population-focused care; improve quality from a systemic, holistic view; integrate care with other aspects of the system; support self-management; and counsel clients in a way that is focused on the person, not the disease. As the experience with interprofessional education and care in Ontario demonstrates, both pre- and post-licensure education must be done in tandem. Learners and new practitioners need to develop their practices in a clinical structure that enables them to work in new ways (HealthForceOntario, 2007).

The Government of Canada invested $20 million from 2003–2009 to support interprofessional education across the country (Health Canada, 2003), which resulted in 20 projects based primarily in universities. Further investments have supported a national project, *Accrediting Interprofessional Health Education*, which brings eight health education accrediting bodies representing six professions to develop standards for interprofessional education (Accreditation of Interprofessional Health Education, n.d.). The Association of Faculties of Medicine of Canada (n.d.) has led the Future of Medical Education in Canada project that has a clear recommendation on the need to educate medical students in intra- and interprofessional collaborative practice, using a population-based approach, focusing on generalism. The recommendations from this report apply equally to other health professional education programs.

In addition to professional education and development, creating a system that enables practitioners and researchers to learn collaboratively and share information across sites and provincial boundaries will be critical. Such learning can be created in institutional models such as the Institute for Healthcare Improvement in the U.S., and more organic learning models, such as the municipality of Jönköping, Sweden (Baker et al., 2008), which has developed a centralized quality learning centre for the country as a whole out of its own local improvements.

In Canada, learning networks have been established in recent years, including the Saskatchewan Chronic Disease Management Collaborative, learning collaboratives in Alberta and British Columbia, IMPACT BC, the Western Canadian Interprofessional Health Collaborative, and the Quality Improvement and Innovation Partnership in Ontario (see Appendix C). These bodies form a strong initial network that can be tapped into to enhance, share, and build on the islands of innovation already underway in Canada.

Summary

Currently, we have a healthcare system that is oriented toward the provision of acute care, functioning well on single focus health issues, but ill suited to the management of multimorbidity and chronic conditions. When Canada is viewed strictly from a report-card perspective on some of the indicators related to relevant healthcare system improvements, we are clearly lagging behind similar countries. At the same time, when a complex adaptive systems approach is taken, there are many points across the country where current practice and innovation are already in place that can be linked, enhanced, expanded, and learned from to improve care. In a decentralized, idiosyncratic country like Canada, there is no single, correct comprehensive approach—the key is to begin somewhere and to enhance and expand the aligned work already underway.

PART 2:
IMPROVING HEALTH OUTCOMES
FOR PEOPLE WITH
CHRONIC HEALTH CONDITIONS

CHAPTER 5
AN APPROACH FOR SYSTEM TRANSFORMATION

Canadians value an effective healthcare system. Yet Canada's performance is not meeting the needs of people living with chronic conditions. There is evidence about efficacious models and approaches that can improve care, there are pockets of initiatives and energy in Canada moving in the right direction, and there are gaps where innovation has not yet spread. Healthcare system transformation is needed.

Several researchers have observed that the Canadian healthcare system is a complex, adaptive system. Such systems require approaches to change that recognize that large innovations can come from small shifts (and vice versa) and that what emerges through relationships and connections is usually more significant and effective than overly managed, centralized change.

This chapter applies complex adaptive system theory to identify approaches for creating effective change throughout the Canadian healthcare system. The approaches include: identifying simple patterns, building on healthcare reforms, making linkages for system-wide transformation, applying simple rules for planning and implementation, and setting the core direction for the Canadian healthcare system.

Identifying Simple Patterns

One of the approaches of accomplishing system change in a complex adaptive system is to identify simple patterns that can be applied in any context. They must be meaningful as the system continues to adapt, new connections are made, and new ideas and initiatives emerge.

Using this approach, the Expert Panel examined significant healthcare system transformations in five other countries as well as historical system reforms in Canada (see Appendix D for high-level findings from the case studies). These included:

- full-scale transformation of the healthcare system in Jönköping County, Sweden, which became a model for quality and learning across the country;

- deep embedding of community health and health promotion approaches in Finland, through gradual innovation over decades across a highly decentralized structure;

- major reforms to the healthcare funding system in the Netherlands since 2006, involving a shift to heavily regulated, community-rated compulsory universal private health insurance, and the commensurate quality improvement actions within primary and hospital care;

- transformations to the National Health Service in the U.K., particularly to primary care, over the past decade; and

- large-scale reforms to the Veterans Health Administration in the U.S., providing veterans with universal, high quality primary care.

In analyzing successful change in all these countries as a whole, the Expert Panel identified six simple patterns related to the transformation of healthcare systems. These patterns provided the rationale for and made it possible for them to make system-wide changes to their healthcare systems:

- All health (primary care and chronic disease management) systems are works in progress—there is no one "right way," no panacea, and no finish line.

- There are many approaches to system transformation, ranging from whole-scale transformation to incremental, or gradual, innovation. The best approach is the one that has natural established "grooves" in the particular environment or where there is already momentum, because this is a ready-made pathway for change.

- Decentralization (federations and regionalization) needs connectors for system-wide transformation to occur. Local innovation can ignite meaningful change, especially when supported by centralized and efficient research, guidelines, and key infrastructure.

- There is a movement towards creative partnerships (e.g., public, nongovernmental organization, and private collaborations are growing).

- Learning through comparison leads to quality improvements—standardized performance measurements are prerequisites and incentives are enablers.

- There is an increasing expectation of transparency and accountability of governments and institutions, including decision-making and system change processes that are responsive to the needs and priorities of affected people.

In summary, the primary lesson for Canada from this global survey of work is that there is no one right approach to transforming healthcare systems for improved health outcomes—the key is to begin somewhere, use ready-made pathways for change, enhance and expand the aligned work already underway, link multiple efforts in a concerted direction, and build in accountability.

Building on Healthcare Reforms

Recognizing the need to understand and build on the natural grooves in each system, the Expert Panel considered some of the historical healthcare reforms in Canada including the introduction of universal public insurance, the introduction of the *Canada Health Act* (1985), and the three reviews of the Canadian healthcare system initiated by the federal government in the past 15 years—the *National Forum on Health, 1994–1997* (Health Canada, 2004); *Building on Values: The Future of Health Care in Canada—Final Report* (Romanow, 2002); and *The Health of Canadians: The Federal Role* (Kirby, 2002). In addition, the Expert Panel acknowledged there have been numerous pivotal provincial reports by Mazankowski (2001) in Alberta, Fyke (2001) in Saskatchewan, Clair (2000) in Québec, and others.

The Expert Panel observed there is a pathway that previous successful healthcare system reforms have followed in Canada:

- There is a trigger for change, often at a community level, such as escalating costs, concerns about quality or equity, or a personal tragedy that sparks widespread public concern or conversation.

- Public pressure and a willing champion or leader converge and advocate for change at a provincial or territorial level.

- Health professionals, especially doctors, influence the degree and pace of change to the local healthcare system.

- Federal, provincial, and territorial negotiations take place; in some cases this is followed by an infusion of federal funding or policy.
- Individual provinces and territories interpret the macro direction and take action (usually in unique ways), with attendant shifts in delivery, policy, or structure to the system.

The introduction of universal public health insurance most clearly illustrates the frequent appearance of these listed elements. With the Great Depression and World War II as a recent backdrop, Saskatchewan was the first province to establish universal, public hospital insurance in 1947 and, 10 years later, the Government of Canada passed the *Hospital Insurance and Diagnostic Services Act* to share in the cost of these services with the provinces and territories. By 1961, all the provinces and territories had public insurance plans that provided universal access to hospital services. Despite a province-wide strike where 90 per cent of doctors closed their doors in protest, Saskatchewan again pioneered in providing insurance for physician services, beginning in 1962. The Government of Canada adopted the *Medical Care Act* in 1966 to share the costs of providing insured physician services with the provinces and territories. By 1972, all provincial and territorial plans had been extended to include physician services.

All elements may not always be present and the sequence may change; however, applying this approach of using a "ready-made pathway for change" helps in planning the transformation of the Canadian healthcare system. The implementation plan in Chapter 7 was designed with this pathway in mind.

Making Linkages for System-Wide Transformation

The Canadian healthcare system is decentralized (see Chapter 1), and there are many areas of local innovation (see Chapter 4). When applying the findings from the previously described simple pattern for healthcare system transformation, there needs to be connectors for health-system-wide transformation to occur in Canada. This includes better linkages and coordination between existing policy initiatives, strategic research, and on-the-ground innovations by: engaging providers and people with chronic conditions and their family and friend caregivers, sharing and using pre-existing infrastructure and natural networks, and building on pre-existing innovations so that all Canadians benefit.

