## HEALTH COMES HOME: A CONVERSATION ABOUT AGING AND CHRONIC CARE

PART 2





## WE ALWAYS OVERESTIMATE THE CHANGE THAT WILL OCCUR IN THE NEXT TWO YEARS AND UNDERESTIMATE THE CHANGE THAT WILL OCCUR IN THE NEXT TEN. DON'T LET YOURSELF BE LULLED INTO INACTION.

- BILL GATES

In part one of this four-part series, we detailed the fundamental truths, or key trends, that are poised to influence our society and the future of the world around us. For the purposes of this series of papers, we have selected the year 2027 as a key future point of reference. In the year 2027, the first of the Baby Boomers will turn 80. As they have for the last 60 years, the Baby Boom generation will exert their influence by sheer force of numbers. Their lifestyle and life experiences have consistently shaped societal norms and will shape their expectations of the public health care system in the years to come. Given the influence of this generation, tremendous political momentum will follow the expectations of "Boomers" as they age - placing intense pressure on an already strained health care system and demanding that government and health system planners think differently about how to respond. With this in mind, we outlined key questions that, through research and engagement with Ontario health system leaders, emerged as a starting point for a discussion.

Among these questions were:

## What should we expect from our health system?

## How will we come together to meet the needs of patients?

## How will we pay for a transformed system?

## How will we value and care for our informal caregivers?

In this paper, we examine these questions through the lens of Ontarians, as they move through life and experience changes in health status. An adult with chronic health needs may transition to a senior with complex health conditions, and ultimately to end of life requiring thoughtful approaches to hospice palliative care. Through our interviews, we heard a growing chorus of concern surrounding our capacity to meet the future needs and expectations of Ontarians. Concurrently, we heard resounding confidence in the wealth of talent, ingenuity and capabilities in Ontario. How well we coordinate ourselves to make effective use of these assets will dictate our success in responding to the opportunities and challenges of delivering a more effective health care system and improving the health of Ontarians.

To initiate the dialogue, we explore areas of health care in Ontario that are working well and have the potential to be scaled for greater reach and impact - including an examination of the nuanced needs of Ontarians that have chronic health conditions, seniors with complex health conditions, and those who may require hospice palliative care. We also explore the evolving role of home and community care in the context of these patient populations and highlight the potential for improving outcomes through a more effective home and community care sector. Finally, we identify lessons for Ontario from other jurisdictions and introduce some of the "big questions" that our society will need to resolve in shaping the transformational big plays that will be required by 2027.



## TOWARDS 2027 REVISITING THE FUNDAMENTAL TRUTHS

Without question, the world in 2027 will be much different from today. Advances in technology and communications will continue to transform society and provide new tools with which to meet the challenges we face ahead. Demographics, economic constraints and the expectations from a more informed and empowered public are all likely to shape the demands of the world we live in and the provincial health care landscape of tomorrow. Understanding the implications that these and other factors may have on our health system's capacity to meet the needs of Ontarians will be crucial to how we organize components of health and social services to meet the needs of Ontarians.

## Shifts in demand across the trajectory of life and health

In Ontario, a shift to caring for people with increasingly complex health and social needs in the community is well underway. Ontario is on the leading edge internationally in supporting people with complex care needs in their own homes. As we approach 2027, this trend will continue with more people with higher levels of complexity looking for care options that will allow them to live at home as long as possible. Among these are people with chronic health needs, seniors with complex health conditions, and patients requiring hospice palliative care. Ontarians will also demand focused measures to change their health trajectory and keep them as healthy and well as possible.

## Our shifting demographics and care needs towards 2027

By 2027:

- Approximately five million Ontarians will have one or more chronic conditions (e.g., heart failure, COPD)
- · The number of seniors will have nearly doubled
- 70 per cent of Ontario's seniors will have two or more chronic conditions
- · Over 40 per cent more deaths will occur each year

As a result, the nature of health services demand and the response of health system planners will need to adapt to meet the needs of patient populations as they traverse various life and health stages.

## New constraints in responding to heath system challenges

As our population ages, so too will the health care professionals that our system counts on. As more health care professionals begin to leave the workforce, their skills and experience will need to be replenished in addition to the health care professionals required to meet population growth and the increasing demands of an aging population. These health care professionals will also need to be better prepared and supported

# 70% OF ONTARIO'S SENIORS WILL HAVE TWO OR MORE CHRONIC CONDITIONS

to meet the needs of Ontario's population towards 2027. As described in Ontario's Seniors Strategy, our current educational curricula for health and social care professionals provide limited exposure to and perspective on geriatric care and the specific issues likely to be faced by our health care professionals.

