GOING UPSTREAM

Toward an Ontario Chronic Disease Strategy, starting with diabetes

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FOREWORD

Start with diabetes to stop the chronic disease cascade

Imagine our lives and health as a river, starting with birth and flowing through each stage of life.

In the past, given shorter life expectancy, that journey was usually short and calm if one made it through the rough waters of infancy.

Today, the journey is much different. Many of us who get ill live long parts of our lives with chronic disease – an often-difficult personal challenge of constantly striving for better health while keeping one or more potentially dangerous and painful conditions at bay.

Chronic diseases are also challenging because over time and as diseases progress, controlling their impacts becomes much more difficult and it can cause many other effects. In fact, the onset of one condition can trigger a series of interconnected health problems. For instance, obesity can lead to diabetes, which may subsequently result in heart disease and other complications.

Addressing these diseases earlier in their progression – at their source, when they are usually far more manageable – can prevent further issues and improve overall health outcomes. By intervening upstream, closer to the source, we can break the cascade of disease progression, enhance the quality of life for individuals affected by chronic conditions and, ultimately, relieve pressures on our health system.

The key problem, however, is that the basic structure of Ontario's health system was created in the 1960s, mainly to manage acute health care issues. Someone would get sick or have an accident, visit a doctor, maybe spend time in the hospital, and then not require the health system until the next illness or incident. Far fewer were living with chronic diseases that required regular and ongoing health interventions of varying complexity for many years, even decades.

Yet that is what our health system now faces. Almost three quarters (73%) of Canadians aged 65 and older are affected by a chronic disease,[1] leading to a tremendous demand on our health system that will only grow over time as the population continues to age.

In this context, Ontario must take IMMEDIATE action to prevent the flooding of a healthcare system that was not created to handle such a cascade of chronic diseases. This is a huge problem and a massive initiative to undertake. Like any large task, it can't be done in a single, sweeping action – it requires a series of smaller steps that yield meaningful, positive results over time. We didn't get into this situation overnight, so it will take time and effort to see improvements.
As the old saying goes, a journey of a thousand miles begins with the first step.

On April 19, 2023, the Government of Ontario took an important first step with the unanimous passage of Motion 45, which recommended that the Minister of Health:

> *"develop a provincial framework that ensures that every Ontarian has access to quality care for chronic diseases and that is designed to improve chronic disease care, addressing prevention, management and treatment* ***with an initial focus on diabetes*** *(emphasis added) and aligned with the existing Indigenous diabetes strategy, and that Ontario Health table its progress through public reporting within one year and provide annual updates on the state of care for persons with chronic diseases in Ontario."*[2]

The initial focus on diabetes is important. As the Ontario government has recognized, taking immediate actions to help in the prevention, care and treatment of diabetes, the most prevalent chronic disease and a "gateway" condition, can help prevent numerous other serious chronic diseases from developing. Actions and programs initiated for diabetes can then be used as learnings to apply to the many other serious chronic diseases faced by Ontarians.

However, since the passage of Motion 45 almost two years ago, there are few signs of progress on the proposed provincial framework. The promised report on progress after one year never appeared. It is past time for action.

This paper aims to jump-start progress by outlining both immediate and long-term actions needed for a chronic disease strategy, beginning with diabetes.

Executive Summary

Chronic diseases are the leading cause of death and disability in Ontario. The onset of one condition can trigger a series of interconnected health problems. For instance, obesity can lead to diabetes, which may subsequently result in heart disease and other complications. Addressing these diseases earlier in their progression can prevent further issues, improve overall health outcomes, and, ultimately, relieve pressures on our health system. However, Ontario's healthcare system, originally designed for acute care in the 1960s, is ill-equipped to manage the long-term, complex needs of patients with chronic diseases.

Recognizing these challenges, the Ontario government initiated a promising step with the 2023 passage of Motion 45, calling for a provincial framework to improve chronic disease care, starting with diabetes. However, progress has stalled, and urgent actions are needed to deliver on this mandate.

This vision paper outlines a number of recommendations to help inform the development of a comprehensive chronic disease strategy, starting with immediate actions for diabetes.

Key recommendations include:

Immediate Actions for Diabetes:

- Establish a dedicated diabetes management team within Ontario Health
- Expand diabetes screening in pharmacies
- Develop targeted awareness campaigns and education programs
- Promote community initiatives like Cities for Better Health
- Streamline administrative processes, particularly for lifelong conditions like type 1 diabetes
- Integrate diabetes-specific mental health care
- Prioritize and consolidate the treatment of diabetes-related complications

Long-Term Initiatives for Chronic Diseases:

- Strengthen early detection and monitoring of at-risk populations
- Partner with patient organizations and health professional groups to advance education on prevention
- Adapt or create new data collection systems
- Embrace innovation and technology in care delivery
- Improve access to care and treatment
- Enhance the role of allied health care professionals
- Identify consistent pathways for care

By implementing these recommendations, Ontario can lead the way in reimagining chronic disease management, starting with diabetes and extending to other chronic illnesses. The time to act is now.

Message from Life Sciences Ontario

Life Sciences Ontario is proud to champion this important work related to the prevention and treatment of chronic diseases in Ontario, starting with actions related to diabetes.

We hope this vision paper will empower the Government of Ontario to make the key changes that are necessary and start solving these issues. Motion 45, approved by the Ontario Legislative Assembly in April 2023, was an important start, but it will remain just a symbol unless it is put into action through concrete initiatives and projects.

The vision outlined in this paper is not just about providing more money to help fight chronic diseases. It is about thinking and doing things differently, starting with some immediate actions related to Ontarians with diabetes to provide models and learnings to subsequently role out a broader program for those with other chronic diseases.

For the longer-term, we need to focus on three key pillars of the chronic disease landscape: prevent, mitigate and manage. We need to lessen the incidence and prevalence of those diseases that can be prevented. We need the systemic and structural changes that are required to make a fundamental difference in how we deliver care. And we need different ways to manage prevention and care services tailored specifically for chronic diseases.