This approach led to recommendations that build on existing pockets of action, linking them by bolstering and shifting existing infrastructure, redirecting resources, setting expectations and accountability.

Applying Simple Rules for Planning and Implementation

The shifts recommended through this assessment provide opportunities for change at all levels of the system, from individual practices, through regional authorities, to policy development and funding decisions by governments and regulators. Change leaders in all these parts of the system require flexibility to innovate while still following some simple rules for planning and implementation.

For robust planning, it is essential to: share information with people and providers, and between provinces, territories, and health regions; use the best available data; build on what exists to spread ideas and actions and use the available evidence; and identify where there are gaps and target future research in these areas.

For viable implementation, it is necessary to: provide value for money and reward measurable progress, begin with prototypes and existing initiatives, and build toward the best; plan for concurrent implementation since every recommendation is key to achieving the desired outcomes; and be pragmatic about what can be done and ensure that there is flexibility for provinces and territories.

Setting a Core Direction for the Canadian Healthcare System

Social innovation comes from asserting a direction for change that is expected to be reshaped and adapted as the system changes, new perspectives are drawn in, and new possibilities emerge (Westley et al., 2006). The Expert Panel identified three interrelated and mutually dependent perspectives that form the core direction for healthcare system transformation in Canada:

put people first, expect the best, and manage for results.

Put people first: System-wide changes are needed to focus on and to further engage people and their family or friend caregivers who want and need to be partners in their care. Clinicians need to be involved in changing and continuously improving the system.

Expect the best: We know what is needed for high quality care that is coordinated across the continuum of health services. Many examples of innovative services and systems already exist within and outside of Canada. As a starting point, we need to learn from and, where possible, to build on these pockets of excellence so that all areas in Canada can expect the best health services.

Manage for results: We need to consistently monitor what we are doing so that we know what to change. A continuous improvement, blame-free environment will produce the best results to improve quality, safety, and efficiency. We need to create a learning culture that allows us to learn from our mistakes and near misses as well as from our successes.

Summary

The Canadian healthcare system is complex and adaptive; therefore, it requires a unique approach for transformation. The proposed approaches include: identifying simple patterns, building on healthcare reforms, making linkages for system-wide transformation, applying simple rules for planning and implementation, and setting the core direction for healthcare system transformation in Canada. These approaches informed the development of the Canadian Academy of Health Sciences-appointed Expert Panel's recommendations (see Chapter 6) and the suggestions for implementation (see Chapter 7).

CHAPTER **6**
VISION AND CALL TO ACTION

Canadians with chronic conditions and the family and friends who care for them need a healthcare system that meets all of their needs. Some people's needs are relatively simple, involving the management of a single chronic condition, while other's needs are more complex, requiring the co-management of several chronic conditions.

Chronic health issues are a part of everyone's lives at one point or another and improving care for people with chronic conditions is an imperative that will ensure that Canadians can achieve the best quality of life possible and can contribute to the vitality of their communities.

Canadians value a sustainable healthcare system and recognize that system reform must be both meaningful and financially viable. Investments in healthcare system transformation must be strategically targeted toward the most consequential needs or innovations, include sufficient accountability mechanisms to ensure that money flows into the most critically important areas, and be linked to performance. The shifts must reform the healthcare system across the country and assist all regions (e.g., rural, remote, urban, and inner-city) and all populations, especially people with multiple conditions, people with mental health issues, disabled individuals, children and youth with chronic conditions, and those who experience significant health inequities.

By strengthening and connecting the innovative work already underway, Canada has a framework to create a system that improves experiences, health outcomes, and well-being for all Canadians, especially those with chronic conditions.

This chapter presents a vision of what is needed and an action plan with the priority recommendations to make this happen—a strategy based on the best available evidence and the consensus of the Expert Panel. The approach from the previous chapter informed the development of the strategy, with emphasis on the three core directions: put people first, expect the best, and manage for results.

The Vision and Recommendations

The vision for the healthcare system emerging from the Expert Panel appointed by the Canadian Academy of Health Sciences is:

> **"All Canadians with chronic health conditions have access to healthcare that recognizes and treats them as people with specific needs; where their unique conditions and circumstances are known and accommodated by all of their healthcare providers; and where they are able to act as partners in their own care."**

The foundation for this vision is that people must have seamless experiences of healthcare, with primary care practices as the hub for coordination, and continuity of care with specialty, acute, community, and social services.

To achieve this vision, the Expert Panel appointed by the Canadian Academy of Health Sciences has made the following overarching recommendation, which includes six enabling recommendations and an implementation recommendation. In combination these recommendations are a comprehensive strategy—all recommendations are equally essential and actions need to take place concurrently and be integrated.

Enable all people with chronic health conditions to have access to a system of care with a specific clinician or team of clinicians who are responsible for providing their primary care and for coordinating care with acute, specialty, and community services throughout their life spans by:

1. **aligning system funding and provider remuneration with desired health outcomes;**
2. **ensuring that quality drives system performance;**
3. **creating a culture of lifelong education and learning for healthcare providers;**
4. **supporting self-management as part of everyone's care;**
5. **using health information effectively and efficiently; and**
6. **conducting research that supports optimal care and improved outcomes.**

Federal, provincial, and territorial ministers of health should review these recommendations with a view to making them part of the 2014 renewal of the federal-provincial-territorial accord on healthcare.

These recommendations are mutually interdependent. When implemented concurrently, they will generate momentum for all populations in all regions across Canada to realize this vision over the next five years. Figure 5 illustrates how Canadian people are at the centre of this strategy and will be supported by a healthcare system with three core directions — **put people first, expect the best, and manage for results.** Throughout the healthcare system there will be movement with concurrent connected activity related to the six enabling recommendations.
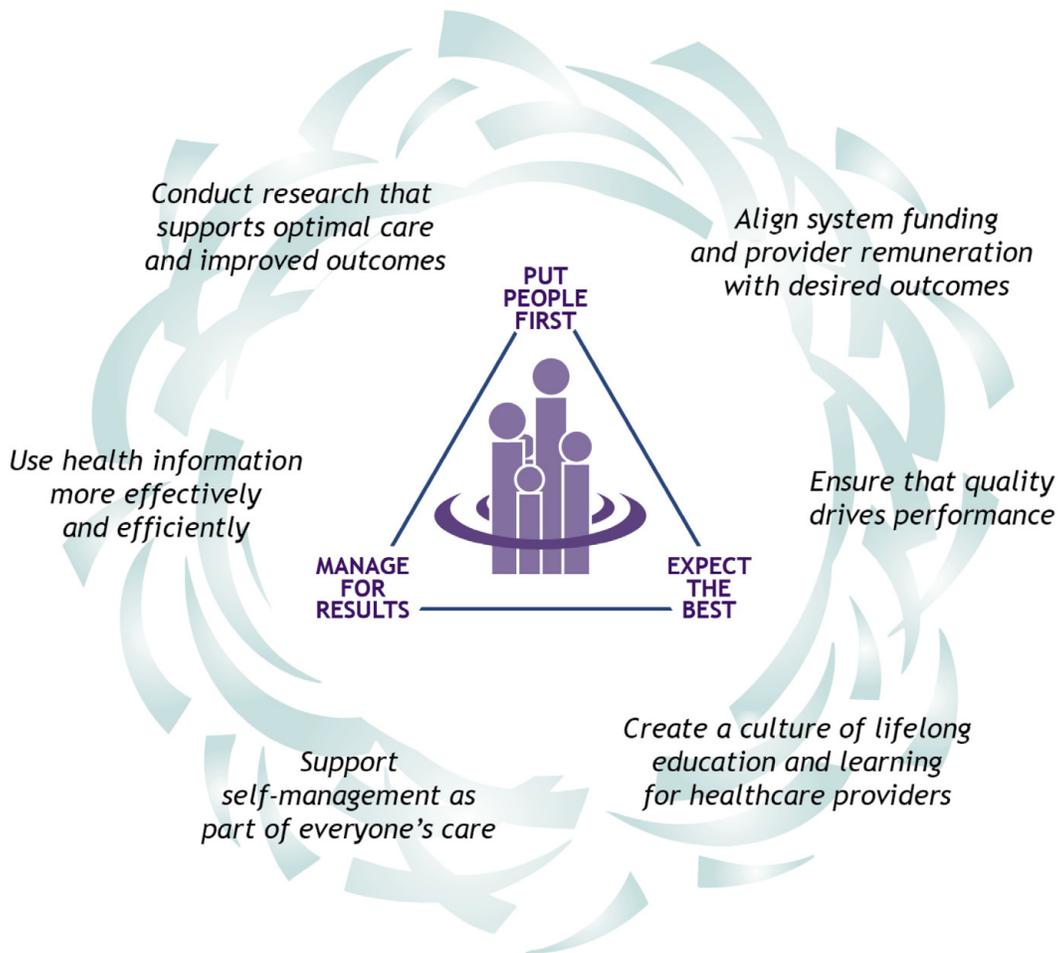
**Figure 5: Vision and Recommendations for Healthcare System Transformation
to Improve Health Outcomes of People with Chronic Conditions**

Recommendations

To enable the high quality system described in this vision, the evidence and insights outlined in Chapters 3 through 5 lead to an overarching recommendation with six enabling recommendations to make this change happen. The following section describes these recommendations with clear actions for implementation in each area.