Beyond the health human resource constraints identified above and other widely recognized economic and fiscal constraints of governments, a lesser-known constraint will pose an even greater challenge to health system planners: *The capacity and availability of family and informal caregivers.* While this constraint may not be widely talked about in health system planning circles, it will be increasingly felt on the front lines and in the homes of patients with chronic health needs, complex seniors, and people requiring hospice palliative care. Informal caregivers currently provide 70 per cent of the care for these and other patients residing in their homes.<sup>2</sup>

The capacity and availability of Ontario's informal caregivers will grow increasingly constrained due to a number of factors that include:

- Aging caregivers who, along with their loved ones who require care, will be less able to independently support the care needs of their family members
- Smaller family sizes resulting in fewer children to contribute to and share the burden of caregiving for their aging parents
- Children who are part of an increasingly mobile workforce are moving away from their home communities for economic and career opportunities elsewhere.

#### Balancing expectations with capacity to deliver

As Ontario's population ages and experiences more complex health conditions, enhancing the value-for-money Ontarians receive from their health care spending will be non-negotiable. With nearly 42 cents of every dollar spent on provincial programs already being streamed to health care today, changes in our approach to health service delivery will be essential to ensure that the provincial budget can support other societal priorities including social services and education.<sup>3</sup>

In addition to the economic necessity to contain the increasing cost of health care, a central area of focus is the need to meet the expectations of Ontarians. Boomers in particular have shaped policy and society throughout every stage of their life, including the health and social services required to meet their needs.

As Boomers age, they will undoubtedly continue to influence the manner in which they receive health care services.

### Care settings as a driver of health system cost

So much of the cost to deliver health care services is dependent on the setting in which it is delivered. Homeand community-based care is receiving more attention from health system planners and government, in large part due to the favourable economics.

In Ontario, home care currently costs approximately \$42 per day, while care provided in hospital or long-term care costs \$842 and \$126 per day respectively.

In the case of hospice and palliative care, the average cost of caring for someone dying in a chronic care facility is \$36,000 as opposed to \$16,000 at home.

Homecare Ontario

http://www.homecareontario.ca/public/about/home-care/system/facts-and-figures.cfm

## Boomers' desire to choose may challenge long-held standards and policy

Boomers will also influence and initiate public discourse on more fundamental social policy issues. For example, federal and provincial dialogue on physician assisted suicide was recently sparked by well-informed and well-loved member of the Boomer generation and Ontario medical community, Dr. Donald Low, who, eight days before his own death, called for Canada and Ontario to allow physician-assisted suicide and patients to choose "dying with dignity."

Canadian Hospice Palliative Care Association, 2012 - Source: http://hpcintegration.ca/media/24434/TWF-Economics-report-Final.pdf



IN ONTARIO, HOME CARE CURRENTLY COSTS APPROXIMATELY \$42 PER DAY, WHILE CARE PROVIDED IN HOSPITAL OR LONG-TERM CARE COSTS \$842 AND \$126 PER DAY RESPECTIVELY.

### Technology underpinning the art of the possible

The power of technology is changing the world that we live in. It is also one of the most transformational elements enabling a more effective society and health care system:

- Remote clinical interactions supported by technology exist and are growing in use (dermatology consultations, remote monitoring, health coaching, etc.)
- Robotics is and has been transforming industries such as manufacturing and supply chain, and will be increasingly integrated into health care through surgical interventions, advancements in prosthetics, and exoskeleton body suits
- Connected and comprehensive electronic medical records will be a reality for all Ontarians
- Big data, analytics, and decision support systems will increase the extent of human knowledge available to health professionals and patients in driving health practices to achieve the best possible health outcomes

Revolutionary innovations such as these and others not yet invented will no doubt extend into our homes and enable a host of new options for how patients will receive health care in the comfort of their own homes.

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<sup>3</sup> Ontario's Action Plan for Health Care

# **OUR OPPORTUNITY**

## - THE FUTURE OF A MORE EFFECTIVE HEALTH SYSTEM IS OURS TO LOSE

Through our conversations with health system leaders, a persistent call to action was, how will we come together to meet the needs of patients and their caregivers in a manner that offers value greater than the sum of our individual parts. We heard several perspectives on some of the widely known challenges of our current health and social system structures including the need for enhanced care coordination, navigation, information sharing, integrated inter-professional team-based care, and better support for informal caregivers.

What became clear in discussing the trajectory of Ontarians' experience with health and illness – ranging from adults with chronic health needs, to complex seniors, to people requiring hospice palliative care – was that while these conditions have a common thread, they manifest themselves in very different ways. These differences are reflected in the form of patient and caregiver needs that vary widely based on the stage in life/health condition(s), family circumstance, and broader

social determinants of health (such as childhood environments, income, availability and quality of education, food, housing, employment, working conditions and social services).