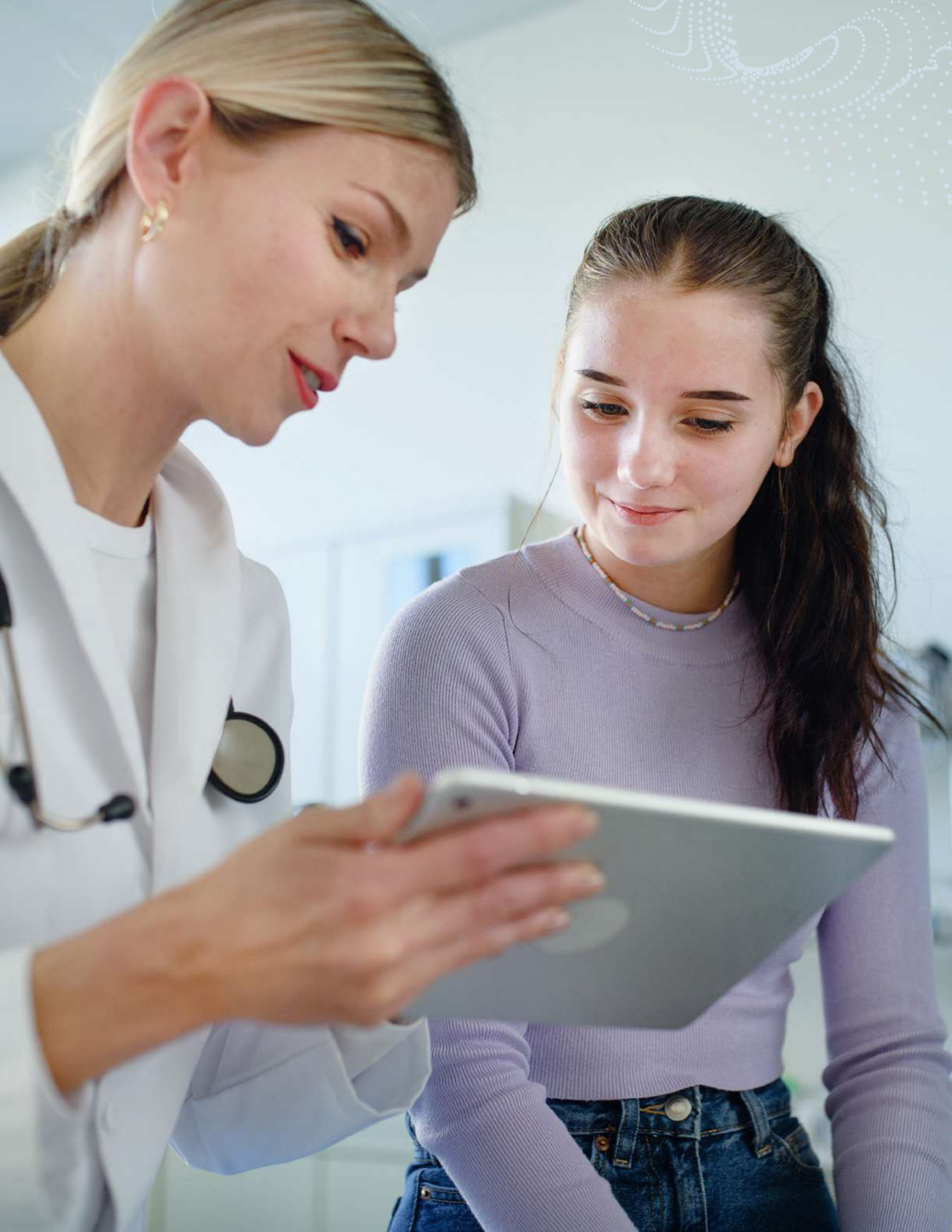
The effort and collaboration that has gone in to developing this vision paper shows very clearly that stakeholders are ready to mobilize to help the government achieve these important societal goals and are already working to do what they can. They want to work with government to do even more.

It's not just about the health system either. It involves a much broader societal approach to educate and make it easier for people to have the healthier lifestyles that we know will prevent chronic illnesses and assist in their management when they do occur.

Life Sciences Ontario has been pleased to work with its major partners in developing this paper: Diabetes Canada and the Health Charities Coalition of Canada. They represent all the wonderful work that gets done now to help Ontarians with chronic diseases, but more is needed from government and our health system to complete the job.

It was the work of an Ontarian, Dr. Frederic Banting, a century ago that turned diabetes from a deadly acute disease into a chronic one. We need a similar dedicated effort to change how we work to prevent, mitigate and manage chronic diseases. We hope this will be the start of that vital work.

Dr. Jason Field
President and CEO, Life Sciences Ontario



The Vision – Where we want to be

Taking the actions needed to effectively prevent and manage diabetes and other chronic diseases in Ontario is not a luxury. It is absolutely crucial for the long-term health not only of Ontario residents but of the province's health system.

We cannot continue to manage as we have over the recent decades as the health system has failed to respond with systemic changes while the number of patients with chronic diseases has continued to grow inexorably.

The first step in making any fundamental change is to determine where you want to go or need to be. Almost all aspects of chronic disease management in Ontario need to be changed. This is not a problem unique to Ontario. Nor is it a criticism of those who have managed the province's health system in recent decades.

Rather, it is a sign of great progress. Over time, incremental advances in our understanding of chronic diseases – including how they are identified, managed, and treated – have led to significant improvements. As a result, many Ontarians are now living longer with one or more chronic diseases. However, they are often required to navigate a health system created in the 1960s – one that was designed to care for short-term, acute illnesses and accidents. This needs to change.

Let's imagine Ontario 15 years from now, in 2040. A recent study suggests that 3.1 million people in Ontario in 2040 will be living with a major illness. What should our society and health system look like for them?

Here's what it could be:

- A place where young people have grown up to be well-informed about how to eat and live their lives with the best chance of preventing chronic illness thanks to education programs they have been exposed to since childhood.
- Testing services are readily available to those at risk for major chronic diseases (diabetes, cardiovascular illness, lung diseases, cancer) to catch conditions at the earliest possible stage and initiate treatment when it can be most effective.
- When a chronic disease is diagnosed, there are specialized clinic services available to all Ontarians that provide effective in-person and remote consultations on how patients should treat their disease and adjust their lifestyle to best accommodate it.
- All people with chronic disease can track their biometric data, symptoms and response to therapies electronically for easy review by medical personnel to quickly learn what works best for each patient to maximize effective management of their illness.
- Medical services for chronic diseases are provided in clinics and resource centres exclusively for that disease or a group of chronic illnesses, reserving the services of general hospitals mostly for care of accidents as well as acute illnesses and major health issues for those with chronic diseases.

Is this a dream? No. Is it an ideal? Yes. Can it be made to happen? Certainly, if we want it.

However, achieving this long-term vision will require some time. For this reason, it is equally important to identify short-term solutions that can be implemented right away. This vision paper outlines both immediate and long-term initiatives, beginning with actionable steps to support individuals living with diabetes.

But first, let's explore the magnitude of the chronic disease problem in Ontario today.

Chronic disease in Ontario today

In medicine, something chronic is defined as “any condition that lasts a long time or recurs over time.” These are distinguished from acute conditions, which are those that “come on suddenly, often with severe, but short-lived symptoms.”[3]

Chronic conditions and diseases are serious medical issues. The website of Public Health Ontario introduces them as follows: “Chronic diseases and conditions are the leading cause of death and disability in Ontario. The most common are cancers, cardiovascular diseases, chronic respiratory diseases and diabetes. Unhealthy eating, physical inactivity, harmful use of alcohol and tobacco use are major contributors to the burden of chronic diseases.”[4]

Health Canada notes that four chronic diseases – cancer, cardiovascular diseases, diabetes and chronic respiratory diseases – account for over 60% of all deaths in Canada.[5]

That may be true, and certainly makes them serious, but the greater impact of chronic diseases is on people while they are still alive, particularly because, thanks to research and innovation, we keep doing better at allowing people to live with chronic diseases rather than die from them.