Overarching Recommendation:

Enable all people with chronic health conditions to have access to a system of care with a specific clinician or team of clinicians who are responsible for providing their primary care and for coordinating care with acute, specialty, and community services throughout their life spans.

a) **Establish primary care as the cornerstone of the provision of chronic care. This requires a health human resources plan to ensure an adequate mix and numbers of providers and that all primary care practices: include responsibility for a defined population that is captured in a roster or registry, have appropriate infrastructure and staffing to support the management of individuals with multiple chronic conditions, and coordinate with other aspects of the healthcare system.**

b) **Optimize the contribution of the providers of specialty care for the care of people with complex chronic conditions. This requires improved access by primary care providers to specialized care, shared care models, and targeted provision of highly specialized care that is linked to a geographically based roster or registry.**

c) **Shift to a population-based model of care for primary and specialized care. This requires that these practices consider all the people for whom they are providing care as a population and assess how their healthcare needs can be best met. This may lead to group education, support sessions, or increased engagement of other healthcare providers.**

d) **Alleviate the pressure on emergency rooms that currently serve as the locus for the management of destabilized patients with complex chronic conditions by expanding access to primary care and fully utilizing community services, such as home health, community-based residential facilities, and volunteer organizations.**

e) **Integrate health promotion activities advocated by public health and support this work through the reinforcement of the determinants of health.**

f) **Ensure smooth transitions as people age, especially as children with complex chronic conditions become adults, to ensure there is appropriate continuity of care.**

g) **Plan for quality end-of-life care so that the arc of chronic diseases does not end in a frenzy of acute care utilization, but rather is managed according to the preferences of people with chronic conditions and their families.**

This overarching recommendation will require considerable change in practice, placing a greater responsibility on primary care providers and requiring key supports, including strengthened relationships between providers in other parts of the continuum of care. The following six recommendations will enable the needed changes.

Recommendation 1:
Align System Funding and Provider Remuneration with Desired Health Outcomes

Realignment in system funding is needed to support the shift from the current focus on acute, episodic health issues to addressing the complexities of living with chronic conditions over a lifetime. Many practices need to change the way healthcare is delivered to improve the health outcomes of people with chronic conditions, especially those with multiple morbidities. These changes in practice require a shift in health provider remuneration linked to quality of care and outcomes. This can be achieved by:

a) **Providing sufficient funding for homecare and chronic care services to meet the needs of people with chronic conditions and support their family and friend caregivers;**

b) **Ensuring that all provinces and territories provide equal access to the essential medications (i.e., key classes of prescription drugs) Canadians need to effectively manage their chronic conditions, including covering catastrophic drug costs;**

c) **Shifting remuneration of family physicians away from exclusive fee-for-service to salary, capitation, or a blended payment model with dedicated budgets for primary care practice infrastructure (i.e., electronic medical records) incentives to pursue excellence in chronic condition management (e.g., continuity of care, easy access, and attachment) and accountability for population-based outcomes;**

d) **Providing greater flexibility in specialty physician remuneration to ensure timely and coordinated care, rewarding them for working closely with primary care providers, compensating for increased time spent for more comprehensive care, and adopting of shared care models;**

e) **Creating incentives for primary care practices to provide comprehensive care for people with chronic conditions who currently rely on acute or multiple specialty care services. This includes funding for case management models that help individuals navigate through the system, particularly linking to specialized care and community services; and**

f) **Constructing a remuneration system for healthcare professionals who are not physicians (e.g., nurse practitioners, pharmacists, mental health workers) so that they can be part of the primary care system.**

Recommendation 2:
Ensure that Quality Drives System Performance

A culture of quality improvement throughout the entire healthcare system will result in continuous improvements. This drive for quality must be encouraged and supported at a pan-Canadian as well as at provincial and territorial level and must be operationalized at a local level. As a starting point, quality can drive performance by:

a) **Creating an overall pan-Canadian quality improvement strategy that includes goals and objectives for managing chronic conditions, provides suggestions for core metrics, and outlines a process for linking the efforts of existing organizations to support data collection and analysis and sustained implementation;**

b) **Developing and strengthening regional structures and processes to engage specialty physician and primary care practices in examining their performance to improve health outcomes; and**

c) **Developing quality improvement programs focusing on population-based outcomes, including leadership development of health professionals to drive the redesign of primary and specialty care practices.**

Recommendation 3:
Create a Culture of Lifelong Education and Learning For Healthcare Providers

There is an endless flow of new findings emerging from current innovations and research. This knowledge inspires continuous practice improvement to achieve better health and quality of life outcomes for people with chronic conditions. New models of health professional education are needed that include:

a) **Strengthening pre-licensure education and training of health professionals and managers across all health professions to ensure that they have the core competencies needed to improve outcomes for people with chronic conditions, in particular related to collaboratively identifying diagnoses and appropriate care for people with chronic conditions, drug management of multimorbidity, population-based approaches to healthcare, team-based care, promoting and supporting self-management, and quality measurement to inform practice change; and**

b) **Increasing access to skills development for practitioners and managers across all health professions to shift the nature of the relationship between clinicians and people with chronic conditions to person-focused care by developing interprofessional modules in key areas: managing the complexities of multiple chronic conditions such as decision making when there is uncertainty and ambiguity, applying a population-based approach to clinical care, supporting self-management, and using quality measures to improve practice.**

Recommendation 4:
Support Self-Management as Part of Everyone's Care

Depending on their status and capacity, people with chronic conditions and their family and friend caregivers already self-manage in different ways. To support each person's unique needs, people require secure Internet access to their health records (see Recommendation 5) and easy access to primary care practices that provide comprehensive care (see Recommendation 1). In addition to these top priorities, the healthcare system needs to better support self-management by:

a) **Assuring that all primary care practices have the appropriate mix of trained staff to provide effective self-management supports;**

b) **Empowering people to share and manage their own health information and contribute to emerging knowledge through web-based technology; and**

c) **Helping people and their family and friend caregivers to identify and access all the community-based health and social services they need to improve their health through the development of case management expertise within primary care.**

Recommendation 5:
Use Health Information Effectively and Efficiently

Electronic health information systems need to enable interaction between providers and people with chronic conditions and their caregivers and to enable innovative approaches to care, such as peer connections and support, virtual care, provider communities of practice and patient-driven knowledge development. There are sufficient ready-made health information systems that can be implemented in specialty and primary care practices and linked to systems in other sectors. At this point it is essential that all future funding guarantee that existing health information systems be used more effectively and efficiently by:

a) **Establishing national unified standards for electronic health records that are accepted and implemented by all jurisdictions across Canada;**

b) **Developing mechanisms for easy and secure transfer of information between all sectors in the healthcare system, especially among specialty and primary care practices, acute services, and residential care facilities;**

c) **Shifting funding away from development of new software to providing technical assistance for specialty physician and primary care practices to implement and maintain an electronic health record that is networked across the healthcare system;**

d) **Providing clinical decision supports to optimize care, especially for multimorbidity, and include the integration of appropriate clinical guidelines, e-prescribing, and where appropriate national accreditation standards and regulatory body standards for practice;**

e) **Using health information systems to facilitate population-based analysis at the individual practice level by requiring all practices to register or roster their patient population; and**

f) **Ensuring easy and secure Internet access by people to use and contribute to their own health records.**

Recommendation 6:
Conduct Research that Supports Optimal Care and Improves Outcomes

Improving practice, better understanding multimorbidity, and identifying and addressing knowledge gaps in care are key to improving health outcomes for people with chronic conditions. Consequently, research priorities for improving care for people with chronic conditions include:

a) **Building consensus on a limited number of key performance indicators that will provide the best information for measuring quality outcomes;**

b) **Developing reliable rapid-cycle evaluations of the implementation of health policy interventions;**

c) **Ensuring that research is relevant and inclusive of people with chronic conditions, especially research related to medications, practice guidelines, and protocols and standards that apply in the context of multimorbidity;**

d) **Building capacity so that primary care practitioners, administrators, and all health professionals involved in the care of people with chronic conditions are partners and participants in research;**

e) **Conducting ongoing comparative evaluation studies of new models of primary care across jurisdictions to better understand and share the elements in care delivery that are successful for managing multimorbidity and address the health needs of individuals with chronic conditions; and**

f) **Articulating knowledge gaps in the provision of chronic care that might be closed by appropriate research.**

Implementation Recommendation:
Federal, provincial, and territorial ministers of health should review these recommendations with a view to making them part of the 2014 renewal of the federal-provincial-territorial accord on healthcare.