As a result, no-one-size-fits-all solutions from health, social, and other public providers will alleviate the challenges across the spectrum of needs. Health and social system planners must seek a balance to better understand and standardize responses to a fundamental set of patient and caregiver needs – while enabling the flexibility to individualize care to support the best possible health and social outcomes in the context of individual circumstance.

The table on the next page illustrates the common high-level needs and nuanced differences across an illustrative trajectory of health that must be understood and integrated into our approaches to transforming the way in which we care for patients and their families.



<sup>&</sup>lt;sup>8</sup> Equifax Canada's Q2 2-13 National Consumer Credit Trends Report.

## High-level needs in common

### Illustrative view of the nuanced needs throughout a trajectory of life and health

## People with complex chronic health needs

#### Complex seniors

## Patients in need of hospice palliative care

## Care coordination / Navigation

Development of a team-based care plan supported by a "single point of contact" to coordinate care based on patient needs as they change Coordination of multiple services and ensuring continuity of care plans across care settings (e.g., transition from acute care to home or community care) Need to marshal health and non-health resources to address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears

#### Information sharing

Health care professionals monitoring patient health status (e.g., Telehomecare) while providing self-management, health coaching, and system navigation information Including informal caregivers in the information sharing and decision making process based on the health and individual circumstances of the patient and their caregivers

Information sharing across the team including: medical, clinical and professional services such as physicians, nurses, hospice staff and volunteers, psychosocial/ spiritual support, rehabilitation specialists and therapists, as well as personal support workers and homemakers, day programs, Meals on Wheels, transportation and social programs with members of the care team communicating on the progress of the individual and updating the care plan as necessary

## Flexible and integrated care teams

Teams of multidisciplinary professionals (e.g., primary care physicians, registered nurses, social workers, care coordinators, personal support workers, homemakers etc.) with access to specialists and training for:

- Complex chronic conditions and keeping patients as healthy as possible
- Complex seniors (e.g., geriatrics, pyschogeriatrics)
- Palliative care physicians and advanced practice nurses to support the variety of care and support needs

## Engagement in their care and self-management

Patient education, health coaching and self-management

Engaging patients in directing the services they receive on a daily basis (e.g., caregivers asking what the most important thing is that they could help with in a given visit, taking time at the end of a visit to ask if there is anything else the patient needs)

Advanced care planning for making personal health care decisions and choices in the event of future incapacitation

#### **Psycho-social support**

Changing behaviours to minimize impact of the disease and maximize treatment protocol

Coping with emotions and disruptions to work and family life related to their illness

Coping with age-related transition or conditions (e.g., dementia, widowhood, loneliness/isolation)

Assisting with information and decision-making to promote discussion and advanced care planning

Facilitating family meetings to allow all family members to be heard and understood

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## Illustrative view of the nuanced needs throughout a trajectory of life and health

chronic	health needs

## Complex seniors

## Patients in need of hospice palliative care

#### Clinical / Medical / Pharmacological Care

Managing interactions among illnesses or conditions

People with complex

Managing interactions among medications

Access to clinical care 24/7 to enable transition and maintain patients at home and in non-acute settings

Education and support of safe medication use

Sporadic exacerbations of pain and other symptoms

Medical surgical interventions (e.g., bowel obstructions)

Disease-modifying, restorative, or rehabilitative care

#### Cognitive / Behavioural

Managing depression associated with diagnosis of chronic conditions and change in quality of life Primarily addressing the needs of health care professionals and informal caregivers in dealing with aggressive behaviours Supporting patients, caregivers and health providers in dealing with grief, depression, anxiety and behavioural changes

## Ongoing needs of informal caregivers

Caregiver competency building in skills to carry out tasks

Psycho-educational support in providing information and psychological/counseling approach to decrease caregiver distress Care plans and supports that recognize the needs of aging caregivers and their ability to support patients at home Bereavement support for individuals, families and friends

Coordinated and integrated professional and volunteer supports

Spiritual care

In examining the nuances across the high-level needs considered above, it is clear that finding new ways to care for patients in the comfort and security of their own homes and communities must become an even greater health system priority. Moreover, our efforts must evolve service models that deliver the most value to patients with common care needs – while remaining flexible and agile enough to deliver (and finance) care that is responsive to individual circumstance, health and social care needs.



