COME PREPARED TO DEBATE!

Voice your opinion and vote on the top 3 motions to be debated.
Prepare to Debate!

We are very pleased to present to you the issue briefs for the top 8 motions going forward to the 2018 Great Canadian Healthcare Debate!

These 8 issue briefs are the result of a process that began in early 2018 when the Call for Motions for the Great Canadian Healthcare Debate was issued. As you know, the Policy Resolution Committee, whose mandate is to oversee the process and to recommend the top motions that go forward, has decided that we should take a deeper dive in the top motions adopted for the last three years. The 2018 debate will be an opportunity to update on our progress and to further advance the past motion themes: mental health, Indigenous health and seniors health.

The Committee, identified the top motions using the criteria newsworthiness, potential for revealing new insights, appeal to Canadians, impact, ability to generate concrete outcomes and to create positive policy change. The process resulted in a list of the top 8 motions framed within one of the three topics. You will find them listed in the back of this booklet. Congratulations to each of the top 8 motion sponsors!

On Monday, June 4th, you will be given an important opportunity to engage in this year’s Debate. You will be asked to vote on the top 3 motions that will be debated, one for each of the three topics. Your vote will set the stage for an exciting morning on Tuesday, June 5th, when the sponsors of the top 3 motions make the case for why theirs is the number one priority.

So, come prepared to debate and make this a dynamic discussion! Conference delegates will have an opportunity to make their voices heard. Read these issue briefs carefully; each sets out very thorough information about an important issue that health leaders are facing today in mental health, Indigenous health and seniors health. Formulate some questions and/or comments that you can share. Prepare to support your top motion. Explain why it is your top priority. Tell us how you or your organization can contribute to moving any or all of these motions forward.

Thank you for being part of the Debate!

Sincerely,

Wendy Nicklin, CHE, FACHE
Chair, Policy Resolution Committee

Policy Resolution Committee members:
Ms. Wendy Nicklin, CHE, FACHE (Chair); Mr. Patrick Dumelie; Ms. Maria Judd; Mr. Greg Lawrie, CHE; Dr. Bernard Leduc; Ms. Sharon Nettleton; Ms. Jennifer Pougnet, CHE; Ms. Chris Power, CHE; and Mr. Michael Redenbach, CHE.
NHLC: Ms. Sue Owen, CHE; Mr. Paul-Emile Cloutier; Mr. Jonathan Mitchell, CHE; Ms. Lucie Boileau; and Ms. Siri Chunduri.
Voice your opinion and vote!

The Great Canadian Healthcare Debate offers health leaders a unique opportunity to debate and advance policy resolutions that reflect the current Canadian health system context and address the most pressing issues facing healthcare and health leaders today. This year, the resolutions fall under the last top motions policy themes adopted for the last three years: mental health, Indigenous health and seniors health. Chosen by an esteemed Policy Resolution Committee, these are the eight motions from which conference delegates will select the three motions - one per policy theme - that will be debated this year.

1. MENTAL HEALTH

1.1 Achieving Universal Mental Health Care

Be it resolved that health leaders continue to support increased investments and policy changes to overcome the factors that impede achieving universal access to a full continuum of evidence-based mental health services and supports for all people in Canada.

SUBMITTED BY: Ed Mantler, Vice President, Programs and Priorities, Mental Health Commission of Canada and Nicholas Watters, Director, Knowledge Exchange Centre, Mental Health Commission of Canada

1.2 Zero Suicide

Resolved that, Canadian healthcare leaders across the country work collectively to view every death by suicide, whether among those under care or those living in the community, as an unacceptable outcome and offer the necessary systems, programs (including culturally appropriate services and supports) and policies that strive to make suicide a “never event.”

SUBMITTED BY: Michel Rodrigue, Vice President, Operational Performance and Public Affairs, Mental Health Commission of Canada

1.3 Maternal Mental Health

Resolved that, the federal Ministry of Health working with the local, provincial and territories government develop a national strategy on Maternal Mental Health; this action would be achieved through the implementation of a national screening & treatment program for expectant and new mothers. The strategy should be ready by June 2020 and be put into action by the provinces in order to assist the 76,000 new mothers who experience a Postpartum Mood & Anxiety Disorder each year by providing early treatment to lessen the negative impacts on mothers, infants, and families.

