Evidence Informed Improvement Package

A SUPPORT FOR HEALTH LINKS

bestPATH

Person-centred • Appropriate • Timely Healthcare

Chronic Disease Management

Ontario
Health Quality Ontario

Section 1

Introduction & Overview

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The workbook is divided into six sections for ease of use:

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1.1 bestPATH Overview

Health Quality Ontario's bestPATH initiative focuses on the three key elements of health care delivery that define the best "PATH:" *Person-centred, Appropriate, Timely Healthcare.* bestPATH will focus the healthcare system on optimizing the care it delivers to Ontarians with chronic diseases. Individuals with one or more conditions such as: diabetes, congestive heart failure, coronary artery disease, stroke, and chronic obstructive pulmonary disease have complex care needs involving primary care, home care, hospitals, and specialists. Establishing seamless communication, continuity of care and smooth **transitions** between these areas of care is critical to managing these conditions and ensuring that people consistently receive the treatments that are scientifically proven to benefit them. When they don't, the results could be a worsening of their conditions and hospitalizations that might have been avoided. But when they receive evidence-informed, safe and reliable care that is better coordinated — the right drugs, monitoring, and timely access to services and procedures — their quality of life can be improved, and the burden on families and the health care system can be reduced.

bestPATH will focus on three areas of improvement that are distinct, but interrelated throughout the health care system: transitions of care, chronic disease management, and enabling people to live independently and safely at home.

Chronic Disease Management

Transitions

Supporting Health Independence
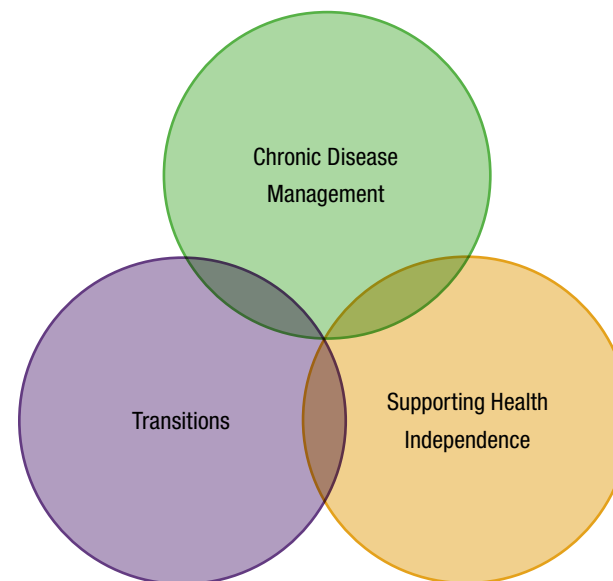
1.1 bestPATH Overview

Addressing these gaps in health care delivery requires nothing less than system-level transformation. Through its curriculum, bestPATH will strive to achieve this transformation with a triple aim approach that will re-focus the system to deliver:

1. **best Care** – Improve the care experience by making care more accessible and provide a smooth journey through the system by ensuring clear communication and strong engagement, both among providers and between providers and recipients

2. **best Health** – Improve outcomes for persons with chronic conditions through the use of evidence-informed best practices

3. **best Value** – Ensure that care occurs in the most appropriate setting, reducing the rate of unnecessary hospitalizations and contributing to more appropriate resource utilization

1.2 Sources of Evidence used in this Change Package

The change concepts and ideas presented in this change package have come from a number of sources and represent a range of evidence. These include topic-specific evidence-based analyses and reviews conducted by Health Quality Ontario or others, evidence-informed change packages/programs published by other organizations (such as the Institute for Healthcare Improvement, Canadian Patient Safety Institute), peer-reviewed articles, and grey literature. Therefore the extent of evidentiary support for the change concepts varies.

Importantly, the experiences of persons who live with chronic disease and the burden of illness, as well as a broad array of providers (e.g., different sectors, professional roles) were collected.

Based on external consultations and emerging evidence, a handful of a themes featured in all three of the bestPATH change packages. These are: a focus on incorporating evidence-informed practice guidelines; strengthening **health literacy** and one's ability to self-manage health and health care; and reducing **fragmentation of care**. Importantly, these themes speak to the barriers to collaboration and focus on putting an individual's needs front and centre.

The continuum of evidence referenced to generate each of the change concepts is included.

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How to use this Change Package
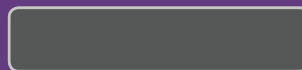
2.1 How to Use This Change Package

Changes That Will Lead to Improvement

Change doesn't always lead to improvement. However, all improvement requires change. Developing, testing and implementing change is integral for any improvement work. However, what types of changes will lead to improvement? This guide describes the **change concepts**, or ideas and innovations which have been shown to be useful in a variety of healthcare environments, in developing specific ideas or changes that will lead to improvement.[1] Some of the change concepts are general are meant to inform the reader of potential themes for improvement, while others are specific and apply to a particular problem or focus area.

Combining these concepts with knowledge about the current performance and challenges inherent in your system will strengthen your team's ability to test and implement solutions that will address the root causes of problems, while not trading off cost and quality.

Organization of Content

This change package provides information that can be accessed sequentially to complete a specific task (or series of tasks), or selectively and independently depending on the user's needs.

Included in this package:

- **An overview** of why effective chronic disease management is important and how a lack of knowledge and management can result in even worse results for individuals with chronic disease

- **Five (5) key change concepts** that should be considered when managing the health of an individual with a chronic disease

- **A deeper dive into the change concepts**, including evidence on why these concepts are important and how they factor into effective chronic disease management. Also included are relevant tools and resources and discussions of where there commonly are breakdowns and challenges

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Section **3**

General Overview of Chronic Disease Management

3.1 General Overview of Chronic Disease Management

Chronic Disease Management is complex and difficult for the person with chronic conditions, their family members, and health care providers. Wagner's Chronic Care Model (CCM) describes chronic care as "the prevention, diagnosis, management, and palliation of chronic disease".[2] This definition is accepted globally as the main strategic response to the challenges of chronic disease. The many challenges to delivering optimal care to individuals with chronic conditions include: the need to vigilantly monitor a variety of health indicators to optimize therapeutic interventions, as well as the need to develop collaborative and productive relationships between the care recipient and their family, specialists and other health care providers who support them in the daily management of their conditions.

Ontario's Chronic Disease Prevention and Management (CDPM) Framework features **self-management** 📄 skill development and supports. Ontario's CDPM Framework is based on British Columbia's Expanded Care Model[3] and the Chronic Care Model (CCM)[4] which recognizes that with proper training and support, many people can alter the progression of their chronic conditions by becoming active agents for their own health.