#### Stepwise Towards Transformation

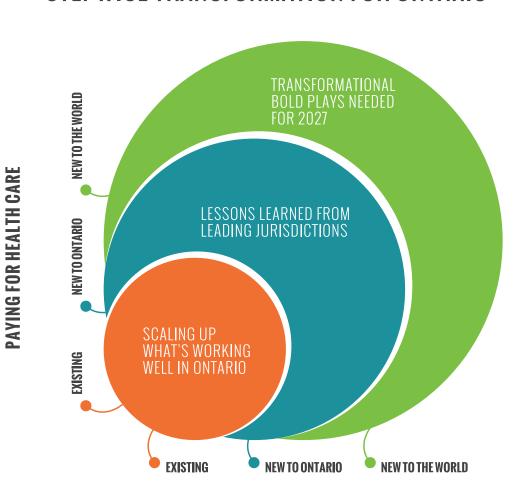
MODELS AND APPROACHES TO

In refining our approaches to health system transformation, Ontario health system leaders were clear that we need to make stepwise changes to how we structure, deliver, and pay for health services, so that we can provide the publically insured services that Ontarians will need in 2027.

In considering the change required and the catalysts to accelerate this transformation, health system leaders were quick to point to some of the positive developments underway today in Ontario and across leading jurisdictions as examples of what the future could look like. They emphasized the need to:

- 1) Scale up the positive attributes of innovative models in place in Ontario today
- 2) Import approaches and valuable lessons learned from other leading jurisdictions
- 3) Focus on liberating the talent, ingenuity, and dedication of health system stakeholders in Ontario; to this end. Health system leaders submitted that our ability to re-shape our health system to meet the needs of Ontarians is limited only by our willingness to examine long-term questions that are not often enough the focus of political or public dialogue. These questions include: How will we continue to pay for health care? What will we expect from each other and what health services will society provide? What will we expect from families and informal caregivers? And, how might communities at large come together to care for Ontarians across their trajectory of health and illness?

## STEPWISE TRANSFORMATION FOR ONTARIO



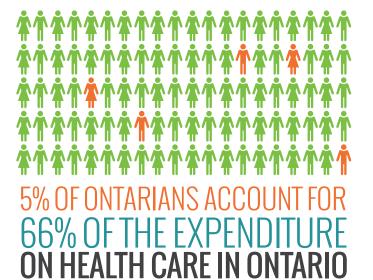
MODELS AND APPROACHES TO CARE AND SERVICE DELIVERY

#### Scaling up what is working well in Ontario

In discussing the ways in which the Ontario health system has already begun to respond to the needs of patients and caregivers, many health system leaders emphasized the current work underway and ongoing investment in health information and system-level data with increased analytics capacity to segment and better understand the needs of high users.

They suggested that there is a need to reexamine the ways resources (health and social) are marshalled around the needs of patients and their informal caregivers to reach the best possible health outcomes at the lowest health system cost. Deliberate and strategic choices must be made about where health system resources are focused.

The need for focused efforts is supported by the disproportionate amount of health system resources consumed by a very small number of Ontarians. It has been widely reported that one per cent of Ontario's population consumes 34 per cent of its health system resources; the next four per cent of the population consumes an additional 32 per cent of Ontario's health system spending.<sup>4</sup> Beyond producing better health outcomes for these patients, there needs to be a focus on modifying the health/illness trajectories of these patients to maximize their health and minimize future intensity of health system use and associated cost.



In many ways, Ontario is leading the way forward in shifting care and health system utilization. Already, Ontario has seen a dramatic rise in the complexity and intensity (hours) of care required for Ontarians receiving home care services. These efforts have improved the health and independence

of many patients, diverted patients from more costly emergency department visits and hospital readmissions, and reduced the length of stay and sub-optimal patient outcomes associated with patients waiting in acute care beds for long-term care or other more appropriate care settings.

## Home First – Enabling complex seniors to recover faster and regain their independence at home<sup>5</sup>

Home First is a shared philosophy of care arising from the partnership among Ontario's Community Care Access Centers (CCACs), hospitals and other local providers to enable seniors (most of whom may be considered frail/complex seniors) to recover and regain their independence in their own home. By starting with the shared goal of supporting patients to come home and providing the home care and community support services they need, Home First allows seniors to leave the hospital, continue their recovery and reside in their own homes, or wait safely at home for a long-term care bed.

With a strong collaborative partnership between hospitals, Local Health Integration Networks (LHINs) and Community Support Agencies, CCAC care coordinators help caregivers and patients whose acute care treatment is completed to create a plan of care to support each patient's unique needs. CCAC in-home care can include nursing, personal support, occupational therapy, social work, among others.

In the 2012/2013 fiscal year, CCACs helped 192,344 people return home from hospital with CCAC care through Home First and other channels.<sup>6</sup> For every patient with high care needs served in the community instead of a hospital, the health care system saves approximately \$384 dollars per day. Fifty per cent of patients referred through hospitals get home care service within one day of referral.<sup>7</sup>

#### Scalable benefits

Home First is an example of how a shared commitment to patient-centred care at home can:

- Support patient choice and empower patients to participate in their care
- Get patients home sooner, minimizing the risk of hospital-acquired infection and functional decline
- Enable patients to live safely and comfortably at home for as long as possible
- Enable patients to make life-changing decisions, such as a moving to long-term care, from their own homes

<sup>&</sup>lt;sup>4</sup> Driving Value with a Patient-Centered Health System - Woodchis

 $<sup>^{\</sup>rm 5}$  OACCAC, CCAC Quality Report 2011/12: Putting people at the heart of all we do, (2013)

<sup>&</sup>lt;sup>6</sup>OACCAC, CCAC Quality Report 2011/12: Putting people at the heart of all we do, (2013), 2.