SUBMITTED BY: Claire Kerr-Zobb, Founder & Executive Director, Life With A Baby

2. INDIGENOUS HEALTH

2.1 Embedding Cultural Safety in Core Curriculum

Resolved that, all Indigenous people deserve to receive care from practitioners who are self-reflective/self-aware regarding their position of power and the impact of this role in relation to patients to ensure people feel and are respected and safe. All Provinces, Territories and the Federal Government support Indigenous communities in co-designing a mandatory national education program/curriculum that promotes cultural safety for all health providers, volunteers and students.

SUBMITTED BY: Maryanne D’Arpino, Senior Director, Safety Improvement Projects, Canadian Patient Safety Institute and Markirit Armutlu, Patient Safety Improvement Lead, Academic Faculty Development, Canadian Patient Safety Institute

2.2 Indigenous Health

Resolved that, in order to understand and address the patient safety incidents experienced by Indigenous (First Nations, Metis, and Inuit) people, Canadian healthcare leaders and Indigenous communities will jointly develop a meaningful consultation process that respects diverse, holistic approaches to health, and recognizes the importance of strengthening health literacy and patient engagement as critical conditions for patient safety.

SUBMITTED BY: Jan Byrd, Patient Safety Improvement Lead, Canadian Patient Safety Institute
3. SENIORS HEALTH

3.1 Family Caregivers of Seniors
Resolved, that Canadian healthcare leaders recognize and embrace family caregivers of seniors as valued members of the healthcare team by committing within the next two years to changing the culture in the healthcare system to actively involve family caregivers in care settings and by educating healthcare providers on the value of respecting and acknowledging the crucial role family caregivers play.

SUBMITTED BY: Dr Anwar Haq – Covenant Network of Excellence in Seniors’ Health and Wellness and Dr. Jasneet Parmar, Medical Director, Convenant Network of Excellence in Senior’s Health and Wellness

3.2 Advanced Care Planning
Resolved, that Canadian health-care leaders and provincial and territorial Ministries of Health commit within the next two years to adopt routine, early integration of Advance Care Planning (ACP), as an enabler for person-centred care, into the care of capable seniors in all care settings, by development of policies, care processes, training programs, funding models and a registry to boost ACP awareness and enhance the capacity for consistent initiation of ACP conversations, documentation storage and access throughout the health system.

SUBMITTED BY: Eman Hassan and Kathleen Yue - BC Centre for Palliative Care

3.3 High Quality Palliative Care
Resolved, that recognizing access to high quality palliative care is an important issue for Canadians, health care leaders promote Palliative Care Matters, adopt the Collective Impact Framework (CIF) and work together toward a framework for an integrated approach to funding and delivery of palliative care.

SUBMITTED BY: Ms. Karen Macmillan, Senior Lead for the Palliative / End-of-life Strategy, Covenant Health and Dr. Konrad Fassbender, Scientific Director, Palliative Institute, Covenant Health
THEME: MENTAL HEALTH

1.1 Achieving Universal Mental Health Care

Be it resolved that health leaders continue to support increased investments and policy changes to overcome the factors that impede achieving universal access to a full continuum of evidence-based mental health services and supports for all people in Canada.

SUBMITTED BY
Ed Mantler, Vice President, Programs and Priorities, Mental Health Commission of Canada and Nicholas Watters, Director, Knowledge Exchange Centre, Mental Health Commission of Canada.

PURPOSE
This motion offers tactics to redress the longstanding impact of the narrow scope of eligible mental health services under the Canada Health Act that do not involve amending the Act.

ISSUE
Many evidence-based mental health services are still as inaccessible to people in Canada as they were twelve years ago when the Senate Study, Out of the Shadows,1 was released calling for a major transformation of Canada’s mental health services or six years ago when Canada's first Mental Health Strategy, Changing Directions Changing Lives,2 was released and offered a blueprint for change. One key core service in mental health – psychotherapy – remains only available in the public system in a very limited way or, privately only to those who can afford to pay or have a workplace health plan. Not only do the latter too often cover no more than a couple of sessions, an estimated 12 million Canadians do not have any employment-based supplemental health benefits of any kind.3 Yet, psychotherapies are especially important in treating depression, a condition which is at least as prevalent in Canada as other chronic diseases such as diabetes and hypertension — yet close to 50% of people living with depression do not access health services for their illness.4 This would be considered a crisis if the same treatment rates applied to diabetes or hypertension.