Every chronic disease results in different impacts on patients and their families, but they all have certain key elements in common:

- Rising prevalence as the population ages
- Higher demands on health care resources, including doctors and hospitals
- Increased use of medications and costs to public and private drug plans
- Loss of productivity and income for those of working age
- Loss of disposable income for patients to meet out-of-pocket costs, some of which can be considerable
- Impact on friends and family members to assist with care

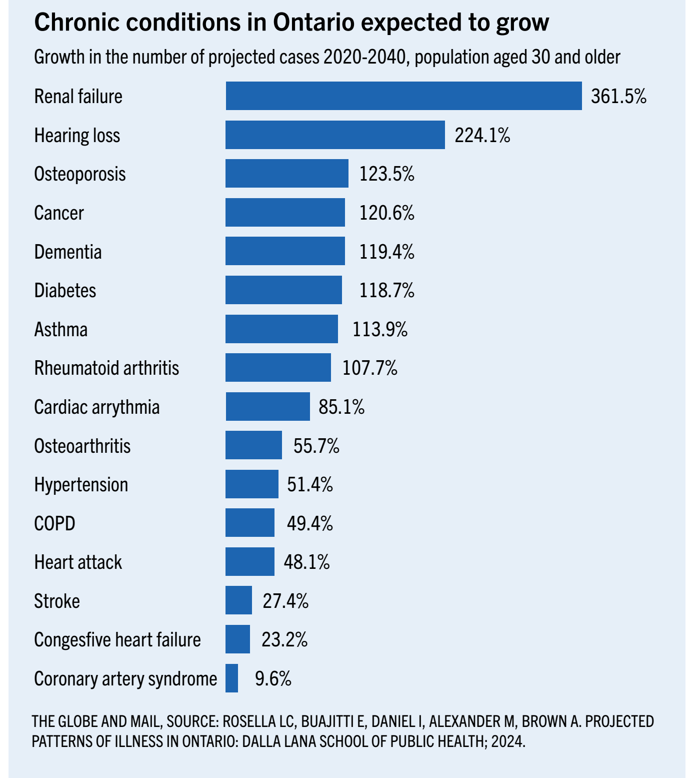
In 2019, Public Health Ontario and Cancer Care Ontario (CCO) issued a joint review of the impact of chronic diseases in Ontario.[6] The report makes a number of important observations, including:

- About three-quarters of all deaths are due to chronic diseases.
- There were 1.3 million people with diabetes, 1 million with ischemic heart disease, 900,000 with chronic obstructive pulmonary disease and 600,000 who had a cancer diagnosed in the past.
- Cardiovascular diseases accounted for the largest number of new chronic disease cases as well as the largest number of hospitalizations.
- The total annual economic burden of chronic disease risk factors was estimated to be $7.0 billion for tobacco smoking, $4.5 billion for alcohol consumption, $2.6 billion for physical inactivity and $5.6 billion for unhealthy eating, including $1.8 billion for inadequate vegetable and fruit consumption.
- Chronic diseases have a disproportionately high impact on Indigenous peoples in Ontario – the number of chronic diseases, deaths and risk factors are all higher, and the incidence of cancer is also increasing more rapidly than in the non-Indigenous population.

These challenges are only expected to intensify in the coming years. A study released in October 2024 by the University of Toronto’s Dalla Lana School of Public Health in conjunction with the Ontario Hospital Association (OHA) projects that in 15 years:

- 3.1 million adults will be living with major illness in Ontario in 2040 – an increase of 72% from 1.8 million in 2020 and more than triple the 960,000 in 2002.[7]
- Approximately one in every four Ontario adults over the age of 30 in 2040 will be living with a major illness requiring significant hospital care. This is double the figure of approximately one in eight individuals living with a major illness in 2002.[8]
- Major illnesses will be affecting more than 10% of the population aged 30 to 64, up from 5.7% in 2002.[9]

The bar chart below illustrates the major chronic illnesses that are expected to grow over the next 15 years in Ontario.



Large increases in a wide variety of major chronic medical conditions are expected in the Ontario population over age 30 between 2020 and 2040.[10]

Each one of these illnesses has profound effects on the Ontario health system and the resources it needs to meet the demand (see appendix for insights on the impact of diabetes, arthritis and dementia in Ontario).

Unfortunately, there has been limited action to address these challenges. The most recent Ontario Chronic Disease Prevention Strategy for 2020-2023 is now out of date. [11]

Immediate actions for diabetes

According to Diabetes Canada, 1.7 million Ontarians or 11% of the population had been diagnosed with either type 1 or type 2 diabetes in 2024 and this number will increase to nearly 2.3 million by 2034.[12] The direct cost to the Ontario health system was $2.2 billion in 2024.

The impact of diabetes is also felt in the additional health issues the disease can cause. Diabetes is a contributing factor in 30% of strokes, 40% of heart attacks, 50% of kidney failure requiring dialysis, 70% of all non-traumatic leg and foot amputations and is a leading cause of blindness.

Ontario is exposed to higher rates of type 2 diabetes due to several non-modifiable risk factors in the population, including age, gender and ethnicity. Almost 19% of Ontarians are over 65 years old and the risk of developing type 2 diabetes increases with age. Another risk factor is that over a third of Ontarians self-identify as being of African, Arab, Asian, Hispanic or South Asian descent, all groups that are of higher risk of developing type 2 diabetes. Additionally, there are over 400,000 Indigenous people in Ontario who face significantly higher rates of diabetes and adverse health consequences than the overall population.

In addition to these non-modifiable risk factors, Ontario has high rates of other factors that could be modified with effective collective and individual action. This includes high rates of adults and youth aged 12 to 17 being physically inactive (49% and 61% respectively), adults being overweight (35%) and obese (30%), adults not eating enough fruits and vegetables (80%) and adults smoking tobacco (8%).

Social determinants of health also play a large role in the rate of diabetes because they influence these modifiable risk factors. Ontario has one of the highest prevalence rates of low income among all provinces and people living with diabetes in Ontario face high out-of-pocket costs to manage their diabetes effectively. The costs for those with type 1 diabetes range from $694 to $5,245 (2% to 17% of average family income) while costs for those with type 2 diabetes range from $287 to $4,985 (1% to 17% of average family income).

In this context, immediate actions to address diabetes will deliver cascading benefits for all patients across the chronic disease spectrum, as learnings can be used to inform a more comprehensive chronic disease strategy down the line.