OACACC, CCAC Quality Report 2011/12: Putting people at the heart of all we do, (2013), 2.

- Improve discharge planning effectiveness
- Reduce the number of patients waiting in hospital for other care settings, thus ensuring people are in the most appropriate and cost-effective setting
- Shorten emergency department lengths of stay
- Provide better access to hospital and long-term care for those who really need it
- Improve collaboration between hospitals and CCACs to help patients in their transition to home
- Promote effective workflow and communication between the patient and the health care team

#### Integrated Client Care Program for Frail Seniors<sup>8</sup>

The Toronto Central Integrated Client Care Program is a collaborative care model focused on breaking down silos and improving care for the top one per cent of frail seniors with complex needs, who receive care from multiple providers and are at ongoing risk of hospitalization and transition to long-term care. Building on partnerships between the Local Health Integration Network, the Community Care Access Centre, primary care, specialists, acute care, complex care, rehabilitation, emergency medical services (EMS), community pharmacists, social services and others, the model was designed to work within existing resources and has seven areas of focus:

- 1. Medical support and self-care with close partnerships between primary care and community care providers,
- 2. Medication management through the use of a single pharmacy,
- 3. Smooth transitions (including the development of an emergency department transfer package)
- 4. Navigation and coordination across the continuum of care,
- 5. Rapid response through integration and communications loops between primary care, home and community care, EMS and acute care,
- 6. Activation and socialization based on client and caregiver goals, and
- 7. Independent living that supports patient and caregiver choices.

The model has contributed to a 50 per cent reduction in patients waiting for alternate levels of care in hospital and a 20 per cent reduction in the number of patients waiting for long-term care home placement in hospitals.

#### Scalable benefits for the rest of Ontario

The Toronto Central Integrated Client Care Program for Frail Seniors is an example of how collaborative partnerships, clear roles and responsibilities and communication between providers can optimize existing resources to improve patient outcomes and:

- Reduce pressures on acute care settings
- Decrease the frequency of unnecessary emergency department visits
- Reduce the number of patients waiting in hospital beds to move to long-term care homes
- Help more patients with complex needs living at home
- Improve communication and patient-focused collaboration across the continuum of care
- Provide better patient and caregiver care experiences.

## eShift – Leveraging technology to enhance palliative care for patients in remote communities<sup>9</sup>

eShift, an initiative of the South West CCAC, deploys mobile technology that connects up to four enhanced-skill personal support workers (ePSWs) working overnight shifts in the homes of patients with a remote registered nurse (RNs) via a web-enabled iPhone.

The program currently serves families of medically fragile children and palliative care patients, but has the potential for spread to other patient populations that need high levels of support and ongoing supervision.

#### Scalable benefits for the rest of Ontario

eShift is an example of how technology, in partnership with health care professionals and patients can:

- Support more patients and provide higher levels of support at a lower cost by enabling each paediatric registered nurse to monitor, mentor, and manage care at up to four locations simultaneously
- Maximize health professional scope of practice and value to the health system
- Reduce patient visits to the emergency department
- Enable more patients to die at home, fulfilling their wishes and reducing the cost associated with hospitalization
- Provide improved access to nursing care for patients in remote rural communities
- Improve access to and reach of valuable nurse specialists
- Provide more support for caregivers

These approaches are examples of scalable Ontariomade innovations that demonstrate that care can be effectively shifted from hospital to the home and community, providing quality outcomes for patients and improved value for the health care system.

<sup>&</sup>lt;sup>8</sup> Toronto Central Integrated Client Care Program (ICCP), October 24, 2013

#### Lessons for Ontario from other leading jurisdictions

In addition to models that have proven their value in Ontario, other jurisdictions dealing with similar challenges have developed new and innovative models of care and care coordination that extend the reach of care providers into the homes and communities of patients.

Through the distillation and thoughtful consideration of what is working well in other health systems, Ontario may be able to import key lessons learned for adaptation and deployment within the Ontario health system.