According to Wagner, chronic disease is best managed by productive interactions between the individual and his or her clinical health team, within a setting that utilizes a reliable, evidence-based approach to self-management.[5] The ultimate goal of the management model is an informed, proactive and engaged person with chronic conditions, as well as a proactive and prepared practice team.[6]

Chronic conditions develop slowly and get worse over time. Medicine is instrumental in slowing the progression of chronic disease. However, cures are rare. Many factors contribute to the development and progression of a chronic condition, including lifestyle choices such as smoking, drinking excessive amounts of alcohol, poor diet, lack of exercise, and many other factors which put people at risk of developing a chronic disease, having a lower quality of life and/or dying prematurely. Thus, evidence suggests that many people can prevent or slow the progression of their condition and associated symptoms, with proper education and support.[7] Bodenheimer *et al.* remind us that people with chronic conditions are their principal care-givers. Health care professionals, as consultants, can be instrumental in supporting them in their role. Each day, it is the person who decides what he/she is going to eat, whether he/ she will exercise, and to what extent they will follow the agreed **care plan** 📄 or consume prescribed medications.[8]

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3.1   General Overview of Chronic Disease Management

Figure 1: Ontario's Chronic Disease and Prevention Framework
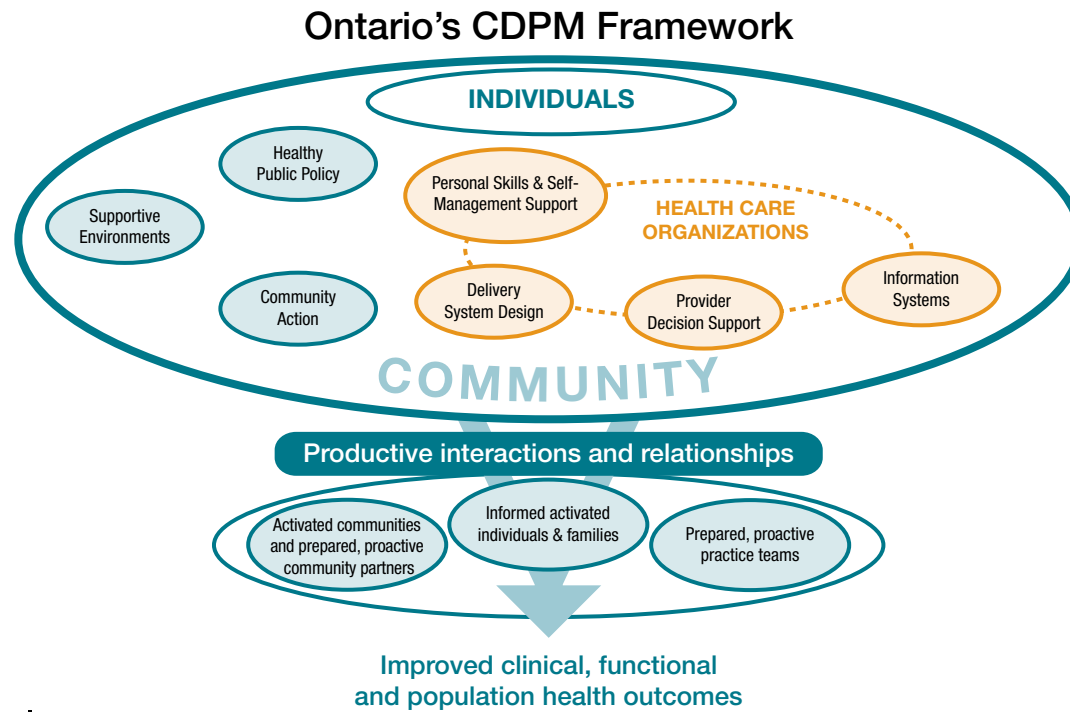
Ontario's CDPM Framework

INDIVIDUALS

Healthy Public Policy

Supportive Environments

Personal Skills & Self-Management Support

HEALTH CARE ORGANIZATIONS

Community Action

Delivery System Design

Provider Decision Support

Information Systems

COMMUNITY

Productive interactions and relationships

Activated communities and prepared, proactive community partners

Informed activated individuals & families

Prepared, proactive practice teams

Improved clinical, functional and population health outcomes

3.1 General Overview of Chronic Disease Management

Why focus on Chronic Disease Management?

Chronic diseases such as congestive heart failure, diabetes and lung disease are becoming increasingly prevalent, especially as the population ages.[9] In Canada, it is estimated that approximately one out of every three people lives with a chronic disease.[10] Additionally, clients who experience chronic disease are often faced with a complex trajectory as a result of multiple co-morbidities.[11] Chronic diseases are typically managed outside of the hospital, with the involvement of specialists, community based and primary care teams, and the clients themselves.[12] However, if care and communication about care are not well coordinated, people are at risk of medication errors and insufficient monitoring, which may lead to frustration and uncertainty for clients and their families. Clients diagnosed with a chronic disease are also at risk of a lower quality of life, adverse health outcomes, emergency department visits and repeated hospitalizations if their conditions are not well controlled.[13]

Ontario's health care system was designed to address acute illness rather than chronic illness. As a result, medical practices are generally organized to respond to a person's acute illnesses which tend to be short, urgent, relatively easily diagnosed and treated. Care tends to be reactive – responding to acute health problems when they present. As a result:

- Medical practitioners rely on the individual to contact the system

- Patients are usually passive while medical practitioners direct treatment

- Visits focus on symptoms rather than achieving goals and optimal health

- Promoting the client's overall health, preventing disease, injury, disability, and ensuring continuity of care across providers are not system priorities

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3.1 General Overview of Chronic Disease Management

These features render the established model of care inappropriate for tackling chronic illness.[14] With this in mind, the change concepts outlined in this change package are designed to help health care delivery teams become more proactive and prepared by answering a handful of key questions:[15]

- What can we do, at every interaction with the person and/or their family, to promote them as the expert in overseeing their chronic condition?

- How can we provide person and family-centred **self-management support**, and who can/ should do this?

- How can self-management support consistently incorporate evidence-informed care?

- How can we organize and use person-level and population-level data to facilitate self-management support?

- How can we be active participants in mobilizing the community to strengthen self-management support?

- How can we create an organizational culture, processes and mechanisms that promote safe, high quality, self-management support?

How Can Chronic Disease Management Be Improved?

Chronic conditions can be more effectively managed using a customized approach which requires collaboration and communication between individuals and their caregivers.[16] The use of technology to manage information and to communicate with all sectors of the health care system, including providers, the individuals and their caregivers will ensure a comprehensive approach to care. Coaching individuals to become partners in their care will ensure optimal self-management. Developing cooperative relationships with specialists and other community partners will lead to improved monitoring and management of chronic diseases.