Below we provide a number of immediate actions that can be taken to address diabetes – the most serious and prevalent chronic disease in Ontario.

1) **Establish a dedicated diabetes management team within Ontario Health**: In alignment with Motion 45, which calls for the development of a comprehensive diabetes strategy in Ontario, we recommend establishing a dedicated diabetes management team within Ontario Health. This team would be exclusively focused on coordinating all diabetes-related programs and activities across the province. It would also serve as a central point of collaboration with civil society organizations, such as Diabetes Canada, and private-sector partners, including pharmacies and testing service providers, to drive concrete action and ensure an integrated approach to diabetes prevention, management, and care.
   A core element of this strategy must include meaningful engagement with Indigenous communities, recognizing the disproportionate impact of diabetes and respecting the Truth and Reconciliation Commission's Calls to Action. The team will prioritize partnerships with Indigenous leaders and organizations to ensure culturally relevant approaches and equitable outcomes.

2) **Expand diabetes screening in pharmacies:** Work with pharmacies and fund additional diabetes screening services in pharmacies to diagnose and treat people with diabetes at the earliest possible stage to help mitigate future complications.

3) **Develop targeted awareness campaigns and education programs**: Promote a two-pronged approach to address diabetes prevention and management among at-risk populations:
   a. Develop targeted awareness campaigns designed to increase disease understanding, encourage early testing, and identify individuals at risk.
   b. Empower and fund culturally appropriate diabetes education programs that support individuals in achieving effective self-management by providing relevant tools, resources, and guidance tailored to their unique needs and circumstances.
   c. Support people with diabetes by supporting healthcare providers who have different levels of diabetes expertise with funding, raising awareness and promoting Diabetes Canada Healthcare Provider Education Programs and Resources.

4) **Promote community initiatives like Cities for Better Health:** Advocate for all municipalities across Ontario to follow the example set by the *Peel Region*. For example, the City of Mississauga by joining the Cities for Better Health project and the Novo Nordisk Network for Healthy Populations. Municipalities are encouraged to develop their own tailored Healthy City strategies, aligning with this proactive approach to foster healthier environments, improve population health, and curb the prevalence of diabetes at the local level.

5) **Streamline administrative processes, particularly for lifelong conditions like type 1 diabetes:** Identify and address areas of excessive administrative burden that hinder access to care and the effectiveness of professional practice. For example, individuals living with type 1 diabetes are currently required to submit annual attestation letters from an endocrinologist to maintain access to certain products and services. Given that type 1 diabetes is a lifelong condition with no cure, this requirement places unnecessary strain on both healthcare providers and those living with diabetes. Streamlining processes like these is essential to alleviate resource demands, enhance care delivery, and respect the time and needs of all involved.

6) **Integrate diabetes-specific mental health care:** Integrate diabetes-specific mental health care into Ontario's existing mental health system, ensuring that practitioners are equipped with the specialized knowledge and skills provided by the Mental Health + Diabetes Training Program.

7) **Prioritize and consolidate the treatment of diabetes-related complications:** Build and expand on the expertise of the varied local diabetes programs under one administration to ensure consistent delivery of services and care and void unnecessary duplication of efforts. Foster meaningful partnerships among patients, caregivers, researchers, and healthcare providers to collaboratively define priorities, design implementation strategies, and drive knowledge mobilization efforts to enhance care delivery, improve patient outcomes and reduce the burden of complications such as diabetic retinopathy and lower limb amputation across the province.

Longer-term actions for all chronic diseases

Prevent

> *"The doctor of the future will give no medicine but will instruct his patient in the care of the human frame, in diet, and the cause and prevention of disease."*
>
> – **Thomas A. Edison (1847-1931)**

We have not yet reached this "future" as imagined by Thomas Edison a century ago. Indeed, medicines are more important than ever and play a vital role in the prevention of disease, such as statins and high blood pressure treatments to prevent cardiovascular and heart disease or, of course, vaccines.

Nonetheless, prevention has a crucial role to play in managing chronic diseases, even if we won't see the fruits of today's efforts for many years, perhaps for a whole generation. But there is no doubt the seeds of prevention planted today will, eventually, bear sweet fruit.

The key to prevention is education, and that is where any comprehensive program to prevent chronic diseases in the future must start – in the schools and with other educational opportunities. The effort needs to be intense, sustained and sustainable – half measures, or symbolic measures, will not do.

Fortunately, we know that it can be done. Over the past 60 years, huge strides have been achieved in preventing multiple diseases from the use of tobacco. In 1965, about 50% of Canadian adults over age 15 (and more than 60% of men) smoked. In 2020, the rate of adults smoking was 10% – a reduction of 80%.[13] In 2020, the Canadian Cancer Society reported that "incidence and mortality rates (for lung cancer) among males have been declining for over 20 years. The decline in incidence has been especially notable since 2012. Among females, rates began to decline in 2012 for incidence and in 2006 for mortality," tracking the delayed decline in smoking rates among females.[14]

Successful prevention work has also been done elsewhere. The National Health Service (NHS) in England says it has been "keenly focused on prevention work" since its creation in 2013. NHS England says it developed the world's first national diabetes prevention program and that it resulted in a 7% reduction in the number of new diagnoses of type 2 diabetes in participating areas between 2016 and 2018. The program also helps people change their habits related to the top six risk factors driving mortality and morbidity in England: tobacco use, high blood sugar levels, high body mass index, dietary risk, high blood pressure and alcohol use. For example, the NHS Digital Weight Management Programme provides targeted support for adults with obesity who also have a diagnosis of diabetes, high blood pressure or both.[15]

In this context, here are actions that can help with chronic disease prevention:

1) **Partner with patient organizations and health professional groups to advance education on prevention:** This work would focus on chronic diseases in general and education and risk management of the key preventable potential causes of chronic disease: poor diet, tobacco and alcohol use, and lack of adequate physical activity.

2) **Strengthen early detection and monitoring of at-risk populations:** This is the next crucial step after prevention – find illness early when it can be more efficiently and effectively treated with fewer resources, rather than waiting for it to become a crisis. Doctors have played an important role in delaying or preventing many chronic diseases in recent years by such actions as prescribing statins to lower high cholesterol or medications to lower high blood pressure, which help prevent more serious cardiovascular illness. It is time to harness new technologies and new ways of delivering health education and knowledge to help people recognize the early signs of chronic illness so action can be taken right away to prevent disease progression. Every month or year gained at the early stages of illness can reap large rewards for patients and the health system.