The 10-year federal-provincial-territorial health accord of 2004 will soon expire. This is an opportunity to set a clear policy direction, invest strategically, and assign accountability for the needed changes to the Canadian healthcare system.

Summary

When the vision is achieved, Canada's healthcare system will be integrated, person-focused, and population-based, with primary care practices as the hub for coordination and continuity of care with specialty and acute care and community and social services. This integrated healthcare system will:

- have primary care practices that are responsible for a defined population;
- be person focused (and family or friend caregiver focused);
- provide comprehensive services through interprofessional teams;
- link with other sectors in health and social care; and
- be accountable for outcomes.

Primary care will become the cornerstone of the provision of chronic care. People with chronic conditions will be served by their encounters with both the acute care and primary care sectors. Primary care will be linked with specialty, acute, and community care and all will have a population management approach.

Healthcare system funding and remuneration models will enable the necessary shifts to better care for people, especially those who have multiple and increasingly complex chronic conditions. There will be greater flexibility in remuneration of all health providers in specialty and primary care with incentives linked to comprehensive, quality care and health outcomes.

A pan-Canadian quality strategy will ensure **quality improvement** activities and processes are fully integrated into culture and practice and are connected within regions and across the country to share what is learned. All specialty and primary care practices will be engaged and supported by the healthcare system to examine and improve their clinical performance.

There will be a culture of **lifelong education and learning** within the healthcare system. All students and practitioners across all health professions will have the core competencies needed to improve health outcomes for people with chronic conditions using a population team-based approach. Quality improvement programs will support providers and administrators in the redesign of and continued quality of care in primary care practices.

All people with chronic conditions and their family and friend caregivers will be supported as they manage their own care in the way appropriate for their conditions and circumstances. This **supported self-management** will enable people to be equal participants in decisions about their care. People will be provided with understandable and credible information about their health conditions and treatments and will be able to track their condition over time.

Health information will be easily transferable and accessible across the entire system, and technology will enable more virtual and innovative types of care and interaction, both between providers and people with chronic conditions and among peers. Specialty and primary care practices will have health information systems that support optimal care safely and efficiently. Practices will use their health information systems to conduct population-based assessments of their patient population for quality improvement and care planning purposes.

Research will include people with comorbidities and multimorbidity to generate findings that are relevant to optimal care of people with complex conditions, wherever they are receiving care, particularly in primary care practice. Health providers, administrators, policy makers, and people with chronic conditions will participate in practice-based research to improve healthcare delivery. Applied or implementation research would particularly support improved quality of care and patient experiences.

There will be **commitment** to embed these actions into policy and support to enable and ensure action across all the needed areas.

As a result, the Canadian healthcare system will **put people first, expect the best, and manage for results.**

CHAPTER **7**
MAKING IT HAPPEN

This assessment has resulted in a strategy for transforming the Canadian healthcare system so that:

> **"All Canadians with chronic health conditions have access to healthcare that recognizes and treats them as people with specific needs; where their unique conditions and circumstances are known and accommodated by all of their healthcare providers; and where they are able to act as partners in their own care."**

This vision and the recommendations in Chapter 6 provide clear direction for the necessary changes. These recommendations are realizable: much of the infrastructure for this transformation already exists, and there are many other bodies that have recently identified the need for changes commensurate with this strategy (Association of Faculties of Medicine of Canada, 2010; Canadian Medical Association, 2010).

As described in Chapters 4 and 5, the Canadian healthcare system is a complex system that has some performance gaps and many innovations. Change in such a complex system is best achieved by building on existing infrastructures and natural networks. Furthermore, enhancing the Canadian healthcare system through low-cost and feasible actions is best achieved by building on, linking, and learning from existing innovations.

With this understanding, this chapter identifies the key stakeholders and change leaders with existing accountabilities and, for each recommendation, presents promising existing models, and suggests potential action points. By taking action throughout the system in each of the recommendations while maintaining the core direction of "put people first, expect the best, and manage for results," transformative change is possible.

Key Stakeholders and Change Leaders

Disparate players across our healthcare system must make the changes that move us toward this vision. The report points to many innovations that can be realized by clinicians at the practice level, as well as to system enablers, such as more flexible remuneration that clinicians can influence through their professional bodies. There are many ideas that must be considered by policymakers, regulators, governments, regional health authorities, research bodies, and educators. Simultaneously, there are many opportunities for partnerships between key organizations, such as the single-disease-focused research and advocacy groups, the bodies that regulate and represent health professionals, clinicians, researchers, policymakers, and other governing bodies.

Collaborative action by many stakeholders is clearly needed and at the same time, as the primary funders of Canada's healthcare system, federal, provincial, and territorial governments have the unique capacity to provide direction, offer leadership, and demand accountability for coherent action across all the recommendations. The different roles for change are shown in Figure 6. First, the citizens of Canada can influence and advocate for the changes that will support their needs. The federal government has national agencies and pan-Canadian mechanisms that are well-positioned to take the lead in areas where consistency is important and feasible. Provincial and territorial governments have primary responsibility for healthcare and structures for comprehensive health planning and delivery at provincial, territorial and regional levels. Regional health authorities have flexibility and delegated responsibility to meet their population's unique needs. Voluntary health agencies provide some key services and supplies to support

people with chronic conditions. Specialty and primary care practices are composed of committed professionals who have autonomy over their own practice delivery and who are influenced by educational organizations, professional associations, and regulatory bodies. Research funding bodies inform innovation and practice.

CITIZENS OF CANADA
People with chronic conditions, their family and friend caregivers, and patient advocacy groups such as nongovernmental agencies demand the care and information they need, continue to be informed, engage in dialogue, and advocate for the healthcare system needed.
FEDERAL GOVERNMENT
The Government of Canada plays a key role in setting the strategic direction for the healthcare system by facilitating pan-Canadian collaboration, targeting health transfer funding to provincial and territorial governments, and ensuring accountability for this investment. Federally funded organizations, such as Health Canada, the Public Health Agency of Canada, Canadian Institute of Health Information, and Infoway, facilitate pan-Canadian collaboration along with providing targeted incentive funding with accountability expectations.
PROVINCIAL AND TERRITORIAL GOVERNMENTS
Provincial and territorial health ministries have constitutional responsibility for the provision of healthcare services. They develop and implement the strategic policies needed to fully transform the healthcare system, especially by investing in and evaluating progress on priority areas, providing infrastructure that ensure efficient and effective integration of health services and linking of innovations, and by negotiating remuneration of health professionals.
LOCAL AND REGIONAL HEALTH AUTHORITIES
Local and regional health authorities and their acute and community-based services plan, deliver, and evaluate health services, as well as provide some of the infrastructure that is needed for local integration. They initiate, facilitate, and implement many of the innovations in the Canadian healthcare system.
PROVINCIAL ASSOCIATIONS AND VOLUNTARY HEALTH AGENCIES
Professional associations represent their members (health providers) and help inform and shape government policy, influencing the direction and pace of system change. Voluntary agencies, such as the Cancer Societies, Heart and Stroke Foundations, Diabetes Association, and Alzheimer's Societies, are uniquely positioned to mobilize the public across the country to generate support for the needed policy changes.
REGULATORY AND ACCREDITATION BODIES AND QUALITY COUNCILS
All of these agencies have existing quality reporting mechanisms, albeit with different foci (i.e., health professionals' practice, education programs and health services, population health), and can support healthcare system transformation by reviewing their standards to encourage further quality improvement and work together to leverage their mandate for public accountability and for generating a culture of learning.
ALL HEALTH PROFESSIONALS IN BOTH SPECIALTY AND PRIMARY CARE PRACTICES
All health professionals work together to learn from each other and develop a shared commitment for greater accountability. The design of individual practices greatly influences the experience of people with chronic conditions.
EDUCATIONAL ORGANIZATIONS
Educational organizations and practicum placements prepare the health professional workforce for the future and through this play a key role in influencing the culture within the healthcare system.
RESEARCH FUNDING BODIES
Research funding bodies, such as the Canadian Institutes of Health Research, National Alliance of Provincial Health Research Organizations, and charities, influence policy and practice through prioritizing funding applications in key areas and creating new opportunities in areas that have not yet been addressed.