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Change Concepts

4.1   Change Concepts

Five (5) key change concepts have been identified to address major gaps in helping people – with or without chronic illness – live independently and safely at home.

CHANGE CONCEPT	CONTINUUM OF EVIDENCE
1. Introduce decision supports to deliver evidence-informed care	Grey literature, expert opinion, promising practices via field testing
2. Use information management systems to assist in the development of a proactively-planned care approach and to help patients be more informed	Systematic review conducted by others, grey literature, expert opinion, promising practices via field testing, grey literature, expert opinion, emerging innovations
3. Enable the person to take a central role in their health and in managing their chronic illness	Published systematic review, grey literature, expert opinion, promising practices via field testing
4. Provide optimal monitoring and management of chronic and preventative care	Grey literature, expert opinion, promising practices via field testing
5. Integrate specialists and community-based resources into the primary care practice or team	Grey literature, expert opinion, promising practices via field testing

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4.1 Change Concepts

Introduce decision supports to deliver evidence-informed care

- Use flow sheets (or electronic medical record (or electronic medical record [EMR] stamp) to prompt evidence-based discussion and care planning during the person's visit (e.g., annual retinopathy and neuropathy foot check for people with diabetes, smoking cessation discussion for individuals who smoke)

- Use alerts and electronic recall functions to notify the care team that a person is due for primary and secondary prevention activities (e.g., vaccinations, blood work and follow up diagnostic examinations such as HbA1C test)

- Share and discuss evidence-informed care information with the individual; help him/her to recognize optimal care and to manage their care at home

- Educate primary care team members about evidence and best practice guidelines

Use information management systems to assist in the development of a proactively-planned care approach and to help patients be more informed.

The purpose of designing effective health care information management systems is to ensure that both person and population-level data is accurate, comprehensive and accessible. This permits:

- Proactive care planning and delivery based on;

  ° Timely alerts and reminders for providers and clients/ patients regarding upcoming appointments or milestones

  ° Identification of relevant sub-populations targeted to receive more involved or complex care

- Individualized care planning, including;

  ° Optimal medication management

  ° Follow up on diagnostics, referrals and consultative reports

  ° Summary of goals and progress (monitoring)

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4.1 Change Concepts

- Sharing of relevant information with the person and providers to coordinate care

- Monitor the performance of the health care team and system

The individual has a central role in their health and in managing their chronic illness

- Each interaction between the individual and their primary care provider should include an assessment of the person's self-management skills as well as their clinical status

- Build self-management support including assessment of skills, goal setting and action planning, monitoring, problem solving, and active follow up into the practice and every interaction. Create a shared care plan

- Provide care that the individual and their caregivers understand and that meets their stated goals and preferences. Share and discuss information (lab results, consultation results) with the individual and their caregivers. Use graphs or other displays to help people understand their condition

- Create tools for the individual to bring to their next visit, such as self-monitoring logs, episodes or concerns, questions, up to date medication lists

- Similarly, for every visit, give the person and/or their family caregivers an opportunity to share their experiences and ask questions. For example, in the last two weeks, have you;

  ° Felt short of breath when walking?, etc.

  ° Had difficulties with ordinary activity?, etc.

  ° Felt depressed or little interest in doing things?, etc.

  ° What would you like to discuss during today's visit?, etc.

- Organize practice and care delivery systems to support person-specific and person-centred care. Know and understand the person's goals, monitoring requirements and milestones

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4.1 Change Concepts

Provide optimal monitoring and management of chronic and preventative care

- Prepare, in advance, for the next person's visit (e.g., ensure referral information/consultation is available in the chart, as are up to date lab results)

- Conduct primary care team huddles to review the day (or week) ahead, based on the needs of people who are scheduled to visit, discuss resource requirements, concerns, etc. to prepare for visits and meet demand

- Use standing orders and medical directives (e.g., for adjusting insulin) to deliver evidence-informed care

- 'Max pack' visits to address multiple patient needs while they are in the office

- Provide advanced access (or day of choice access) for all persons in the panel

- Book next visit before the person leaves the office

Integrate specialists and community-based resources into the primary care practice

- Establish processes for use of specialized services – referral procedures, information needed and processes for getting information back from specialized services about the individual's visit and the resultant care plan

- Connect individuals to appropriate community resources (e.g., public health smoking cessation programs, CCAC, local recreation facilities, NGO programs/groups/supports)

- Establish processes for smooth transition and communication for individuals who have received specialty and acute care

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4.2 A Deeper Dive Into the Change Concepts

This section provides a more in-depth look at each of the change concepts, why they are important, and what breakdowns can occur in these aspects of an individual's care. This section also provides some tools and resources that are specific, evidence-based that provide instructions and templates on how to implement the change.

Introduce Decision Supports to Deliver Evidence-informed Care

Why is this Important?
Decision support begins, but cannot end, with the dissemination of evidence-based guidelines.[17] A number of guidelines cross the desktops and line the bookshelves of care teams across all health sectors. While it is important to be familiar with the evidence and guidelines relevant to practice, it may be difficult to incorporate this evidence *into* practice. Clinical decision making based on evidence is easier when the evidence is available in real time (e.g., during the patient's visit)

Guidelines support the implementation of primary and secondary screening activities as well as the treatment of disease. Through exploration of data and monitoring of practice indicators aligned with guideline recommendations, health care organizations can improve individual and population management. For example, nursing resources may be redeployed each fall to support influenza vaccination clinics in the community, primary care, long-term care and hospitals. A primary care office may partner with a local optometrist to increase retinopathy screening for individuals with diabetes.

Individuals have more access than ever to information pertaining to management of their health and wellness and living with chronic disease. One way in which care teams can support and enable individuals to make informed decisions is through the sharing of evidence-based guidelines in a format and delivery appropriate to the user. Consideration needs to be given to the individual's level of health literacy and preferences for obtaining, organizing and synthesizing information. This will require care teams to develop skills in collaborative practice, interviewing, and self- management support, in order to have effective interactions with patients.

Health care education and professional development need not be limited to the clinical arena. New skill sets are required to create the kind of patient-provider interactions and practice changes that will lead to prepared, proactive health professionals and teams as well as informed and activated patients.

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4.2 A Deeper Dive Into the Change Concepts

TIP!