Unlike most people facing almost any other health problem, the 7.5 million people in Canada living with a mental health problem or illness do not now have universal access to mental health care. Historical decisions that led the Canada Health Act to exclude care in free standing psychiatric hospitals and by non-physician health professionals have entrenched health funding patterns in Canada that have significantly disadvantaged mental health care for many years.5

This has resulted in at least one third of people with a mental illness not receiving the services they need,6 a wide gap in and lack of parity of funding for mental health services (at 5 to 7% of total public spending on health in Canada compared to commonwealth benchmark of nearly 13%);7 and a two-tiered system for access to at least one care service in mental health care – psychotherapy. Psychotherapy is shown to be as or more effective than many common physical interventions such as cataract surgery or the flu vaccine.8 As repeated often in recent years, “the barriers to accessing high quality mental health services are not because we don’t have services that work, but because our public health services don’t fund their full range.”9

BACKGROUND
Even though the goal for the Canada Health Act10 was to create a system of health services “that will promote physical and mental health and protection from disease”, mental health care has historically been treated differently under the Act - primarily because free standing psychiatric hospitals which were classified as providing long term custodial care rather than medically necessary care.

Additionally, mental health care has been especially impacted by Medicare’s focus on financing for medical and acute care and its exclusion of health professionals who are not physicians. Implementation of good practices in mental health services and universal mental health care depends heavily on non-physicians for the provision of the continuum of services, such as psychologists, social workers, occupational therapists and other regulated psychotherapists or counsellors. This legacy has created entrenched systemic barriers that have prevented non-physician mental health professionals from delivering services according to the full scope of practice for which they have been trained, whether through limitations in scope of practice legislation, requirements for physician referrals to regulated non-physician mental health professionals, how professionals are organized on teams, and other longstanding cultural and organizational practices.
There is a perception that mental health is now adequately “out of the shadows” because of the attention it receives in the media, the efforts over the past ten years in part by the Mental Health Commission of Canada and many others, and the recent new federal targeted investment of $5B over 10 years through the Health Accord. This is an important first step, but it barely takes off one percentage point off the funding gap. Despite tremendous progress to date, mental health is far from achieving parity with other health conditions. History tells us that without adequate, secure funding and more attention to addressing entrenched policy barriers that impede system transformation, mental health can easily go back into the shadows.

The evidence is resounding that addressing the large systemic gaps in mental health care will benefit the entire health system:

- Improving access to psychotherapy not only improves outcomes and quality of life it saves the economy about two dollars for every dollar spent;
- Offering one session of counselling for high users of emergency rooms – the cost of which is offset from averted hospital visits and savings from earlier return to work – results in net savings of $21 per client in the first month;
- Providing six psychotherapeutic sessions in primary care for aging adults, results in measurable quality of life improvements, versus only providing sedatives or no treatment, with a quantifiable economic benefit of as much as $13,000 per person.

CONSIDERATIONS

While in the past there were calls to amend the Canada Health Act to redress the historic exclusions, legislating inclusion of psychiatric hospitals and non-physician providers at the federal level will neither ensure more funding is allocated to these services nor change practice. While this would have been an important policy lever when the federal government contributed fifty cents on every dollar spent by the provinces and territories on health, this no longer is the case. The power to ensure new federal investments in mental health redress the legacy of exclusion and make mental health services universally accessible rests equally with health leaders at the provincial, territorial and point of practice levels.

NEXT STEPS

To achieve universal in mental health care, health leaders need to continue to sustain pressure to further close the funding gap for mental health in both health and social policy budgets. They need to ensure that mental health is protected in provincial and local level health budgets and not redirected under fiscal or administrative budgetary pressures. They also need to lead cultural, policy and practice changes that will allow non-physician health professionals to provide services according to their full scope of practice. Without sustained pressure to close the funding gap, protect new funds, and a cultural shift on scopes of practices, history tells us that mental health can very easily go back into the shadows.