Figure 6: Stakeholders and Their Primary Roles

Translating Recommendations into Action

The Expert Panel appointed by the Canadian Academy of Health Sciences has made the following overarching recommendation that includes six essential and enabling recommendations and an implementation recommendation for concurrent implementation in an integrated manner.

Enable all people with chronic health conditions to have access to a system of care with a specific clinician or team of clinicians who are responsible for providing their primary care and for coordinating care with acute, specialty, and community services throughout their life spans by:

1. **aligning system funding and provider remuneration with desired health outcomes;**
2. **ensuring that quality drives system performance;**
3. **creating a culture of lifelong education and learning for healthcare providers;**
4. **supporting self-management as part of everyone's care;**
5. **using health information effectively and efficiently; and**
6. **conducting research that supports optimal care and improved outcomes.**

Federal, provincial, and territorial ministers of health should review these recommendations with a view to making them part of the 2014 renewal of the federal-provincial-territorial accord on healthcare.

The general approach for implementing this strategy is to create more links and formal accountabilities through existing structures so that the overall Canadian healthcare system is strengthened and the individual pieces are more tightly connected.

In the following six tables, the Expert Panel has identified specific agencies that already have some responsibility and resources in each of these areas and hence the potential to effect change. These agencies need to be further empowered and held accountable for these recommendations. In addition to those with primary responsibility, other key stakeholders are included in each group with the challenge to work together to realize these recommendations. This is not intended to be an exclusive list and there are others beyond those mentioned in this chapter that will need to be involved.

Related to this guiding principle, implementation of this strategy requires a shift to sustaining, connecting, and building on existing promising models, rather than the current focus on creating new pilot projects in health. This approach will expedite the spread of locally appropriate innovation across Canada. In listing specific innovations, others, perhaps equally promising, are missed. The key message is that *it is possible to implement each of these recommendations as this has already happened somewhere at some time.*

Table 2: Recommendation 1 - Align System Funding and Provider Remuneration with Desired Health Outcomes

WHAT NEEDS TO HAPPEN?	HOW CAN IT HAPPEN?
a) **Provide sufficient funding for homecare and chronic care services to meet the needs of people with chronic conditions and support their family and friend caregivers.**	Primary responsibility lies with provincial and territorial governments and requires support and facilitation by the federal government and collaboration with regional health authorities, and chronic care service providers. **Existing promising models:** • The Veterans Independence Program offered by Veterans Affairs Canada • Edmonton's Comprehensive Home Option for Integrated Care for the Elderly **Possible action points:** • Enact the recommendations from the Canadian Healthcare Association's *Home Care in Canada: From the Margins to the Mainstream* (2009). • Develop a national homecare strategy to ensure equity in access across the country.
b) **Ensure that all provinces and territories provide equal access to the essential medications (i.e., key classes of prescription drugs) Canadians need to effectively manage their chronic conditions, including covering catastrophic drug costs.**	Primary responsibility lies with provincial and territorial governments and requires support and facilitation by the federal government. **Existing promising models:** • Complete population coverage achieved by Québec's Prescription Drug Insurance Plan **Possible action points:** • Update and implement the nine elements of the National Pharmaceuticals Strategy laid out in the 2004 *10-Year Plan to Strengthen Health Care.* • Enact the recommendations from the Health Council of Canada report on *Generic Drug Pricing and Access in Canada: What are the Implications.* • Harmonize prescription drug policies across the country. • Increase cooperation across provinces and territories.
c) **Shift remuneration of family physicians away from exclusive fee-for-service to salary, capitation, or a blended payment model with dedicated budgets for primary care practice infrastructure (i.e., electronic medical records), incentives to pursue excellence in chronic condition management (e.g., continuity of care, easy access, attachment), and accountability for population-based outcomes.** d) **Provide greater flexibility in specialty physician remuneration to ensure timely and coordinated care, rewarding them for working closely with primary care providers, compensating for increased time spent for more comprehensive care and adoption of shared care models.**	Primary responsibility lies with provincial and territorial governments and requires collaboration with professional organizations (medical associations), regional health authorities, and specialty and primary care physicians. **Existing promising models:** • Family Health Team payment models in Ontario • Primary Care Networks in Alberta • In British Columbia, the Rapid Access to Cardiac Expertise initiative (or equivalent) fee codes for specialty consultants • The process used by the General Practice Services Committee **Possible action points:** • Build support for this shift by sharing existing successful approaches for implementation. • Encourage clinicians to build basic comprehensive, population-based, integrated principles into all practice changes they undertake. • Update existing agreements and negotiate new agreements to enable these shifts. For example, link a portion of physician fees to the desired areas of change, such as providing payment for gathering patient-reported outcomes, conducting group visits, undertaking phone and email consultations, implementing disease prevention interventions, supports for self-management, and shared care models. • Build in accountability for all the funds, closely monitoring the implementation. • Compensate primary care and specialty practices (not individual health providers) based on practice-based performance reports.

WHAT NEEDS TO HAPPEN?	HOW CAN IT HAPPEN?
e) **Create incentives for primary care practices to provide comprehensive care for people with chronic conditions who currently rely on acute or multiple specialty care services; this includes funding for case management models that help individuals navigate through the system, particularly linking to specialized care and community services.**	Primary responsibility lies with regional health authorities and their individual hospitals, in collaboration with specialty physicians and primary care practices and supported by provincial or territorial governments and professional associations. **Existing promising models:** • Virtual Ward in Toronto, Ontario (partnership between Women's College Hospital, the Community Care Access Centre, and the South East Toronto Family Health Team) • Interprofessional Model of Practice for Aging and Complex Treatments at Sunnybrook Hospital in Toronto, Ontario • The Integration Project by the Divisions of Family Practice in British Columbia **Possible action points:** • Use existing data (e.g., hospital admissions, pharmacare payments, physician billing data) to identify the people with chronic conditions who most frequently use acute services or multiple specialty services, then apply predefined criteria to determine who within this population should qualify for more intensive coordinated services within primary and specialty care. • Shift or share a portion of the financial and human resources used by the acute care sector in managing their conditions to designated primary care practices (not individual health providers). • Provide practices with the flexibility to use funding to best meet this specific population's needs, including covering the cost of community-based services or medical supplies. • Create accountability mechanisms to track the effectiveness and to allow for funding to increase when there is demonstrated cost avoidance in the other sectors.
f) **Construct a remuneration system for healthcare professionals who are not physicians (e.g., nurse practitioners, pharmacists, mental health workers) so that they can be part of the primary care system.**	Primary responsibility lies with regional health authorities and primary care practices, and requires support from provincial and territorial governments and professional associations. **Existing promising models:** • Local Health Integration Networks-Physician Collaboration Incentive Fund and salary support for registered nurses to be added to eligible physician practices in Ontario • Groupes de médecins de famille in Québec • Interior Health Authority (nurse practitioner and family physician collaboration) in British Columbia **Possible action points:** • Establish "contracts" between health authorities and primary care practices to fund or "loan" other healthcare professionals to be part of the primary care system. • Provide core grant funding or stipends to primary care practices (not individuals) to support activities beyond individual patient–physician-based interactions. • Advocate for shifting a portion of existing fees or direct future fee increases into core funding for primary care practices.