- Make the right thing to do the easy thing to do for care team members: embed guidelines in flow sheets, EMR stamps and templates and have guidelines accessible in user-friendly formats that provide information at a glance

- Share the guidelines with individuals and their **caregivers** 📄 in a format that is easy to understand. Consider literacy as well as culturally appropriate presentation of the information

- Understand the many ways and places that individuals search for and access information and navigate their lives

Typical Breakdowns and Challenges

- It is a challenge for any one provider to stay on top of emerging evidence and updated guidelines

- Based upon new and emerging guidelines and evidence, practice resources require ongoing monitoring and updating to maintain relevance; patient handouts, EMR stamps, templates, flow sheets require ongoing review

- There may be a number of different guidelines with conflicting recommendations where multiple risk factors and co-morbidities exist

- Patients receive information from a number of sources. They may receive too much information, conflicting information, or gain access to unreliable information

- The needs and preferences of individuals are often not considered when they are provided with evidence informed materials. A "one size fits all" approach to educational and support materials is not effective. Individual needs should be considered and accommodated

- Patient education and self-management support begins and ends with the distribution of handouts, tools and web resources. Reference to best practices and evidence needs to be woven through ongoing conversations and contacts, supporting individuals to make informed decisions about managing health and living with a chronic disease

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4.2 TOOLBOX *All tools and resources were accessed / verified in April 2013.*

Resources to help embed clinical guidelines into each visit and share evidence with the person and/or their family members.

- Stand Up to Diabetes – Passports and Goal Card
  http://www.health.gov.on.ca/en/public/programs/diabetes/card/

- COPD Action Plan www.lung.ca/pdf/1408_THOR_ActionPlan_v3.pdf

- Recommendations for the management of COPD – 2008 Update
  http://www.respiratoryguidelines.ca/sites/all/files/cts_copd_slim_jim_2008.pdf

- My Favourite Medicine: Dr. Mike Evans' blog on sharing evidence with patients
  http://www.myfavouritemedicine.com/

Improving Chronic Care
http://www.improvingchroniccare.org/index.php?p=CCM_Tools&s=237
A catalogue of free, downloadable Assessements, Guides, and Decision Support tools to improve chronic care and self-management, including:

- Converting Guidelines into practice

- Diabetes Standing Orders

- Depression Management Tool Kit

- Assessments

- Engaging the Community

- Self management

Assessing your Primary Care Practice. A suite of tools are available via HQO'sAdvanced Access, Efficiency, and Chronic Disease Management website: http://www.hqontario.ca/quality-improvement/primary-care/learning-community

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4.2 TOOLBOX *All tools and resources were accessed / verified in April 2013.*

See ***Diabetes Self-Management Support Toolkit for Health Professionals in Ontario*** for examples of tools which demonstrate sensitivity to health literacy and can be tailored to the needs of users. To order the toolkit, visit http://www.health.gov.on.ca/en/pro/programs/diabetes/tools.aspx

Navigating health behaviour change – creating new relationships with patients. Kaiser Permanente http://kphealtheducation.org/bnroadmap/index.html

The *C-ChangeInitiative* highlights barriers to implementing evidence into practice and addresses the harmonization of guidelines for the prevention and management of cardiovascular diseases. http://www.cmaj.ca/content/183/15/E1094.full.pdf+html

Clinical Practice Guidelines

Canadian Respiratory Guidelines http://www.respiratoryguidelines.ca/toolkit

Canadian Heart Failure Network http://www.chfn.ca/practice-guidelines

Canadian Psychiatric Association http://publications.cpa-apc.org/browse/documents/67

Canadian Medical Association. Atrial Fibrillation Guideline http://www.cma.ca/learning/atrial-fibrillation-guideline-update

Canadian Continence Foundation http://www.canadiancontinence.ca/english/health-profs/clinicalpractice.html

College of Family Physicians of Canada http://cfpc.ca/ClinicalPracticeGuidelines/

Canadian Thoracic Society and COPD http://www.respiratoryguidelines.ca/guideline/chronic-obstructive-pulmonary-disease

British Columbia COPD and Treatment Guidelines http://www.bcguidelines.ca/pdf/copd.pdf

Lung Association and information for patients http://www.lung.ca/diseases-maladies/copd-mpoc_e.php

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4.2 A Deeper Dive Into the Change Concepts

Using Information Management Systems to Manage and Organize Care

Why is this important?

The quality of care for chronic illnesses is often poor as treatments known to be beneficial are provided only about 50% of the time, and inappropriate treatments are provided as much as 30% of the time. One problem is that health care organizations often utilize care models that respond well to acute problems, but are not designed for treating chronic illness. Improving information flow, both between patient and provider and amongst providers, is beneficial. However, there are difficulties associated with transmitting knowledge and patient information within the treatment environment. Health information technologies (HIT), such as electronic medical records (EMRs), can efficiently improve information flow. Indeed, HIT is specified as critical to the implementation of many chronic care models.[18]

The purpose of designing effective health care information management systems is to ensure that both person and population-level data is accurate, comprehensive and accessible.

This permits:
- Proactive care planning and delivery based on:

   º Timely alerts and reminders for providers and clients/ patients regarding upcoming appointments, interventions or milestones

  º Identification of relevant sub-populations targeted to receive more involved or intensive case management and care

- Individualized care planning, including:

  º Optimal medication management

  º Follow up on diagnostics, referrals and consultative reports

  º Summary of goals and progress (monitoring)

- Sharing of relevant information with the person and providers to coordinate care

- Monitor the performance of the health care team and system

TIP!

- Data clean-up is a requisite investment to support extraction of required data to inform practice

- Standardization of data entry is critical to be able to access person-specific information to extract population-based practice data

- Policies and well-defined processes support and sustain data discipline efforts

- Collaboration across sectors is required to support transfer of data across organizational interfaces

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4.2   A Deeper Dive Into the Change Concepts

Typical Breakdowns and Challenges

- Prevailing data management systems often lack functions that support chronic illness care, such as disease registries, the capability to monitor panels of patients, facilitation of team communication, execution of treatment plans across primary and specialty care lines, and transition from text notes to digital records

- "Garbage in, garbage out" – It is necessary to standardize data entry into the EMR/Information management system. This is a time consuming process and requires strong data discipline to get the most out of the system

- There is significant time and complexity associated with building EMR searches for population-based data

> ## ⚒ Tool
>
> Building a Chronic Disease Management patient registry
>
> http://cdems.com/

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4.2 A Deeper Dive Into the Change Concepts

The Individual has a Central Role in their Health and in Managing their Chronic Disease

Why is This Important?
Patients with chronic conditions spend less than 0.01% of their lives interacting with their health care providers, but are expected to manage their condition 100% of the time[19]. A study by Barlow found that patients with chronic disease had contact with all the health care professionals (physicians, specialists, nurses, physical and occupational therapists and dietitians) totaling 12 hours, and managed on their own 364.5 days or 8,748 hours in a year.[20] This often results in patients not following the directions of their providers. Typical adherence rates are about 50% for medications and are much lower for lifestyle prescriptions and other behaviorally demanding regimes.[21]