Mitigate

> *"It is not the strongest of the species that survives, nor the most intelligent. It is the one that is most adaptable to change."*
>
> – **Charles Darwin (1809-1882)**

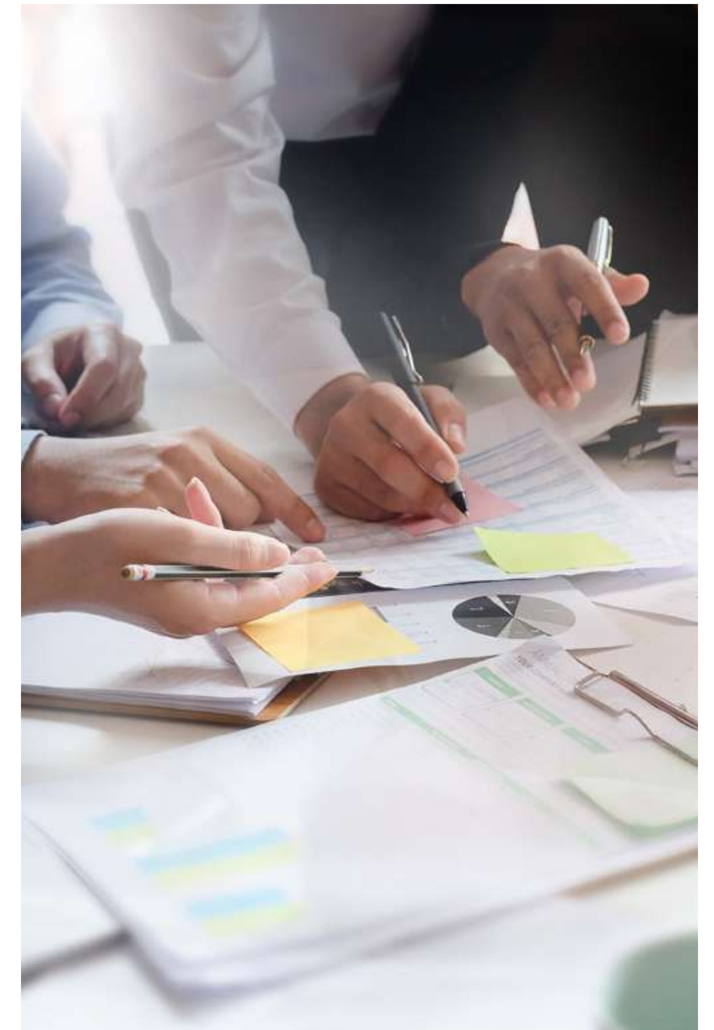
The basic structure of Ontario's current health system was created in the 1960s and has not changed significantly since then.

It is time for fundamental changes to how the Ontario health system operates. Our health system must accommodate the needs of people with long-term chronic diseases, starting with the structure and approach for managing and delivering care.

Here are actions to make this happen:

1) **Adapt or create new data collection systems:** These would help track and learn about chronic diseases, the impact of different investments and programs and to measure overall progress. This information should be regularly reported so the public, academics and decision-makers have transparent access to reliable data about progress with chronic diseases, aligning with Ontario Health's embedded delivery priorities of Clinical Excellence and Health System Performance and Maximize System Value by Applying Evidence.

2) **Embrace innovation and technology in care delivery:** Ontario is vast. With more than 1 million square kilometres it is larger than France and Spain combined. We need to ensure that all Ontarians have access to the chronic disease care and services they need wherever they live. This is far more achievable now than ever before thanks to remote technology. Monitoring technology now allows patients to be supervised by medical personnel from afar, allowing prompt care immediately rather than having to wait weeks or months for an in-person consultation. Providing high-quality and timely care to all Ontarians, no matter where they live, is certainly technically feasible and should be implemented to improve the prevention, diagnosis and treatment of chronic diseases in Ontario.



Manage

> *"Patients don't care about your policies. They care about how you treat them."*
>
> **– Barbara Balik, Institute for Healthcare Improvement**

Most citizens are happy to be blissfully ignorant about how the health care system works provided it is giving them the care they want, need and deserve. In Ontario in 2024, too many are not happy and are therefore seeking both to understand and change the system.

That is not to say that a lot of good doesn't still get done. Many Ontarians have excellent experiences with the health system and have had trusted and dedicated professionals help them over many years. As a result, they have enjoyed long lives in relatively good health despite facing one or more complex chronic diseases that a generation ago would have shortened their lives considerably.

We must not forget the good stories, but they should not cloud our judgment about the need for change, if only to drive better efficiencies from the considerable resources we as a society devote to health care. But we can do far more than just do things more efficiently and save money. More can, and must, be done for patients. The Ontario government's $1.8 billion investment to connect two million more people to a publicly funded family doctor or primary care team within four years is an important step for change and recognition of the burden on primary care doctors. Our goal is not to add to this burden, but to ensure they have the resources and tools needed to be more effective alongside this investment.

We need to improve diagnosis, treatment and care services for citizens with varied needs that change over long periods of time by making some important changes.

Here are three proposed actions:

1) **Improve access to care and treatment:** The Canadian and Ontario public health system is focused on providing universal doctor and hospital care, with pharmacare available to almost all and, perhaps, becoming universal in the near future. However, Ontarians with chronic diseases often need far more in order to live their best life possible with their condition. Strategies to optimize the effectiveness of available therapies, such as introducing biologic therapy early in the course of a chronic disease and using therapeutic drug monitoring to guide treatment with biologics have the potential to improve long-term prognosis and longevity of current medical treatment options. As well, access to physical aids and adaptations to dwelling places will greatly improve a patient's quality of life or even allow them to remain in their own residence.

2) **Enhance the role of allied health care professionals:** Action must be taken to ensure Ontarians with chronic diseases have universal and affordable access to all the services that can help them manage their condition, including counselling, dietician services, physio and occupational therapy. Allied healthcare professionals provide needed guidance and support that improves the quality of life and disease management for people living with chronic diseases.

3) **Identify consistent pathways for care:** There is a pressing need to establish consistent pathways for care that allow people living with chronic disease to receive timely access to suitable care and support for managing their condition, without ending up in or relying on emergency rooms. Standardized collaborative care models should be prioritized, particularly for those living in northern and rural areas who experience gaps in access to specialist care.

Conclusion

Motion 45 was an excellent first step towards doing more to address the problems and challenges of treating chronic disease in Ontario. However, it's just a first step.

This paper makes common-sense recommendations about how to address the problems and challenges Ontario faces in managing the ever-growing issues related to diabetes and other chronic diseases – changes that would also help ease the tremendous overall challenges currently faced by the province's health system.

Clearly, we are asking too much today from a health system designed and organized to treat and manage acute health problems while a far greater level of demand comes from those trying to live with chronic conditions. It's time to adjust to that new reality.

The goal must be nothing short of a complete transformation of Ontario's health system and services, of which preventing and caring for Ontarians with chronic diseases must be a key part.