Table 3: Recommendation 2 - Ensure that Quality Drives System Performance

WHAT NEEDS TO HAPPEN?	HOW CAN IT HAPPEN?
a) **Create an overall pan-Canadian quality improvement strategy that includes the goals and objectives for managing chronic conditions, provides suggestions for core metrics, and outlines a process for linking the efforts of existing organizations to support data collection and analysis and sustained implementation.**	Primary responsibility lies with the quality councils (Health Council of Canada and provincial Quality Councils) and requires coordination with the Canadian Interprofessional Health Collaborative, Canadian Patient Safety Institute, and Canadian Institute of Health Information and support by provincial and territorial governments and regional health authorities. **Existing promising models:** ● National Institute for Health and Clinical Excellence in the U.K. ● Jönköping County, Sweden **Possible action points:** ● Assemble a consortium of the many organizations committed to quality healthcare and empower them to create and monitor implementation of a national quality framework, inclusive of primary care.
b) **Develop and strengthen regional structures and processes to engage specialty physician and primary care practices in examining their performance to improve health outcomes.**	Primary responsibility lies with regional health authorities in collaboration with Assemble a consortium of the many organizations committed to quality healthcare and empower them to work together and spread the existing initiatives. **Existing promising models:** **Clinical governance system in the U.K. with their shared responsibilities by Primary Care Trusts and the National Clinical Assessment Authority** ● Polypharmacy and similar reports linked to service contract negotiations in New Zealand **Possible action points:** ● Build on existing regional "credentialing" infrastructure to register all primary care practices and specialty physicians within the health authority where the office is located. ● From this pool of practitioners, establish a Regional Health Advisory Committee. Empower these committees to determine the key performance indicators from readily available data, ensuring alignment with existing provincial, territorial, and national indicator reporting. ● Provide all specialty physicians and primary care practices with comparative reports on these key performance indicators. ● Set regional targets for improvement and identify mechanisms to align activities with those areas. ● Link participation with incentives, providing supports for quality improvement (e.g., creation of a collaborative for learning).
c) **Develop quality improvement programs focusing on population-based outcomes that include leadership development of health professionals to drive the redesign of primary and specialty care practices.**	Primary responsibility lies with the quality councils (Health Council of Canada, provincial quality councils) informed by the Saskatchewan Chronic Disease Management Collaborative, Canadian Interprofessional Health Collaborative, and Canadian Chronic Care Network, and supported by regional health authorities and educational organizations. **Existing promising models:** ● Institute for Health Care Improvement in the U.S. ● Quality Improvement and Innovation Partnership in Ontario ● Alberta AIM ● Impact BC ● Qulturum—a centralized "quality" learning centre in Jönköping County, Sweden **Possible action points:** ● Assemble a consortium of the many organizations committed to quality healthcare and empower them to work together and spread the existing initiatives.

Table 4: Recommendation 3 - Create a Culture of Lifelong Education and Learning for Healthcare Providers

WHAT NEEDS TO HAPPEN?	HOW CAN IT HAPPEN?
a) **Strengthen pre-licensure education and training of health professionals and managers across all health professions to ensure that they have the core competencies needed to improve outcomes for people with chronic conditions, in particular related to: collaboratively identifying diagnoses and appropriate care for people with chronic conditions, drug management of multimorbidity, population-based approaches to healthcare, team-based care, promoting and supporting self-management, and quality measurement to inform practice change.**	Primary responsibility lies with the educational organizations (universities, colleges, Association of Faculties of Medicine), in collaboration with the professional associations and the accrediting bodies of health education and training programs and supported by the provincial and territorial governments. **Existing promising models:** • Interprofessional education initiatives across the major Canadian universities • Patient's Voice, an initiative through the University of British Columbia College of Health Disciplines • Accreditation of Interprofessional Health Education—a partnership of eight national organizations that accredit pre-licensure education for six health professions in Canada **Possible action points:** • Enact the recommendations from the Association of Faculties of Medicine of Canada's *Future of Medical Education in Canada* report. • Review accreditation standards of all health professions to ensure they embed these competencies. • Develop curriculum in these areas.
b) **Increase access to skills development for practitioners and managers across all health professions to shift the nature of the relationship between clinicians and people with chronic conditions to person-focused care by developing interprofessional modules in key areas: managing the complexities of multiple chronic conditions such as decision making when there is uncertainty and ambiguity, applying a population-based approach to clinical care, supporting self-management and using quality measures to improve practice.**	Responsibility is shared among professional associations, educational organizations, and regulatory bodies, in collaboration with the content experts (e.g., Canadian Interprofessional Health Collaborative, Public Health Agency of Canada, and Canadian Patient Safety Institute) and with the support of provincial and territorial governments and regional health authorities. **Existing promising models:** • Public Health Agency of Canada's Skills Enhancement for Public Health programs, including the Online Training Modules supporting the Core Competencies for Public Health in Canada 1.0 **Possible action points:** • Commission selected educational institutions with programs that excel in the key areas to develop modules for integration into existing continuing professional development programs. • Integrate these competencies into existing quality assurance or continuing competence programs. • Develop partnerships to sponsor mentoring programs.

Table 5: Recommendation 4 - Support Self-Management as Part of Everyone's Care

WHAT NEEDS TO HAPPEN?	HOW CAN IT HAPPEN?
a) **Assure that all primary care practices have the appropriate mix of trained staff to provide effective self-management supports.**	Primary responsibility lies with primary care practices, supported by nongovernment organizations supporting self-management of chronic conditions, regional health authorities, and provincial and territorial governments. **Existing promising models:** • Group Health Cooperative, a healthcare system based in Seattle, Washington • Kaiser Permanente, a healthcare organization in the U.S. • Impact BC's Patients as Partners initiative **Possible action points:** • Develop and support professional development programs on self-management. • Review the staffing composition and roles of the practice to best support self-management.
b) **Empower people to share and manage their own health information and contribute to emerging knowledge through web-based technology.**	Responsibility is shared between citizens (people with chronic conditions and their families) and primary and specialty care practices, with the support of professional associations, regional health authorities, provincial and territorial governments, and the federal government. **Existing promising models:** • Kaiser Permanente's HealthConnect • Group Health Cooperative's MyGroupHealth • CureTogether (http://curetogether.com) • MyOSCAR (open source software) • Mydoctor.ca Health Portal • MiHealth—a patient held health record **Possible action points:** • Develop a privacy framework to guide health professionals on what information they can share, addressing concerns related to liability insurance. • Encourage and help people with chronic diseases to use web-based technology. • Integrate the use of web-based technology to support self-management in professional development.
c) **Help people and their family and friend caregivers to identify and access all the community-based health and social services they need to improve their health through the development of case management expertise within primary care.**	Primary responsibility lies with primary care practices, with the support of regional health authorities, provincial and territorial governments, and advice from the Pan-Canadian Public Health Network's Chronic Disease and Injury Prevention and Control Expert Group. **Existing promising models:** • Group Health Cooperatives' Consulting Nurse Service • Medical help lines across Canada **Possible action points:** • Consider expansion of the role of telephone-based health help lines by improving linkages with primary care practices.

Table 6: Recommendation 5 - Use Health Information Effectively and Efficiently

WHAT NEEDS TO HAPPEN?	HOW CAN IT HAPPEN?
a) **Establish national unified standards for electronic health records that are accepted and implemented by all jurisdictions across Canada.**	Primary responsibility lies with the federal government (through delegated authority to Infoway), in collaboration with provincial and territorial governments (through delegated authority to organizations they have created to be responsible for health information technology, such as the Western Health Information Collaborative, Western Electronic Health Record Regional Collaborative, Physician Information Technology Office in British Columbia, Physician Office System Project in Alberta, and OntarioMD) and in consultation with electronic health record vendors. **Existing promising models:** • Intermountain Healthcare, a healthcare system providing services in two American states. • Kaiser Permanente • Veterans Health Administration in the U.S. **Possible action points:** • Provide leadership for expeditiously implementing clear pan-Canadian standards for electronic health records. • Create accountability mechanisms to support and ensure compliance.
b) **Develop mechanisms for easy and secure transfer of information between all sectors in the healthcare system, especially among specialty and primary care practices, acute services, and residential care facilities.**	Primary responsibility lies with regional health authorities, in collaboration with and supported by provincial and territorial governments through those of their organizations that are responsible for health information technology, and the federal government (through Infoway). **Existing promising models:** • Sault Ste. Marie Group Health Centre in Ontario **Possible action points:** • As a priority, begin with ensuring the ability to track accurate and reconciled medication lists throughout the entire system.
c) **Shift funding away from development of new software to providing technical assistance for specialty physicians and primary care practices to implement and maintain an electronic health record that is networked across the healthcare system.**	Primary responsibility lies with provincial and territorial governments through organizations responsible for health information technology, in collaboration with regional health authorities and the federal government (through Infoway). **Existing promising models:** • Supports provided to physicians in Ontario • Training provided through the Physician Information Technology Office in British Columbia **Possible action points:** • Expand available supports to be more flexible in supporting all practices with electronic health records. • Track and incorporate feedback from the health providers and people using health services.