Managing chronic conditions is ongoing hard work for the individual, their family, informal caregivers and health care providers. The IHI's New Partnerships for Health initiative reminds us that, when it comes to chronic illness, physicians and health care providers can only do so much; if they could cure a disease, it wouldn't become chronic.[22]

Managing chronic conditions is complex and requires collaboration and communication between the patient, physician, other providers and practice staff to help the person optimize their health.[23]

It is up to the individual (and their informal caregivers) to do their part to maximize their health. The goal of the health care team is to wean the patient from system dependency and increase their capacity to self-manage and otherwise participate in their health. Research shows that a focus on patient-centred care can reduce the use of specialists and the number of visits to their primary health care provider by 20%.[24]

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4.2 A Deeper Dive Into the Change Concepts

An effective model of care needs to meet the needs of the patient. At the heart of patient-centred care lies the patient-caregiver relationship: a relationship which needs to be based on trust, empathy, respect, and honesty[25]. Patient-centred care in its broadest terms is organized around the patient[26]. A definition adopted by both the Canadian Medical Association and the Institute for Healthcare Improvement (IHI) states:

> "Care that is truly patient-centred considers patients' cultural traditions, personal preferences and values, their family situations and their lifestyles. It makes patients and their loved ones integral part of the care team who collaborate with health care professionals in making clinical decisions.
>
> Patient centred care puts responsibility of important aspects of self- care and monitoring in patients hands along with the tools and support they need to carry out that responsibility.
>
> Patient centred care ensures that transitions between providers, departments, and health care settings are respectful coordinated and efficient."[27]

Patient-centred care recognizes that patients must balance competing priorities, sometimes responding to one priority at the expense of another. A common situation which illustrates this phenomenon is when a drug (e.g. metformin) is prescribed to a patient; however side effects cause discomfort or embarrassment, resulting in the patient choosing to discontinue or reduce the prescribed dose. Likewise a patient may have difficulty affording the prescribed medication and therefore tries to manage their disease by reducing their dose so the prescription lasts longer. The patient may be embarrassed or feel unable to discuss the problem with their health care provider. The non-adherence or non-compliance to prevention and treatment regimens may appear irrational to the health care provider but may be a completely rational choice and management technique from the patient's perspective.

In a collaborative, patient-centred approach there is the belief that a health care provider can increase a person's confidence that they are able to change by helping them acquire the right knowledge and skills and support to change. Any change and goal setting must be meaningful to the patient and their caregivers.

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4.2   A Deeper Dive Into the Change Concepts

There are many ways that providers can help the individual confidently take a central role in managing their health and care. One of the ways is by connecting the individual to appropriate community resources or partners.

This will involve fundamental changes to the traditional interactions between the provider and the individual and/or their families. Some examples of these changes include:

- Viewing the patient-caregiver relationship as a collaborative partnership

- Incorporating goal setting and action planning, monitoring, problem solving, and active follow-up into the practice and every interaction. Create a shared care plan

- Ensuring that each interaction between the individual and their primary care team includes education and collaborative decision making, an assessment of the person's self-management skills as well as their clinical status

- Provision of care that the individual and their caregivers understand and meets their stated goals and preferences. Share and discuss clinical information with the individual and their caregivers (lab results, consultation results). Use graphs or other displays to help people understand their condition

- Create tools for the individual to bring to their next visit, such as self-monitoring logs, episodes or concerns, up-to-date medication lists, and questions for the primary care provider team

- Similarly, for every visit, give the person and/or their family caregivers an opportunity to share their experiences and ask questions:

  ° In the last two weeks have you felt short of breath while walking?

  ° Had difficulties with ordinary activity?

  ° Felt depressed or little interest in doing things?

  ° What would you like to discuss during today's visit?

- Use proven interview techniques such as the 5 A's (Assess, Advise, Agree, Assist, Arrange) to guide interactions with individuals. Patients spend the majority of their time outside the primary health care office. Building working relationships with community resources supports the patient in the management of their illness, helping make the right choice, the easy choice

- Investigate and provide links to community resources

- Embed the person's goals, monitoring data and milestones into the EMR in order to track and support the person's chronic care journey over time

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4.2 A Deeper Dive Into the Change Concepts

By assessing the person's health literacy as well as their physical, emotional, and psychological well-being, health care professionals are equipped with a starting point to set realistic goals and effectively use the resources available to them to support the person in the management of their disease.

The changing patient-provider relationship is further complicated by the public's increasing reliance on the Internet for information about symptoms, diseases, treatment options, and prognoses. Individuals also use the web to connect with others who are similar needs and experiences. In fact, 8 in 10 family caregivers have regular access to the Internet. Of these, 88% regularly search for health information. Caregivers outpace other Internet users on every surveyed health topic.[28] Health care providers can help patients and their caregivers by identifying appropriate websites and associations that share accurate and reliable information.

Providers and individuals with chronic conditions need to know:

- Where to look for resources

- What resources and specialized services are available in their community

- How to access these resources

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4.2 A Deeper Dive Into the Change Concepts

TIP!

- Hone your motivational interviewing or consider some training

- Tap into the power of peer support for people with specific diseases or burden of illness. Incorporate group support mechanisms and visits into the practice or link people with others who have similar needs and experiences

- Start small and train staff when introducing self-management supports into the practice

Typical Breakdowns and Challenges

- For the patient to play a central role in their care and be viewed as a full partner is a profound shift in how patients and their care providers have historically related and will require learning new ways of relating and communicating

- Capacity to self-manage health is often introduced after the onset/diagnosis of a chronic condition when the person is inundated with medical information and may not be well

- Lack of resources in the community or practice setting to offer self-management programs/personal skill development for individuals with chronic disease and their families

- Those individuals who have self-management skills may encounter providers across the system who are not trained in the provision of self-management support

- Providers may not have the skills to provide self-management support due to a lack of training opportunities or simply due to the fact that they do not have enough time or resources to provide self-management support

- Focus on clinical/medical management and limitations in addressing the other factors that impact the health and wellness of people with chronic illness (for example financial limitations, health literacy, living and working conditions)

- Providers may drive the agenda for appointments with individuals and their families, with only spending a limited amount of time on the issues and goals of the patient

- Changing the behaviour of the care team and patients takes time and requires realistic goal setting, patience and persistence

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4.2 TOOLBOX *All tools and resources were accessed / verified in April 2013.*

The Institute for Healthcare Improvement (IHI) spearheaded a program to develop and test efficient approaches to empower individuals and their families to manage their chronic conditions. IHI's New Health Partnerships initiative published a variety of excellent resources for clinicians and patients. Two key resources from this initiative are recommended below.