A final word from patients

We thank Life Sciences Ontario and its members for their collaboration with Diabetes Canada and the Health Charities Coalition of Canada in the development of this absolutely vital vision paper to show what needs to be done in Ontario to prevent, mitigate and manage the epidemic of chronic diseases in the province.

As organizations working with patients, we know the immense challenges faced by Ontarians with chronic diseases in accessing the care and services they need from a health system that simply wasn't designed to care for them. We acknowledge the tremendous effort of the dedicated workers within the Ontario Health System who continuously adapt to deliver services to meet the growing needs.

This vision paper outlines some of the changes that we believe are necessary to transform our health system from one designed for short-term acute care to one that better reflects the current and future reality where the prevention, diagnosis and management of chronic conditions is the major need. We propose some viable immediate steps that can be initially taken to help Ontarians with diabetes and later be expanded to other chronic diseases, making the process stepwise and feasible.

The intention of these recommendations is to build on Motion 45 by proposing options that will support the immediate and future needs of individuals living with chronic disease while also being cognizant of the costs required to transform and sustain a viable health care system.

We look forward to continuing to work with the Ontario government and all involved in the health system in this province to helping make our vision a reality.

Glenn Thibeault,
Executive Director, Government Affairs & Policy, Diabetes Canada

Connie Côté,
Chief Executive Officer, Health Charities Coalition of Canada

Appendices

A. Where progress is being made: Best practice case studies

Case Study #1 – Remote Hospital Monitoring

An important development in technology could have widespread implications for treating chronic diseases in Ontario – the ability to monitor patients effectively remotely and thus provide virtual care.

One of the "powerhouses" of this new technology is Toronto's Grace Health Centre, as reported in an article in *Canadian Healthcare Technology* magazine in September 2024.[16]

Grace Health specializes in complex, continuing care and in providing post-surgical rehabilitation. Over the past several years it has focused on building its expertise and technical capacity for remote monitoring of patients. In the summer of 2024 it was monitoring 16,000 patients across Ontario but was growing rapidly and expected the number to be 25,000 to 30,000 by the end of 2024.

The hospital has Ontario patients it is monitoring in Toronto from as far away as Thunder Bay, Ottawa and London. Following agreements with other provincial governments, it started monitoring patients in British Columbia in June 2024 and in September it did so for patients in Prince Edward Island.

The goal of this program and expansion, according to Toronto Grace president and CEO Jake Tran, is "to eliminate ALC" in hospitals. ALC stands for Alternate Level of Care and refers to patients who are occupying much-needed beds in acute-care hospitals when, medically, they don't need that level of care but must remain in hospital because there is nowhere else for them to go, such as in continuing care or rehabilitation centres. However, remote monitoring allows many of these patients to return home and still receive the level of care they need, thus freeing up acute-care hospital beds.

Ontario Health, Tran said, has asked Grace Health to keep growing its program because, he said, while a hospital bed costs $500 a day Grace Health will do the monitoring for $10 a day.

According to the article, many of the patients being monitored are older people living with frailty but also with chronic diseases such as COPD, heart failure, diabetes and dementia.

The Grace Health technology, developed by GRTHealth of Aurora, Ontario, includes various devices, including a medication dispensing machine that allows remote tracking to ensure treatments are taken on time, sensors to monitor vital signs that are sent to the monitoring station, a pendant worn by the patient that detects falls and provides voice communication with an SOS button to summon urgent help, as well as sensors in the home and geo-fencing to monitor if the patient is moving normally or needs help.

The command centre at Grace Health is manned by nurses or personal support workers with training in geriatrics who can summon doctors, paramedics or even police when needed.

Grace Health is also developing an electronic toy dog that is capable of conducting conversations to help overcome social isolation of patients at home.

Overall, the project demonstrates the huge potential for cost-effective (and home-grown) technological solutions to some of the most pressing problems facing the health care system, particularly in its management of patients living with chronic diseases.

Case Study #2 – Ontario Diabetes Education Program

As one of the first fatal diseases to start becoming a chronic disease a century ago, diabetes treatments and programs have often been pioneering – particularly in meeting the important need of educating patients and their families about how to live in the best possible way with the disease.

The Diabetes Education Program (DEP) in Ontario grew out of education programs developed in individual hospitals in the province. The Ministry of Health first set diabetes reform as a strategic priority in 1992 when there were 50 such DEPs operating in Ontario hospitals, including nurse and dietitian educators to teach patients skills to care for themselves. In 1996, a Diabetes Complication Prevention Strategy added or expanded 33 DEP projects. Following the launch of an Ontario Diabetes Strategy in 2008, 101 new DEPs were created in 2010-11 in hospitals, community health centres and family health teams, bringing the total to 322. In 2013, administration of the DEPs (except those operated by family health teams and non-profit organizations) was transferred from the Ministry of Health to the province's Local Health Integration Networks (LHINs).[17]

At present, DEPs are available to any Ontario resident 18 years and older who has been diagnosed with diabetes or is at high risk of developing it, has a family history of diabetes or a diagnosed family member. The goal is to help people "develop life plans to help minimize your symptoms and delay or prevent the onset of diabetes complications" as well as to "learn self-management skills from a team of health care professionals." There is no cost to those participating.[18]

A study by Toronto-based researchers published in 2020 evaluated the impact of integrating diabetes education teams in primary care on glycemic control, lipid, and blood-pressure management in type 2 diabetes patients after noting that diabetes self-management education programs and services are under-utilized in Canada, being used by just 25-30% of those with type 2 diabetes. This rate is even lower in older adults (age 65-79), low-income earners, recent immigrants and those with mental health or other physical conditions. It also noted that physician referrals to these programs are low, ranging from 14% to 52%, possibly because of low awareness by physicians themselves.[19]

The study, which assigned some patients to education programs while others were not, showed that "integrating diabetes-education teams, comprising nurses and dietitians, into primary care settings can meaningfully impact patients' ability to meet recommended A1C (hemoglobin) targets over a one-year period." The researchers concluded: "This model is likely to succeed in other settings with similar medical-care resources, as a strategy to improve glycemic control among and support to patients living with type 2 diabetes."[20]

The diabetes experience with patient education programs in Ontario has certainly not been perfect but they do show that there is great potential for doing more in creating special activities to support those not just with diabetes but also living with other chronic diseases.

Many hospitals have specialized clinics and services for other chronic illnesses beside diabetes, such as for respiratory diseases, cardiovascular diseases, mental health disorders and many more. However, there is limited coordination of the nature or type of services these clinics provide, unlike the province-wide coordination of the Diabetes Education Program.

Case Study #3 – Transitioning from Child to Adult Care

A major challenge for children who have a chronic illness occurs when they turn 18 and have to transition from the services provided by a children's hospital into the adult care system. It is often very challenging, not just because it involves a major change for the patient and his or her family but because the services provided adults are usually less comprehensive than those provided for children and often "adults" have to do more care and appointment coordination for themselves compared to what is done by institutions serving children.