WHAT NEEDS TO HAPPEN?	HOW CAN IT HAPPEN?
d) **Provide clinical decision supports to optimize care, especially in the context of multimorbidity, and include the integration of appropriate clinical guidelines, e-prescribing, and, where appropriate, national accreditation standards and regulatory body standards for practice.**	Primary responsibility for implementation lies with the provincial and territorial governments through those of their offices that are responsible for health information technology, with support and coordination by the federal government (Infoway), in consultation with researchers with domain expertise, primary and specialty care practices, and electronic health and medical record vendors, and support by regional health authorities. **Existing promising models:** • The Regenstrief Medical Records System and the Regenstrief Center for Healthcare Improvement and Research • Partners HealthCare, an integrated healthcare system in Massachusetts, U.S. • Intermountain Healthcare's clinical decision supports **Possible action points:** • Review the "meaningful use" criteria that are being implemented in the U.S. and build on this to create Canadian requirements for electronic medical record and electronic health record funding. • Support research and development to ensure clinical decision supports are useful for chronic condition management, especially in the context of multimorbidity (e.g., provision of research and development tax credits). • Create opportunities for clinicians to provide feedback to vendors on usability and appropriateness.
e) **Use health information systems to facilitate population-based analysis at the individual practice level by requiring all practices to register or roster their patient population.**	Primary responsibility lies with provincial and territorial governments in collaboration with primary and speciality practices and supported by the federal government (through Infoway), the Public Health Agency of Canada, and regional health authorities. **Existing promising models:** • Primary care models in Ontario and Québec, and others that have already done this **Possible action points:** • Link rostering to remuneration systems. • Include the ability for practices to register or roster individuals and to use this information to analyze their population as a standard requirement for vendors.
f) **Ensure easy and secure Internet access for people to use and contribute to their own health records.**	Primary responsibility lies with the federal government (through Infoway), in collaboration with specialty and primary care practices and people with chronic conditions, in consultation with health record vendors, and with support by regional health authorities and provincial and territorial governments. **Existing promising models:** • MyOSCAR (open source software) • Kaiser Permanente's HealthConnect • MyGroupHealth online services **Possible action points:** • Create a pan-Canadian standard requiring easy access by people so as to read and contribute to their own health records. • Identify and remove barriers to sharing people's own information with them.

Table 7: Recommendation 6 - Conduct Research that Supports Optimal Care and Improved Outcomes

WHAT NEEDS TO HAPPEN?	HOW CAN IT HAPPEN?
a) **Build consensus on a limited number of key performance indicators that will provide the best information for measuring quality outcomes.**	Primary responsibility lies with research funding bodies (Canadian Institutes of Health Research, Canadian Health Services Research Foundation, National Alliance of Provincial Health Researchers), in collaboration with primary care, quality councils, and the Canadian Institute of Health Information, and is supported by provincial and territorial governments. **Existing promising models:** • Veterans Health Administration, U.S. **Possible action points:** • Prioritize existing indicators so there are a select few that are consensus based. • Where necessary, develop and test new indicators that measure access, attachment, continuity, comprehensiveness, and degree of centering on the person. • Provide targeted funding to support the process.
b) **Develop reliable rapid-cycle evaluations of the implementation of health policy interventions.**	Primary responsibility lies with the federal, provincial, and territorial governments, in collaboration with educational organizations (university-based health policy research centres). **Existing promising models:** • The national evaluation strategy to assess the impact of the smoke-free legislation in Scotland **Possible action points:** • Begin with the highest priority—new models for remuneration and how these influence practice. • Link and invest in rigorous evaluation through partnerships between government and academic researchers. • Ensure evaluations consider how to reduce health inequities by examining the impact on all people with chronic conditions and including them in the evaluation.
c) **Ensure that research is relevant and inclusive of people with chronic conditions, especially research related to medications, practice guidelines, and protocols and standards that apply in the context of multimorbidity.**	Primary responsibility lies with research funding bodies (Canadian Institutes of Health Research, Canadian Health Services Research Foundation, National Alliance of Provincial Health Research Organizations, and nongovernmental organizations and charities), in collaboration with people with chronic conditions and specialty and primary care practices. **Existing promising models:** • Bridgepoint Collaboratory for Research and Innovation • Research on children with special needs and frail older adults that is focused on their experiences of quality of care. • Participatory action and narrative methodologies from the social sciences that are inclusive. **Possible action points:** • Bring together single-disease-focused organizations to jointly fund research on multimorbidity, for example, collaboration between Cancer Societies, Heart and Stroke Foundations, Diabetes Associations, and Alzheimer's Societies. • Prioritize research proposals that focus on multimorbidity, for example prescribing patterns for patients with at least three chronic conditions (e.g., diabetes, hypertension, and heart failure). • Integrate the concept of multimorbidity into the Canadian Strategy on Patient-Oriented Research and Primary Healthcare Research Strategy. • Create policies that require evidence demonstrating safety and efficacy of medications, equipment, and services on populations with multiple chronic conditions prior to approval.

WHAT NEEDS TO HAPPEN?	HOW CAN IT HAPPEN?
d) **Build capacity so that primary care practitioners, administrators, and all health professionals involved in the care of people with chronic conditions are partners and participants in research.**	Primary responsibility lies with research funding bodies (Canadian Institutes of Health Research, Canadian Health Services Research Foundation, National Alliance of Provincial Health Research Organizations, and charities), in collaboration with primary care practices. **Existing promising models:** • The Vancouver Foundation Community-Based Clinician Investigator Program in British Columbia **Possible action points:** • Develop capacity-building grants that reflect the needs of primary care clinicians interested in participating in research. • Support existing connections (e.g., practice-based research networks). • Expand eligibility and support for career awards for researchers studying issues in primary case coordination and primary care practitioners.
e) **Conduct ongoing comparative evaluation studies of new models of primary care across jurisdictions to better understand and share the elements in care delivery that are successful for managing multimorbidity and address the health needs of individuals with chronic conditions.**	Primary responsibility lies with research funding bodies (Canadian Institutes of Health Research, Canadian Health Services Research Foundation, National Alliance of Provincial Health Research Organizations, and nongovernmental organizations and charities), in collaboration with primary care practices, regional health authorities and federal, provincial, and territorial governments. **Existing promising models:** • Western Canadian Interprofessional Health Collaborative **Possible action points:** • Provide targeted funding to create networks between provinces and territories to evaluate elements of these models and share results.
f) **Articulate knowledge gaps in the provision of chronic care that might be closed by appropriate research.**	Primary responsibility lies with research funding bodies (Canadian Institutes of Health Research, Provincial Health Research Organizations, and nongovernmental organizations and charities), in collaboration with health providers, quality councils, Canadian Institute of Health Information, regional health authorities, and federal, provincial, and territorial governments. **Existing promising models:** • The National Institute for Health and Clinical Excellence, U.K. **Possible action points:** • Build on the current Canadian Institute of Health Research four-pillar model to better connect all stakeholders to identify and address priority areas.