The *IHI Partnering in Self-Management Support: A Toolkit for Clinicians* provides information about how a primary care team can support a person's need to self- manage before, during and following visits to the primary care practice. These concepts can, in many instances, be applied to other health care visits and/or environments including appointments with specialists, home care visits, or at rehabilitation clinics, to name a few:
• IHI Partnering in Self-Management Support: A Toolkit for Clinicians(log in required)

  http://www.ihi.org/knowledge/Pages/Tools/SelfManagementToolkitforClinicians.aspx

The *Collaborative Self-Management Support (CSMS) Model* provides information, tools and guidance to people and their families who are dealing with long-term or chronic conditions. The material is organized to help them manage their health and care on a daily basis so as to achieve and maintain optimum health:
• Collaborative Self-Management Support (CSMS) Model. IHI New Health Partnerships. IHI Partnering in Self-management Support Information for People with Chronic Conditions (log in required)

  http://www.ihi.org/knowledge/Pages/Tools/SelfManagementToolkitforPatientsFamilies.aspx

These toolkits and additional resources are available at www.ihi.org (log in required).

In addition to the IHI's New Partnerships Initiatives toolkits, there are numerous resources that can be used by health care professionals as well as the general public to help them prepare for the next visit and enhance the person's ability to participate in care decisions and planning. Key resources are included in the table below.

Specific tools and related activities to guide behaviours and practice changes before, during and after a visit with a health care professional:
IHI Partnering in Self-Management Support: A Toolkit for Clinicians

http://www.ihi.org/knowledge/Pages/Tools/SelfManagementToolkitforClinicians.aspx

4.2 TOOLBOX *All tools and resources were accessed / verified in April 2013.*

IHI Partnering in Self-Management Support Rebuilding Chronic Care Three Patients at a Time

http://www.ihi.org/knowledge/Pages/Tools/SelfManagementToolkitforClinicians.aspx

The College of Family Physicians of Canada. Primary Care Toolkit for Family Physicians. This link includes clinical guides, flow sheets and self care resources for a variety of chronic conditions.

http://toolkit.cfpc.ca/en/continuity-of-care/appendix.php

Specific Tools and Related Activities to help people play a central role in their care:
Note: unless otherwise indicated, tools are available in the IHI's New Partnership resources

http://www.ihi.org/knowledge/Pages/Tools/SelfManagementToolkitforClinicians.aspx

Ask about preferences and experience, help person to prepare for visit, goal setting
• Bubble Diagram

• Dinner Plate Menus for Diabetes (visit preparation form)

• DocTalk Form (visit preparation form)

• Beyond Ask Me 3 (visit preparation form)

• Conviction and Confidence Ruler

• Take Charge Poster

Use appropriate language and tools to help the person learn
• Body outline diagram

• Teach back techniques

Create action plan
• Action plan for patients

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4.2 TOOLBOX *All tools and resources were accessed / verified in April 2013.*

Help the person to know what to expect
- Take charge poster

Use effective communication techniques
- Physician tip sheet for self management (AMA)

    http://www.ama-assn.org/ama1/pub/upload/mm/433/phys_tip_sheet.pdf

Proactively plan visits
- Planned care visit workflow

Self Management Toolkits:

Self Management Support: Information for Patients and Families. (log in required)

http://www.ihi.org/knowledge/Pages/Tools/SelfManagementToolkitforPatientsFamilies.aspx

Self-Management Toolkit- A Resource for Health Care Professionals

http://www.swselfmanagement.ca/smtoolkit/

Catalogue of free downloadable Self-Management tools including;
- 5 A's Behaviour Change Model: Adapted for Self-Management Support Improvement

- Patient Action Planning templates

- Shared Care Plan

http://www.improvingchroniccare.org/index.php?p=CCM_Tools&s=237

Shared decision making portal (Mayo Clinic) http://shareddecisions.mayoclinic.org/

Self Management support program to help healthcare professionals support their patients and clients.
Choices and Changes: Clinician Influence and Patient.

https://www.healthylifeworkshop.ca/

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4.2 A Deeper Dive Into the Change Concepts

Provide optimal monitoring and management of chronic and preventative care

Why is this important?

Access and Efficiency

Access to the right provider at the right time in the right place is a central tenet of the management of health and health care. Primary care is, for most people, the point of entry into the health care system and delays in accessing primary care is one of many delays that can negatively impact the patient and provider experience. For example, it may be difficult to access one's own primary care provider or the most appropriate provider for a presenting issue. An inability to get timely access to a person's usual primary care provider can result in increased reliance on local emergency departments to meet medical needs, with subsequent referral back to the usual provider for follow up and required referrals. Numerous handoffs between providers can result in less than continuous care, duplication of work (re-work) and errors. In Ontario, 37% of **sicker adults** 📄 presented to Emergency Departments for a condition they believed could have been treated by their regular doctor had she/he been available.[29]

Access to a usual provider ensures **continuity of care,** 📄 improves efficiency of service delivery, reduces duplication and errors, and increases satisfaction for patients and providers. Both timely access to primary care and continuity of care have implications for patients and services in other parts of the health care system. A recent report by the Evidence Development & Standards branch of HQO confirms that continuity of care leads to significant reductions in emergency department use by the general population and specifically by people with diabetes or chronic obstructive pulmonary disorder (COPD).[30] The report also asserts that improved clinical outcomes, like improved HbA1C among diabetics, are a result of increased provider or practice continuity.[31]

Efficient processes support optimal chronic disease management. Providers and practice staff often work in environments and work within processes that are not designed to support the work that they want and need to do.

Planned Prepared Visit

A paradigm shift is required to move the health care system from one that reacts to acute episodes of care and a focus on cures, to one that focuses on proactively preventing and managing disease and the burden of illness. This shift requires providers and practice teams to be well prepared and proactive as well as willing and able to work collaboratively with their patients or clients to help them stay as healthy as possible, manage their health and care, and live life to their fullest potential even when chronic conditions become a reality.

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4.2 A Deeper Dive Into the Change Concepts

A planned, prepared provider and/or team commits to ensuring that, at all times;

º The patient knows the purpose of their next visit and is prepared to meet their provider/care team

º The provider/team has assembled and reviewed the person's goals and monitoring data, diagnostics and consultations, medications, and has the appropriate team, equipment and space to conduct the next visit

Furthermore, the primary care team may want to regularly meet – for brief daily huddles or regularly scheduled meetings - to prepare for interactions with their patients. Teams are encouraged to huddle, once or twice per day, to enhance communication between team members (and external consultants as needed) and ensure that the practice team has the required equipment and information needed meet the needs of the patients who are scheduled for appointments that day.