## The Kaiser Permanente – Vision for the future of care delivery design <sup>10</sup>

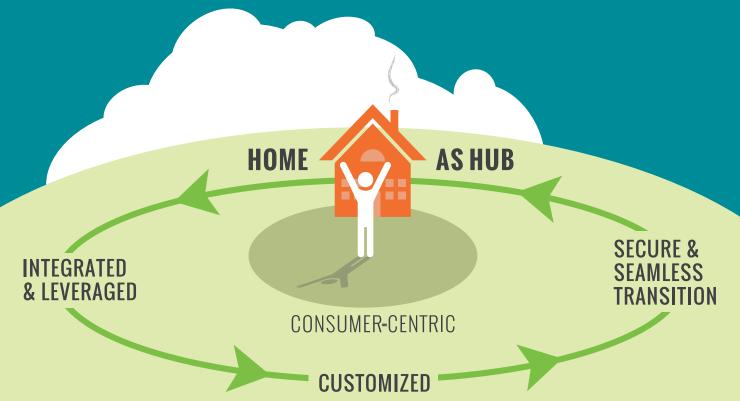
As the largest nonprofit integrated health care delivery system in the United States, Kaiser maintains an overarching agenda for achieving excellence focusing on: high-impact health conditions, goal-oriented tools to analyze population data, proactive identification of patients in need of intervention, systematic process improvements, and collaboration between patients and professionals to improve health.

Health information systems are central to its model, integrating electronic health records with the tools to support health professionals in delivering evidence-based medicine, coupled with a robust online patient portal that enhances members' access to and involvement in their care.

#### Lessons for Ontario

- Home is the care setting of choice for some care delivery and diagnostics. The Home as the Hub program extends the individual's care delivery support system to explicitly include other community and family resources
- "Warm Handoffs" human skill sets and operational processes to deliver care and service effectively, efficiently, and compassionately
- Customization that occurs at any level of the patient journey (choosing health plans, cost sharing, individual care pathways, and communication modalities). Patient-directed customization with response from the system around them
- Medical services are integrated with wellness activities; care delivery processes are integrated with health plan operations
- IT functionality enables Kaiser Permanente to leverage scarce or specialized clinical resources
  MDs, RNs and other clinical staff

## **The Kaiser Permanente Blue Sky Vision**



## Intermountain Health – Reducing acute care utilization and readmissions for chronic conditions<sup>11</sup>

The Intermountain Healthcare System is a highly integrated system in multiple hospitals, primary care practices and clinics, an outpatient heart clinic, home health service, and clinical research institute. Programs that focused on readmission rates to reduce the nearly one-in-five adults in the US that are readmitted within 30 days resulted in: readmission rates in the lowest three per cent of hospitals across the US, and heart failure and pneumonia readmission rates within the best one per cent of hospitals.

While many hospitals and health systems coordinate with home health agencies, Intermountain hospitals take it a step further and schedule follow-up home appointments prior to discharge - making care coordination across providers, including a well-developed home and community care network of providers – an essential part of their health system performance.

#### Lessons for Ontario

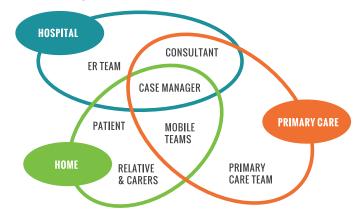
- Proactive care coordination of home care services at discharge from acute care
- Transition acute offerings to community and home delivery to lower inpatient utilization and overall health system costs
- Integration of multiple providers to improve coordination
- Investment in predictive analytics to intercede in a lower cost manner before acute care is needed
- Develop new coordinated care offerings
- Create data connectivity and exchanges to connect care venues throughout the continuum
- Partner with medical staff to standardize care protocols using evidence-based guidelines
- Create incentives for providers and administration based on care innovations developed and implemented
- Establish rigorous monitoring and analytics of innovation efficacy and efficiency

## Hospital Clinic Barcelona – Integrated Care, Home Hospitalization<sup>12</sup>

The Integrated Care Model in Barcelona is a distributed care model designed to move from *usual care* to integrated, coordinated care providing for:

- Citizens at risk of early chronic disease
- Home hospitalization and early discharge
- Home support
- Prevention of hospitalizations
- Treatment of end-stage disease
- Palliative care and end-of-life

A keystone aspect of the program was the role of a strong case manager able to coordinate services across a multi-professional care team to meet the broad range of health and social needs of clients.



Integrated Care Model in Barcelona

#### Lessons for Ontario

- Care team focused on the needs and goals of the patient to determine priorities
- Collaborating and clearly identifying the scope of services, roles and responsibilities for care received in hospital and in the community (home monitoring and home based interventions)
- Strong case managers with the ability to coordinate services, handle unexpected situations, and support a variety of health and social needs
- The ability for various providers to update, view and retrieve timely patient information
- Interventions are normalized for individual patient health/social needs

### How will we pay? The role of public health insurance

Many Ontarians are surprised to learn that public insurance does not cover all of what they might consider essential health care services. Already, 30 per cent of health care in Canada and Ontario is paid in whole or in part out of pocket or by employer benefits for pharmaceuticals, long-term care, ambulance services and some home and community care services.