A paper released by the Canadian Paediatric Society's Adolescent Health Committee in April 2022 recommended that parents and caregivers start transition planning as early as possible, "to ensure youth with complex health care needs receive continuous care during what can be a vulnerable time."[21]

The statement notes that because treatment for many childhood conditions have advanced, the number of youths with complex health care needs is increasing and conditions that used to be very life-limiting are now essentially chronic diseases. For example, children with cystic fibrosis, for which life expectancy used to be very low, can now expect to live well into adulthood, or even old age. The paper says poor outcomes from the transition are seen in patients with cystic fibrosis as well as those with type 1 diabetes, congenital heart disease and other conditions.

That's because despite the medical advances, the health system hasn't kept pace, as noted by one of the authors of the paper, Dr. Megan Harrison, an adolescent health physician at Children's Hospital of Eastern Ontario (CHEO). "Despite our vast knowledge of the challenges associated with transition to adult care, we have not made significant advancements to streamline and safeguard care for youth transitioning to adult services," she said.

The paper also says the system needs more flexibility to manage different needs, rather than forcing all youths into the adult system abruptly at age 18. It says youths "should be given increasing levels

of responsibility over their health care – at their own pace – as they move through adolescence."

Another co-author, Dr. Alène Toulany, an adolescent medicine specialist at The Hospital for Sick Children in Toronto, said, "We need to think outside the box and advocate for more flexible age cut-offs for transfer to adult care. Considering each youth's developmental stage and capacity as well as patient and family needs and circumstances are essential for a successful transition."

The statement said that "a successful transition ensures care that is continuous, coordinated, and adapted to each youth's development and maturity, while improving (or at least maintaining) disease management, patient satisfaction, quality of life, and social participation throughout young adulthood."

The Hospital for Sick Children says its goal "is to help prepare these youth and their families to transition out of SickKids with the necessary skills and knowledge to advocate for themselves (when they have the capacity to do so), maintain health-promoting behaviours, and utilize adult health-care services successfully. We believe that children and youth with chronic health conditions can acquire skills while in the paediatric system that will assist them in managing their health care both now and in the future."[22]

In a comment in a 2023 article about the transfer of a seriously disabled 21-year-old patient from SickKids (a transfer delayed by the COVID-19 pandemic) to an adult hospital for continued treatment of his complex needs, a SickKids spokesperson said: "SickKids Complex Care Program is a unique pediatric program that co-ordinates their comprehensive care needs. There are no equivalent programs for young adults with medical complexity within a single adult hospital in Ontario."

The patient's mother wanted him to continue at SickKids because she had not found doctors with the same resources or knowledge of the care her son, Jacob, needs. "When you have a child like Jacob, it comes down to picking your battles," she said. "This is one that for me and for our family, we truly believe that Jacob's life is at stake, that he will not get the type of care that he needs."[23]

Case Study #4 – Pharmacy health clinics

Several provinces in Canada have been aggressively expanding the medical services that can be provided in pharmacies as a means of alleviating pressure on hard-to-access primary care services in the health care system. These pharmacy services can be particularly useful for patients with chronic diseases who don't have a regular family physician but do need to take regular medication and need adjustments or refills, as well as counselling about symptoms and treatments.

Alberta has been particularly assertive in expanding the role of pharmacists, a May 2024 study from the Montreal Economic Institute (MEI) showed. Alberta pharmacists have the largest prescribing authority in the country – the ability, after special training, to prescribe any prescription medicine (Alberta Schedule One drugs). They can also substitute prescribed medications, which is useful when a patient reports adverse reactions to a prescribed treatment. Pharmacists can also order and interpret lab tests.[24]

Alberta is aggressively expanding its pharmacist-led clinics following the opening of the first one in Lethbridge in 2022. It has seen between 14,600 and 21,900 patients per year since then. Shoppers Drug Mart announced in January 2024 that it would be opening more pharmacy clinics in the province to bring the total to 103 by the end of 2024.[25] Shoppers' promotion for its pharmacy clinics specifically mentions their ability to help people with chronic diseases, saying, "Get the support and education you need to manage chronic diseases like diabetes and heart disease from a Pharmacist."[26]

The MEI report noted that a 2019 peer-reviewed study found that pharmacists could handle 35% of avoidable emergency room visits in Canada. "By enabling pharmacists to play a larger role in its health system, Alberta is redirecting minor cases from emergency rooms to more appropriate facilities," said Krystle Wittevrongel, author of the MEI study. "Just imagine how much faster things could be if pharmacists could take care of 35% of the unnecessary load placed on Canada's emergency rooms."[27]

In Nova Scotia, the province is piloting a program of Community Pharmacy Primary Care Clinics with the Pharmacy Association of Nova Scotia to alleviate waiting lists for those without a primary care physician. The pilot pharmacies are located in areas where there are largest numbers of people without a family doctor. These pharmacist-led clinics provide assessments and treatments for minor ailments such as strep throat and urinary tract infections, as well as what they describe as "Chronic Disease Management (Diabetes, Asthma, COPD)."[28]

Prince Edward Island has also launched a similar service, Pharmacy Plus PEI, which offers residents renewal of eligible prescription and the provision of prescription medicines for various minor ailments.[29]

In Ontario, pharmacists are permitted to prescribe and provide prescription treatments for some minor acute ailments, and the government is considering expanding the list.[30] As for patients with chronic conditions, Ontario pharmacists can renew a prescription that has run out to ensure continuity of care provided they are in possession of the original prescription.[31]

Case Study #5 – Approaches to chronic disease management in Europe

A comprehensive review of the different approaches being taken in 12 different European countries towards the management of chronic diseases shows great variety in how different jurisdictions (at the national, state/region and municipal level) have approached the challenge of helping residents.[32]

The authors conclude: "These generally aim to promote approaches that better integrate care and improve coordination between sectors and levels of care, but countries differ with regard to their vision towards controlling and managing chronic disease."

Beyond this general conclusion, they also reached five more specific conclusions:

1. **The majority of approaches tend to focus on populations with defined conditions:** The five most frequently targeted conditions were type 2 diabetes, asthma/COPD, cardiovascular disease (chronic heart failure, ischemic heart disease, stroke), cancer and mental health problems. The general goal is to enhance coordination of care but there is wide variation in the nature and scope of approaches. The coordination role is most commonly with the patient's family physician.
2. **There is a trend towards strengthening the role of nurses in care delivery and coordination:** Many countries are seeking to enhance the role of nurses to provide self-management support to patients or to perform selected medical tasks. The use of nurses in care delivery and coordination is more common in health systems that have a tradition of multidisciplinary team activities.
3. **Approaches that seek to reduce barriers between sectors remain less common:** Most new approaches in chronic disease management take place within existing organizational and governance structures rather than seeking to overcome barriers between them. They can still be effective but barriers can potentially impede further progress towards a care delivery system better suited to meet complex chronic care needs.
4. **The implementation of approaches frequently involves financial incentives:** New initiatives are generally seen to involve additional funding, most often to support infrastructure and organizational development though in some cases they also involve financial incentives for individual providers or physicians.
5. **Levels of patient and clinician support vary:** Patients usually receive access to new initiatives through their usual care, though many different approaches are used, including some to limit access to people with carefully defined criteria and often involve some form of patient self-management support.