The care team is also encouraged to hold regular team meetings to collaboratively plan for management of subpopulations of patients, (e.g., those with diabetes), to ensure reliable delivery of evidence-based care. For example, if practice data suggests that individuals with diabetes are not getting foot exams, the team would meet to discuss (and eventually test) different ways to consistently and reliably incorporate foot exams into

their system of care. One practice team may decide that a nurse will assume responsibility, for foot exams, while another team may partner with the regional diabetes program to support efforts to increase foot screening.

Proactive Follow-up

This is the hallmark in the shift from reactive to proactive care with self-management support. Individuals are encouraged to book their next appointment(s) when leaving the office, thereby ensuring that appropriate follow-up takes place and that it is not left it to chance (which may result in missed interventions and milestones). Follow-up activities include both formal and informal interactions with the individual between appointments, including (for example), telephone contact from a nurse to follow-up on the progress of an individual's stated self-management goals. Modes of contact may include secure email, text, telephone, or Skype, taking into consideration the manner in which the individual prefers to communicate.

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4.2   A Deeper Dive Into the Change Concepts

Typical breakdown and challenges

Access

- Variation in the availability of the different providers on the practice team (e.g. hospital call, vacation, competing demands) and patient demand (flu season, snowbird season) resulting in further delays to access

- Mismatch of demand and supply (provider availability)

- Complex scheduling systems and rules that contribute to delays and reduced access

Planned Prepared Visit

- Inadequate communication and, in particular, missing or incomplete information results in 'waste' in the form of delays, interruptions and re-work for patients/clients

- Providers and patients are not always aware of the purpose for the appointment and may not be prepared, which results in wasted time, duplication of services, delayed diagnosis or treatment, and frustration for both patients and providers

Proactive Follow-up

- The provider typically sees the individual for follow-up. Providers may be reluctant to allow other members of the care team provide appropriate follow-up

- Onus to follow-up with the care team is often considered the responsibility of the care recipient

- Barriers such as transportation, working conditions, office hours, and medical conditions can affect the individual's capacity to schedule and attend follow-up appointments

- Delays in access to usual providers, referral programs and services may further impact on the individual's ability to follow-up in a timely fashion

TIP!

Planned Prepared Visit

- Anticipate the individual's needs and begin to prepare for the next interaction during the current visit. Prior to the next visit, huddle as a team to support preparation and planning

Proactive Follow-up

- Avoid leaving follow-up to chance. Plan in advance ensuring timely follow-up that works for the individual and provider. Avoid booking follow-up too far into the future to avoid no shows and lost opportunities

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4.2 TOOLBOX *All tools and resources were accessed / verified in April 2013.*

Advanced Access and Efficiency

Tillie Goes to the Clinic (QIIP video)
A story that demonstrates in the relationship of access to the management of chronic disease.
http://216.65.66.162/www.qiipvideo.ca/tillieclinic.html

Advanced Access Articles
Berwick, D, Murray, M. Advanced Access, Reducing Waiting and Delays in Primary Care. JAMA. February 26, 2003; 289, No. 8: 1035-1040

Murray, M. Answers to Your Questions About Same-Day Scheduling. Family Practice Management. March 2005; 59-64

Health Quality Ontario offers regular improvement initiatives in Advanced Access, Efficiency and Chronic Disease Management in Primary Care. For information on upcoming initiatives or to join the Independent Learning Stream at any time, go to: http://hqolc.ca/.

Advanced Access and Efficiency Resources:
HQO Advanced Access and Efficiency in Primary Care Interactive Workbook
http://www.hqontario.ca/quality-improvement/primary-care/learning-community

machealth. Learning without boundaries. This site includes online accredited programs, communities of practice in a variety of topics to enhance health care education.
http://machealth.ca/programs/advanced-access-efficiency-primary-care/default.aspx

Redesign primary care practices
Practice Facilitation is emerging as a promising method of improving primary care. The Agency for Healthcare Research and Quality developed a guide to help primary care teams to run a facilitation program.
For more information visit the AHRQ website
http://pcmh.ahrq.gov/portal/server.pt/community/pcmh__home/1483/PCMH_Tools%20&%20Resources_v2

The Canadian Public Health Association published a toolkit to strengthen chronic disease prevention and management. For more information and to download the toolkit, visit http://www.cpha.ca/en/portals/CD.aspx

4.2   A Deeper Dive Into the Change Concepts

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Integrate Specialists and Community-based Resources into the Primary Care Practice

Why is this important?
Primary care teams do not have the capacity to offer all aspects of care and support required by individuals with chronic illness. Additional care and support is available via specialists, specialized care and in community based agencies.

Referring a person to a medical specialist can be a frustrating experience for all involved. Primary care physicians must wait – sometimes for many weeks and months – to receive word about how the referral went as well as resultant opinion and treatment recommendations. Unfortunately, it is common for primary care physicians to not receive this information. Likewise, specialists meet a person for the first time with little history about the presenting condition or reason for the referral. The person who has been referred is left with an information void that may erode trust in their provider and the health care system, exacerbate their fears, and worsen their condition.

Poor communication between primary care and specialists is a common problem in health care that can lead to many negative consequences including: errors, delayed diagnosis and treatment, wasted resources and fractured continuity of care.

An American study of 4,720 physicians showed large differences in the perceptions of primary care doctors and specialists about communication relating referrals and consultations. For example, 69% of primary care doctors believed that they routinely conveyed a person's history and reason for the referral to specialists, while only 35% of specialists believed that they routinely receive this information. Similarly, while 81% of specialists felt that they send consultations to primary care all or most of the time, only 62% of primary care physicians stated that they regularly receive this information.[32]

Viewing specialists and speciality services as integral parts of the care continuum that complement the ongoing management of health and care in the preventative, acute and chronic phases of illness is a sage starting place. Integrating specialists and specialty services into primary care presents an opportunity to discuss individual cases and subsets of panels with all referral providers prior to the person's next visit, resulting in focused discussion and shared planning and preparation.[33]

In order for this to become a reality, both primary care teams and specialty providers will need to make appropriate adjustments. For example, primary care teams will need to 'free up time and (possibly) space' to accommodate specialists and specialty providers (either in person or virtually using Ontario Telemedicine Network [OTN] for example). Specialists will need to adopt a model that is based on collaboration and share decision-making rather than working in relative isolation. They will need to deliver care and consultation according to their expertise and abilities.[34]