Intermountain Health Care: http://intermountainhealthcare.org/Pages/home.aspx; http://www.commonwealthfund.org/~/media/Files/Publications/Case%20 Study/2011/Apr/1473\_SilowCarroll\_readmissions\_synthesis\_web\_version.pdf

<sup>12</sup> http://www.hospitalclinic.org/; http://www.medtech.cat/sites/default/files/documents/tr\_josep\_roca.pdf

Home and community services are considered an "extended health service" and are not covered in the fundamental principles of the Canada Health Act. As a result, the lines between what is in and what is out of the public insurance framework are already blurring and vary to some degree from province to province. With increasing demand for higher levels of care by more people, the Ontario government is not likely to be able to fully fund home and community care from taxpayer revenues alone. At the same time, the widening gap between rich and poor and increasing levels of debt for Ontario seniors will create challenges to ensuring equitable access to care. How we will pay for health care services as we march towards 2027 is a question that warrants a frank dialogue.

#### Propositions for Ontario

The propositions outlined below surfaced during consultation with health system leaders and research. They are offered as a catalyst to begin a more active, engaged conversation on the possible means and mechanisms that Ontario could consider in meeting the demands our society approaching 2027.

- Initiate a new form of social insurance in Ontario with mandatory contributions based on a percentage of income to pay for health care services not covered by the Ontario Health Insurance Plan (OHIP) such as long-term care and home care services
- Encourage more Ontarians to consider the role of private/supplemental insurance products
  - There are currently 13 life and health insurers in Canada that offer individual long-term care insurance plans, which provides a signal that insurance products are beginning to address the gaps in public insurance to Canadians with means to pay
- Bring government and large employers together to develop a strategy and pilot new approaches to population health and wellness to curb the cost of public and private insurance costs for employees and retirees
- Embark on the prioritization of health, social and other services required by Ontarians and introduce point-of-care user fees based on a consistent set of principles including ability to pay
- Allow for resources currently earmarked for specific baskets of services for Ontarians to be increasingly directed by individuals and their caregivers to ensure that the value they receive through public investment best meets their individual needs and circumstances

 Implement a meaningful tax benefit to better support patients and informal caregivers to defray the costs of long-term and home care and reduce absenteeism and caregiver distress

## A view from Denmark – Long-term care and comprehensive and flexible home care

The Danish long-term care system for the elderly and people with disabilities provides comprehensive coverage for a wide-range of social services, including home adaptation, assistive devices and home care. Home care services include support towards technical aids and equipment, and even activities outside of the beneficiary's home that sustain the individual's participation in activities of daily living.

Local authorities finance the costs of long-term care through block grants received from the government, local taxes and equalisation amounts received from other local authorities. The overall budget for long-term care services is global, and is set annually. Legislation allows local authorities some limited freedom in setting charges for home help and some other non-health related expenses. Thus, user charges only account for a small part of the total long-term care expenses (out-of-pocket payments account about 10 per cent of total long-term care expenditure).

Local authorities may issue a service certificate to private providers meeting quality standards, allowing individuals to employ his/her own personal helper from among qualified individuals and companies.

Source: http://www.oecd.org/denmark/47877588.pdf

#### **Putting elderly care first in Sweden**

Sweden allocates five times the EU average (by proportion of GDP) to elder care, making it the highest investment of GDP in elder care in the world. Of Sweden's 9.5 million inhabitants, 18 per cent have passed the retirement age of 65. This number is projected to rise to 30 per cent by 2030. Of the SEK 95.9 billion, (USD 14.0 billion, EUR 10.7 billion) cost of elder care — only three per cent of the costs are financed by patient charges.

Most elderly care is funded by municipal taxes and government grants. Each municipality decides its own rates for elderly care. The cost depends on the level or type of help provided, and the person's income. A maximum charge for home help, daytime activities, and certain other kinds of care has been established.

More municipalities are privatizing parts of their elderly care. In 2011, private care provided services for 18.6 per cent of all elderly people getting home help. Recipients can choose whether they want their home help or special housing to be provided by public or private operators.

Sources: http://www.sweden.se/eng/Home/Society/Elderly-care/Facts/Elderly-care/

## What should we expect from our families, informal caregivers and each other?

Families and informal caregivers of Canadian patients contribute between \$24-31 billion worth of care each year, representing a considerable resource to the Ontario health system. <sup>13</sup> As Ontario's informal caregivers age and become fewer in number, how will Ontario support them so that they may continue providing care to their loved ones?