REFERENCES

1.2 Zero Suicide

Resolved that, Canadian healthcare leaders across the country work collectively to view every death by suicide, whether among those under care or those living in the community, as an unacceptable outcome and offer the necessary systems, programs (including culturally appropriate services and supports) and policies that strive to make suicide a "never event."

SUBMITTED BY
Michel Rodrigue, Vice President, Operational Performance and Public Affairs, Mental Health Commission of Canada

PURPOSE
Suicide prevention is a major public health issue and leading cause of death in Canada. Efforts have not yet been able to substantially lower rates of suicide across Canada. A different approach is needed in our collective suicide prevention efforts as our current tactics are simply not working. Unless we change course, we will continue to see rising rates of suicide. Every suicide is a tragedy and a failure - a failure of the health system and a failure of our communities to offer effective and culturally appropriate programs, services, and supports to its citizens.

ISSUE
Suicide is a serious public health problem with devastating impacts on individuals, families and communities. Each year in Canada, more than 4,400 people tragically take their own lives (Statistics Canada, 2015). Among those aged 15 to 24, suicide is the second leading cause of death after car accidents. Individuals experiencing thoughts of suicide often fall through the cracks of a fragmented health care system. A system transformation that addresses public health prevention and promotion initiatives is required to reduce the number of suicide deaths.

BACKGROUND
The Federal government has stated that suicide prevention is a national health priority. However, in the last ten years, suicide rates in Canada have not substantially declined. In fact, the suicide rate in Canada has risen from 11.3 individuals per 100,000 in 2011 to 12.3 individuals per 100,000 in 2015. In 2015, 4,405 Canadians died by suicide, which is more than 12 people per day. The impacts of suicide are far-reaching. For every death by suicide, 25 people are severely devastated and 125 people are directly impacted. Among those who die by suicide, a large percentage has a history of mental health problems or illnesses, including depression, bipolar disorder, schizophrenia and post-traumatic stress disorder. Suicide can be prevented through better understanding of suicide combined with evidence-based prevention programs.

Suicide rates are a barometer of how well our systems, programs and policies are meeting the mental health and substance use needs of our population. Suicide, mental illness and substance use are deeply connected; it is estimated that 90% of people who die by suicide were experiencing a mental health problem or illness, and/or problematic substance use. Suicide is also inextricably shaped by the social, political and historical context in which people live. Eliminating suicide in Canada will require comprehensive community-driven and community-specific approaches focused on social justice as well as health system interventions. This will require holistic system transformation that addresses public health prevention and promotion initiatives, including the right continuum of supports from universal precautions to the social determinants of health.

Nationally and internationally, we are seeing evidence that addressing suicide within communities shows promise. Implementing community suicide prevention initiatives in jurisdictions around the world have shown reduction in suicide rates by 20 per cent over a two-year period. In Canada, that could translate to 800 or more lives saved every year. Groups who have adopted these types of approaches and strategies include Australia (Lifespan), the World Health Organization, the European Alliance Against Depression, Quebec (Help for Life), and the Okanagan Nation (Aboriginal Suicide Critical Incident Response Team). A breakthrough concept, ‘Zero Suicide in Health Care’ has a foundational belief that suicide deaths for individuals under care within the health system are preventable. Initiated at the Henry Ford Health System in the United States, they have seen nine consecutive quarters without any suicides. Zero Suicide presents both a bold goal and an aspirational challenge. Effective suicide prevention programs are calling for the engagement of the broader community in support of a system-wide approach to healthcare programs and systems. This combination of community interventions and health
system interventions is the comprehensive approach to suicide prevention that is required in order to achieve a meaningful reduction in suicide in Canada.

CONSIDERATIONS
A joint effort spearheaded by the Mental Health Commission of Canada (MHCC), and financed through provincial investment, Roots of Hope: A Community Suicide Prevention Project is a multi-pronged approach that touches on a range of proven methods to decrease suicide rates. The project works at a local level to strengthen public awareness, improve access to services, restrict means of suicide, and support better education for people in roles of trust and authority. Roots of Hope is currently being rolled out in several communities across the country. The benefits of this program extend beyond the residents of participating communities, as the project will help establish a set of evidence-based recommendations, tools and resources that can be shared with all provinces and territories as part of a national suicide prevention effort. Information learned will be used to develop guidelines and toolkits and support future implementation and scaling up across Canada.