Plans for implementation must begin immediately and can occur concurrently—across all recommendations and at local, regional, provincial, and pan-Canadian levels. Figure 7 builds on Figure 5 in the previous chapter by adding the stakeholders to complete all the components of the strategy, with people with chronic conditions and their family and friend caregivers in the centre, a clear core direction for the system, concurrent action in all the recommendations, and engagement of all key stakeholders.
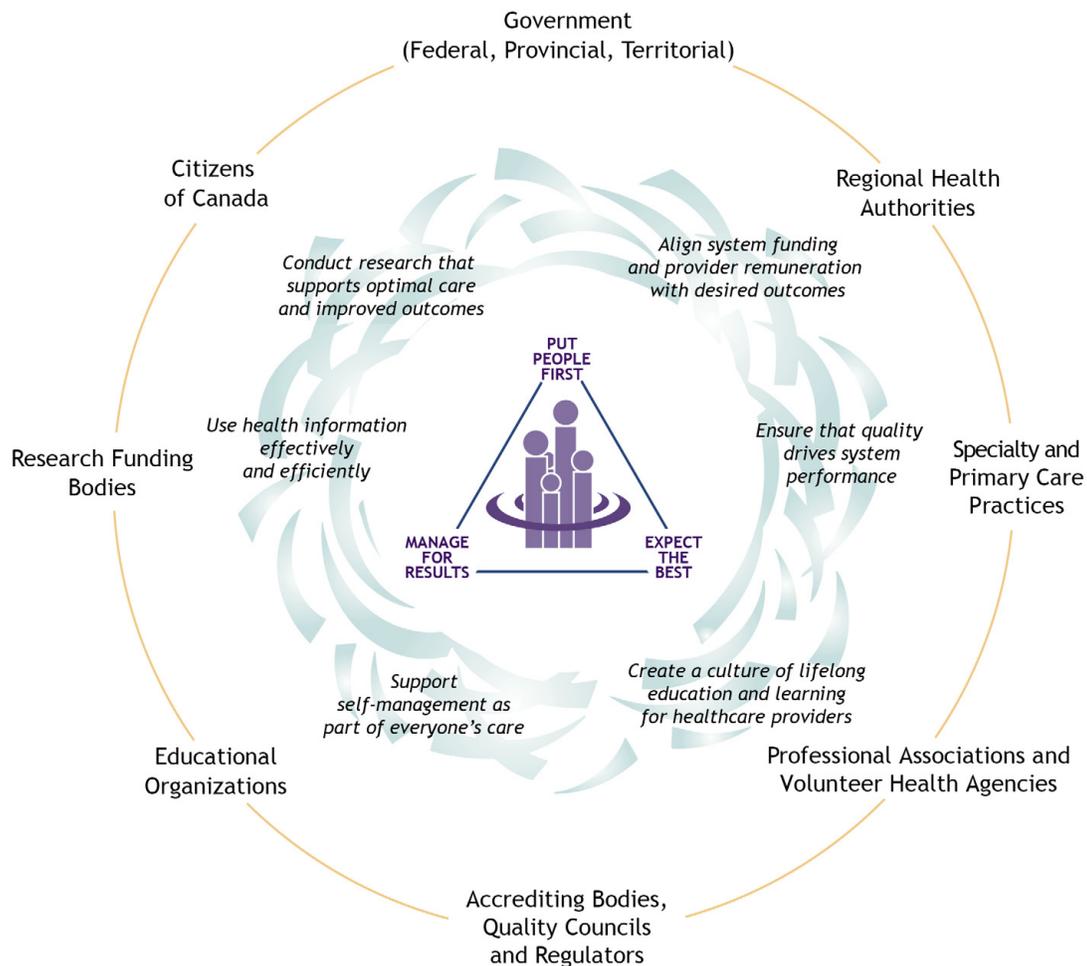
Figure 7: Strategy for Transforming Care for Canadians with Chronic Health Conditions

This leads to the final recommendation that is particularly related to ensuring change.

> **Implementation Recommendation:**
> **Federal, provincial, and territorial ministers of health should review these recommendations with a view to making them part of the 2014 renewal of the federal-provincial-territorial accord on healthcare.**

Primary responsibility lies with all the Ministers of Health, with the support of the Conference of Deputy Ministers of Health. The review of these recommendations must be integrated into their annual meetings, with a plan for implementation directed toward the target of the 2014 renewal.

The ministries have already created the fundamental platforms for implementation of the recommendations, so results can and could be realized within the next five years. Implementation of the recommendations must and should start in areas where inequities exist. This is not only a moral imperative; it is also where the largest gains can be realized.

Summary

The vision is simple.

> **"All Canadians with chronic health conditions have access to healthcare that recognizes and treats them as people with specific needs; where their unique conditions and circumstances are known and accommodated by all of their healthcare providers; and where they are able to act as partners in their own care."**

This requires the Canadian healthcare system be transformed to **put people first, expect the best, and manage for results.**

Over the past 15 years, three federal reviews, and several provincial independent commissions, Canadians have consistently called for changes to their healthcare system. Clearly, the current capacity for the Canadian healthcare system to meet the needs of people living with chronic conditions is limited. The human and economic costs of inaction are unacceptable and growing (see Chapters 1 and 3). The cumulative research and experiences (see Chapters 2 and 4) in caring for people with chronic conditions, combined with what is known about system transformation (see Chapter 5) create a strong evidence base for the actions needed.

The recommendations by the Expert Panel appointed by the Canadian Academy of Health Sciences (see Chapter 6) were developed using a consensus-based approach and futuristic thinking that looked beyond the current body of knowledge at promising emerging ideas. By identifying existing accountabilities, connecting, and building on existing innovation (see Chapter 7), this strategy will improve health outcomes for people with chronic conditions. Furthermore, investing in this vision will lead to better health outcomes for Canadians and will also lead to the more cost-effective, sustainable system Canadians so deeply value.

This is not to underestimate the challenge of implementing changes while continuing to deliver health services. Transforming the Canadian healthcare system will require a tremendous commitment and effort from all levels. However, maintaining the current Canadian healthcare system in the future will be equally or perhaps even more challenging.

The burden of chronic conditions is growing: people with chronic conditions are suffering; the healthcare system and providers are stretched beyond capacity. It is time to challenge the status quo in the interest of improving outcomes for people with chronic conditions in Canada.

GLOSSARY

Chronic Disease: Nolte and McKee (2008) offered a definition of chronic disease as,

> Conditions that require a complex response over an extended time period that involves coordinated inputs from a wide range of health professionals and access to essential medicines and monitoring systems, all of which need to be optimally embedded within a system that promotes patient empowerment. (p. 1)

Chronic (Health) Condition: The focus of this report is on chronic conditions in the broader sense—conditions that require ongoing care or management over years or decades, by both health providers and family members, which "persist over time regardless of treatment" (Starfield, 2010, p. 4). This includes conditions that we think of as disabilities, as well as mental health issues, which have been highlighted in Canada in recent years as "both like and unlike" (Kirby & Keon, 2006, p. 41) physical illness or disabilities.

Complex adaptive systems theory: "Complexity science embraces life as it is: unpredictable, emergent, evolving and adaptable" (Westley et al., 2006, p. 7). It includes understanding connections or relationships within systems and looking to patterns of interaction.

Comorbidity: The presence of one or more disorders (diseases) in addition to a primary disease or disorder, or the effect of such additional disorders or diseases (Wikipedia, 2010, para. 1).

Electronic Health Record: The term electronic medical record is frequently used for office-based systems that track individual histories and care; this assessment uses electronic health record throughout to reflect a broader concept that incorporates office-based electronic medical records but also can be shared with and used by other health professionals and other sectors, including hospitals, home care, and so on. This is consistent with Canada Infoway's description of the electronic medical records as a building block for a broader electronic health record. The term "health" also serves to emphasize that primary care practices should consider broader health and not just medical needs.

Family or Friend Caregiver: People who provide care based on a personal, often long-term, relationship and who are not paid as nurses, home care providers, or assistants to people with disabilities. Family or friend care can be distinguished from care by voluntary sector organizations because the latter is of an organization-client relationship (Lero, Keating, Fast, Joseph, & Cook, 2007).

Home Care: The definition for home care—"an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration and support for the informal (family) caregiver" (Canadian Home Care Association, 2009, para. 1)—is reflected in most of the federal, provincial, and territorial home care programs across Canada.

Multimorbidity: Refers to multiple conditions, some related to each other, some complicating each other, and some that are unrelated but coexisting.

People with Chronic Conditions: This refers to people with one or more chronic conditions and encompasses people with one or more diagnosis of a disease such as diabetes or osteoarthritis; people living with comorbidities, multiple diseases, or other forms of illness; and people living with disabilities or mental health issues.

Primary Care: "The provision of first contact, person-focused, ongoing care over time that meets the health-related needs of people, and coordinates care when people receive services at other levels of care" (Starfield, 2009b, p. 5).

Primary Healthcare: The essential healthcare, based on practical, scientifically sound, and socially acceptable methods and technology, made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. Primary healthcare forms an integral part both of the country's healthcare system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family, and their community with the national healthcare system. It brings healthcare as close as possible to where people live and work, and it constitutes the first element of a continuing healthcare process (World Health Organization, 1978).

Quality Improvement: A term used to describe efforts to improve healthcare services. It is "an umbrella term that included many overlapping concepts such as continuous improvement, organization-wide commitment and worker participation, knowledge of customer needs, systems thinking, systematic analysis of processes, use of scientific data-driven analytic methods and involvement of interdisciplinary and cross-functional teams" (Baker et al., 2008, p.14).

Self-Management: The goal of self-management is to increase people's capacity to take care of themselves and otherwise participate in their own healthcare. The ability of people living with chronic conditions to self-manage is highly dependent on the capacity of individuals and their circumstances.

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