# APPROXIMATELY 25 PER CENT OF INFORMAL CAREGIVERS ARE REPORTEDLY IN DISTRESS.

Approximately 25 per cent of informal caregivers are reportedly in distress. <sup>14</sup> The most common difficulties reported by Canadian caregivers are the emotional demands, increased stress, fatigue, and limitations it places on having enough time for themselves and family. <sup>15</sup> As detailed above, our society will need to face some difficult questions on what publically-funded home, community and social services will provide to support caregivers.

In shaping the future of Ontario's health system, the needs of caregivers must be given equal sway in shaping how we deliver health care services in a manner that supports them and accounts for their individual needs and circumstance.

In addition to the support that the Ontario health system may provide informal caregivers, communities will be called upon to rally and coordinate resources to support Ontario's patients and caregivers.

#### Propositions for Ontario

To transform our health system and advance our society's appreciation for the role and needs of Ontario's informal caregivers, we will need to increasingly incorporate key design elements into the future health system planning, workplaces and policy. Some propositions for Ontario that we encountered through developing this paper included:

- Developing mechanisms to engage and accommodate caregivers in decision-making and account for their individual needs and circumstance within the future models of care and health and social service delivery models
- Clearly delineating what public services are available, establishing minimum thresholds of service levels across Ontario as sources of respite care and assistance in care coordination and health system navigation
- Addressing the personal, employer and broader economic productivity issues of workplace absenteeism due to employee obligations to fill gaps in care as informal caregivers and support their ongoing health and wellbeing in balancing family obligations, career demands, and caregiving
- Raising our society's game in how it responds to the needs of informal caregivers through new ventures, social entrepreneurship and/or collaboration to fill gaps in care and support that public spending cannot address
  - For example, efforts in the United Kingdom (UK) in establishing a Big Society as a means to increase local responsibility for public services to individuals, small groups, charities, local organizations, and businesses

#### **Britain's Big Society**

The Big Society is social funding concept that originated in the UK and has seen influenced policies in other countries. The focus is on giving citizens, communities, and local government the power and information they need to come together, solve the problems they face and build the society they desire. The policy emphasizes that building a Big Society isn't just the responsibility of just one or two Government departments but of every department and of every citizen too.

Some broad policies to help take forward the Big Society framework include

- Giving communities more powers to reform planning systems and take over state-run services shape the nature and level of services available in their community
- Encouraging people to take an active role in their communities including volunteerism, charitable giving and community involvement
- Transferring power from central to local government including devolution of financial autonomy to local government levels to shape how public resources are allocated to meet the needs of the community
- Supporting co-ops, charities, and social enterprises to run and deliver public services
- Publish government data to promote informed community decision making and accountability

Sources: http://www.local.gov.uk/health/-/journal\_content/56/10180/3510418/ARTICLE

<sup>&</sup>lt;sup>13</sup> http://mssociety.ca/ontario/pdf/BriefCaregiverSupportsMay2013.pdf

<sup>&</sup>lt;sup>14</sup> John Hirdes, "Care in the Community" Presentation, WW CCAC 2013 Symposium.

<sup>&</sup>lt;sup>15</sup> "Seniors in Need, Caregivers in Distress." Health Council of Canada, April 2012.

## CONCLUSION

In the year 2027, one of the most influential generations in history will begin to turn 80. The world then will not be as it is now. Demographics, economics, changing family structures, global migration, social conventions, and revolutionary advances in technology will make every aspect of everyday home life vastly different from what it is today.

Among these changes will be the increase in the number of people living with chronic health conditions needs, aging with complex health needs, and preferring to die in their own homes with the assistance of hospice palliative care.

Current policy directions are shifting care away from institutionally based models and towards care that is provided in people's home and in the community. As this trend continues to evolve, the home and community sector will need increased capacity and resources to effectively care for patients. If we continue to think only in terms of shifting from one setting to another, rather than thinking about starting in a different place, our dialogue will be narrow and constrained.

As Ontario ages, there will be proportionately fewer seniors aging in acute and long-term care institutions, more seniors living alone, and more seniors in community settings with increasingly complex health conditions. Many of these seniors will be cared for by informal caregivers, who are themselves aging, and/or by their children who are fewer in number and more geographically dispersed.

The confluence of increased demand and constrained supply of health system resources will necessitate a more forward-thinking dialogue on some fundamental and difficult questions for Ontario. Ontario has the ingenuity, energy and resourcefulness to take on these questions and challenges. In doing so, Ontario has the opportunity to lead the way forward in designing effective responses to the emerging challenges faced by the province, Canada and developed economies around the world.

The advantage of talking about the longer term time frame of 20 years is we have time to expand our dialogue to the bigger questions – the challenge is we have to start now, and refuse to allow ourselves to be limited in our discussion by current constraints.