4.2 A Deeper Dive Into the Change Concepts

> ### TIP!
>
> - Have lists of specialists, speciality services and community-based resources available in user-friendly formats in handy locations for patients and providers (e.g., handouts, posters, TV monitors, 'apps', facebook, and other social media)
>
> - Look for resources that have already been created and are actively managed and updated (e.g., CCAC Online *Information and Referral Services*)

Typical breakdowns and challenges

Specialists and Specialty Services

- There is limited availability of specialists and specialty services in some geographic regions resulting in no, limited or delayed access to specialty care

- Some individuals may not want or be able to travel to access services due to their burden of illness and clinical condition, or because of financial, transportation and language barriers

- Variation in processes for referral to specialists and specialty services can be confusing, time consuming and result in errors and re-work. Specialists/services may not receive the information they require resulting in delays, re-work and waste

- Communication with specialists and specialty services may be limited. Referring providers may not have confirmation of a referral and appointment until after the patient has been seen. Individuals waiting for an appointment may not hear anything for months, wondering if the referral was forgotten. In some cases the referral process may have broken down and need to be re-initiated resulting in further delays. There may be delays in receiving consultation and progress reports (often weeks and months later)

Community Resources

- Lack of awareness of community programs and services available to individuals

- Unreliable processes for referral and the communication of information, resulting in delays

- Duplication of services across sectors and community (e.g., Diabetes programs offered in primary care [FHT's/CHC's], Diabetes Education Centres, hospitals) creating challenges in navigation for individuals and their families

- Lack of communication across providers resulting in delays, re-work, frustrations for providers and patients/clients

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4.2 TOOLBOX *All tools and resources were accessed / verified in April 2013.*

Incorporating specialists and/or specialty programs into primary care

OTN Programs

One service that is showing impressive health care application is the Ontario Telemedicine Network, most commonly referred to as OTN. OTN supports the delivery of care to more than 135,000 patients annually and access to health professional education to more than 360,000 learners at more than 1200 sites.[35]
source: http://www.linkedin.com/groups/Followup-Q-Dr-Ed-Browns-4160686/about
This network is one of the largest and most active of its kind.[36]

OTN has an impressive track record and is gaining popularity amongst patients and providers who are integrating specialists into their primary care practice.

This person-centred service enables timely access to specialists, reduced travel time and expenses whilst delivering care closer to home. What was once thought of as a tool to provide services primarily to rural and northern populations is now seeing growth in the urban setting.[37] The technology enables support for people who need specialist services in the areas of: Clinical Specialties in Telemedicine; Bariatrics, Cardiology, Ophthalmology, Orthopedics, Dermatology, Endocrinology, Pediatrics, Physiotherapy, General Surgery, Mental Health & psychiatry, Rehabilitation Medicine, Speech Pathology, Addiction, Nephrology & Dialysis, Tele-radiology, Tele-stroke, Neurology, Occupational Therapy, Oncology, Urology, ENT and over 30 others[38]. OTN makes it possible for the specialist provider and the elderly or fragile patient to meet without excessive travel.

For the physician, OTN provides specialists with world class technology in a secure encrypted channel. OTN has a growing and searchable directory for the referring physician seeking an OTN savvy specialist. The technology is scalable with emerging opportunities for desktop applications. http://otn.ca/en/services/telemedicine-directory

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Glossary

5.1 Glossary

Care coordination

Care coordination is comprised of the following elements:

• Numerous participants are typically involved in care coordination
• Coordination is necessary when participants are dependent upon each other to carry out disparate activities in a person's care
• In order to carry out these activities in a coordinated way, each participant needs adequate knowledge about their own and others' roles, and available resources
• In order to manage all required patient care activities, participants rely on exchange of information; and integration of care activities has the goal of facilitating appropriate delivery of healthcare services[39]

Caregiver

Along with patients, physicians, nurses, pharmacists, social workers and other professionals, caregivers (family or otherwise), are often involved in the delivery of health care services, and can often have a role in care coordination.[40]

Care plan

A care plan is an agreement between a person and their health professional (and/or social services) to help them manage health day-to-day. It can be a written document or something recorded in patient notes.[41]

Change concept

A general notion or approach that has been found to be useful in developing specific ideas for change that result in improvement.[42]

Continuity of care

Continuity of care is difficult to define and understanding how to achieve it is complex. An evidence based analysis, conducted by the Evidence Development and Standards Branch at HQO, asserts that continuity of care relates to both the quality of care delivered over time as well as the experience of care as it relates to satisfaction and coordination of care between providers.[43]

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Fragmentation of care As described by Dr Edward Wagner et al, "a fragmented healthcare system may be technologically sophisticated and organizationally inept. It is characterized by an emphasis on diagnosis and treatment, expensive duplication of effort, and lost efficiency resulting from inadequately, incorrectly or belatedly sharing information between many providers." [42]

Health literacy The degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions." It represents a collection of skills necessary for people to act appropriately to health care information and to function effectively in the health care environment. Key skills include the ability to interpret documents, read and write prose (print literacy), use quantitative information (numeracy), and speak and listen effectively (oral literacy).[44]

Integration of care While there is no single definition of integrated care, integration of care refers to a means to reduce fragmentation in care through the coordination of services which are planned, managed and delivered by a range of healthcare professionals and informal carers between different organizational units.[45]

Self efficacy The measure of one's own competence to complete tasks and reach goals. Developing a belief in the patient's own ability to make changes is central to managing their illness.[46]

Self-management The ability of the patient to deal with all that chronic illness entails, including symptoms, treatment, physical and social consequences.[47]

Self-management support The terms Self-Management and Self-Management Support are sometimes used interchangeably. Self- Management Support in the context of this document refers to support provided to the patient in response to a patient's need and or request.[48]

Sicker adults The Commonwealth Fund International Health Policy Survey is conducted every year with a focus on general adults, sicker adults or primary care physicians. The 2011 survey included adults who reported at least one of the following: fair or poor health; received medical care in the past year for a serious or chronic illness, injury, or disability; hospitalization in the past two years (other than uncomplicated delivery of baby); major surgery in the past two years. The 2008 survey studied sicker adults as well, while the 2009 survey focused on primary care physicians and the 2010 survey focused on all adults.[46]

Transition A broad range of time-limited services designed to ensure healthcare continuity, avoid preventable poor outcomes among at-risk populations, and promote the safe and timely transfer of patients from one level of care, or from one type of setting to another.[49]

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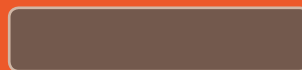Section 2
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