B. Learning the needs and burdens of chronic disease patients

Thanks to the initiatives of some of Canada's leading chronic disease patient groups, there is excellent information and recommendations available about ways Canadians and Ontarians with chronic diseases need and could get improved care, services and assistance of different kinds. Here are a few examples:

Arthritis Society of Canada — *The State of Arthritis in Canada Report Card*

The State of Arthritis in Canada Report Card is a first-of-its-kind report evaluating provinces and territories on access to arthritis care, wellness and commitment to research and innovation.

The report distributed low and failing grades across the nation, underscoring the need for action and innovation in arthritis care. It found a need to invest in research, adopt new models of care, raise awareness and improve data collection to better understand the burden of arthritis and inform actions to improve health outcomes.

This report aims to be an impetus to develop a concrete, solution-oriented national plan to address gaps in arthritis care and research.

See *The State of Arthritis in Canada Report Card*

Asthma Canada — *Charting the path to high-quality respiratory care*

More than 150 certified respiratory educators, respirologists, allergists, general practitioners/family physicians, nurses, pharmacists, and respiratory therapists from across the country participated in the first Canadian stakeholder consensus to lay out a path for high-quality respiratory care for Canadians.

The cost of asthma to the Canadian economy is expected to climb to $4.2 billion annually by 2030. Recommendations from the study present policy makers with a road map and best practices to improve the quality of care, resulting in improved outcomes, quality of life and patient experience for Canadians living with severe asthma and their caregivers.

Concerted action from policy makers and health system leaders will ensure all Canadians living with asthma have access to the quality and timely care they need.

Watch the Asthma Canada video on YouTube: *A Path to High Quality Respiratory Care for Canadians Living with Asthma*

Canadian Cancer Society — *The need to improve palliative care*

A recent report by the Canadian Cancer Society (CCS), *Analyzing Hospice Palliative Care Across Canada: A report on federal, provincial, territorial and community actions*, has found that governments across Canada are falling short of delivering quality palliative care for people with progressive illnesses like cancer, particularly in hospices where beds are few and far between. This is the first time data like this has been available since 2017.

Hospice settings provide critical supportive care for people at the end of their life, and best practices suggest that Canada should have seven hospice beds per 100,000 people. However, most provinces are falling short of this standard so overall Canada had only 3.97 hospice beds per 100,000 people as of May 31, 2022. Of regions surveyed (Quebec and Manitoba did not participate), only British Columbia and Yukon exceeded the standard.

The report was compiled with the Canadian Hospice Palliative Care Association.

See the report: *Analyzing Hospice Palliative Care Across Canada*

Canadian Cancer Society — *The financial burden of cancer*

Another recent report by the CCS reveals the substantial financial toll of a cancer diagnosis in Canada, with the average cancer patient grappling with nearly $33,000 in costs including out-of-pocket expenses and lost income during treatment and recovery.

Canadian Cancer Statistics: A 2024 special report on the economic impact of cancer in Canada was developed by the Canadian Cancer Statistics Advisory Committee in collaboration with CCS, Statistics Canada and the Public Health Agency of Canada with analysis conducted by the Canadian Partnership Against Cancer.

The report is the first of its kind, providing a glimpse into the economic impact of cancer both on patients and the healthcare system itself.

See the report: *Canadian Cancer Statistics: A 2024 special report on the economic impact of cancer in Canada*

Canadian Lung Association — *Virtual pulmonary rehabilitation program*

The Canadian Lung Association's virtual pulmonary rehabilitation program, *Breath Better, Stay Strong,* was developed to meet the needs of those suffering from lung disease who were unable to access local pulmonary rehabilitation services. Pulmonary rehabilitation is a proven way to improve overall health and prevent further illness and hospitalization for those living with lung disease.

The program is available in both French and English and is supported by a once per month virtual support group webinar, hosted by a trained CLA staff member who is a registered respiratory therapist and educator.

Learn about the *BREATHE Better | Stay STRONG* program

Crohn's and Colitis Canada — *Impact of IBD Report*

This updated 2023 report examines the evolving trends in the epidemiology of inflammatory bowel disease (IBD), including updated estimates of indirect and direct costs (including out-of-pocket costs); information specific to IBD in children, adolescents and seniors; issues related to IBD pertaining to sex and gender; information specific to risks associated with COVID-19 and cancer related to IBD; an overview of current treatments for IBD; and evolving care models, including access to care.

See the *Impact of Inflammatory Bowel Disease in Canada* report

Kidney Foundation of Canada — *Financial Burden of Kidney Disease report*

Canadians living with kidney failure face significant financial challenges as a result of dialysis treatment. Starting dialysis often results in a decrease of income at the same time that out-of-pocket costs increase, such as those for transportation to treatment and medication. Government coverage and financial support for people on dialysis varies, resulting in inequalities across jurisdictions.

The Kidney Foundation and the Canadian Association of Nephrology Social Workers (CANSW) partnered to administer a survey of Canadians on dialysis. The findings are outlined in this report.

Core recommendations are: Subsidize transportation costs and expand access to travel grants, particularly for people in rural areas; minimize disparities in accessing medications for people with kidney disease and develop mechanisms to offset costs equitably across jurisdictions; consider the financial and health literacy of patients when operationalizing "home first" policies that aim to maximize the proportion of patients on home dialysis therapies.

See the *Financial Burden of Kidney Disease* report

Additional resources

Diabetes Canada:
https://www.diabetes.ca/

Health Charities Coalition of Canada:
https://www.healthcharities.ca/

Heart & Stroke Foundation:
https://www.heartandstroke.ca/

Canadian Cancer Society:
https://cancer.ca/en/

Arthritis Society Canada:
https://arthritis.ca/

Canadian Lung Association:
https://www.lung.ca/

Asthma Canada:
https://asthma.ca/

Canadian Mental Health Association:
https://cmha.ca/

Alzheimer Society of Canada:
https://alzheimer.ca/en

Crohn's and Colitis Canada:
https://crohnsandcolitis.ca/

Gastrointestinal Society:
https://badgut.org/

Cystic Fibrosis Canada:
https://www.cysticfibrosis.ca/

MS Canada:
https://mscanada.ca/

Muscular Dystrophy Canada:
https://muscle.ca/

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