The approach used in the Roots of Hope project draws heavily on best practices in suicide prevention from across the globe and right here at home. It involves experts and leaders in Canada, including from provincial initiatives as well as from First Nations, Inuit and Métis communities. Initial consultations on this project have shown broad stakeholder support for undertaking a Canadian community-based suicide prevention initiative of this kind. Suicide prevention efforts must engage individuals and communities, as well as government and leaders, and efforts need to recognize the social determinants of health, culture and traditional knowledge, viewing suicide prevention within an understanding of mental wellness.

Suicide is complex and as such there is no single answer or tool that can be applied broadly to reduce the number of suicide deaths. Every community has unique strengths and challenges. For these reasons, participating communities develop a community action plan that builds on local programs and expertise to ensure the project meets their community’s needs, while still aligning with the overarching project pillars and guiding principles. This ensures that the project is grounded in the knowledge and experience of local community leaders.

There is strong evidence that comprehensive, system-wide approaches are most effective in suicide prevention. The MHCC’s Roots of Hope is working at a community level to strengthen and build local community capacity in suicide prevention. By bringing together diverse community groups to address suicide, we will be able to impact the number of suicide deaths in Canada. By implementing Roots of Hope and Zero Suicide in coordination, we can augment our combined efforts in reducing the number of suicide deaths.

NEXT STEPS
The MHCC calls all provinces and territories to join the provinces already participating in Roots of Hope. This will take leadership from all levels of government, including at the federal, provincial, territorial and municipal level, to secure the financial and scarce human resources to dedicate to our collective suicide prevention efforts. Furthermore, Canadian health leaders across the range of health care organizations including the mental health care system, long-term care facilities, and hospitals must commit to implement ‘Zero Suicide in Health Care’ to reduce suicide deaths among those individuals under their care. Without the commitment of health care leaders, the work being done at a community level to reduce the number of suicide deaths will not be as effective. Only by coming together as health leaders, community leaders, politicians, first responders, teachers and youth will we be able to turn the tide to drastically reduce the numbers of suicide deaths in Canada. A coordinated approach that brings together professionals, organizations and individuals from across jurisdictions is the only way that collectively we will be able to make suicide a ‘never-event’.

REFERENCES

This brief was prepared by the Mental Health Commission of Canada.
THEME: MENTAL HEALTH

1.3 Maternal Mental Health

Resolved that, the federal Ministry of Health working with the local, provincial and territories government develop a national strategy on Maternal Mental Health; this action would be achieved through the implementation of a national screening & treatment program for expectant and new mothers. The strategy should be ready by June 2020 and be put into action by the provinces in order to assist the 76,000 new mothers who experience a Postpartum Mood & Anxiety Disorder each year by providing early treatment to lessen the negative impacts on mothers, infants, and families.

SUBMITTED BY
Claire Kerr-Zlobin, Founder & Executive Director, Life With A Baby

ISSUE
Maternal depression is a significant risk factor affecting the healthy development of babies, children and youth. The relationship between maternal mental health and child health outcomes is well-documented and research is continually demonstrating the importance of early detection and treatment of maternal mental illness in early childhood development. Maternal depression can impair the maternal/child bond and result in delayed physical, social and cognitive development with long-term implications for physical and mental well-being and related health outcomes. Mothers who are struggling with their own mental health concerns may find interaction with their child in this capacity more difficult and thus delay or impair this vital component of early brain development.

The World Health Organization (WHO) defines maternal mental health as “a state of well-being in which a mother realizes her own abilities, can cope with normal stresses of life, can work productively and fruitfully and is able to make a contribution to her community.” When confronted with mental illness, many women are unable to function in a way that allows them to contribute at a level that is consistent with WHO definitions. Maternal depression is the second leading cause of disability among women globally and estimates suggest that up to one in five women will struggle with a mental health complication during the perinatal period.

It may surprise you to learn that:
• It is estimated that up to one in five perinatal women will suffer from a maternal mental illness. This prevalence makes mental illness the most common complication of the perinatal period, and a significant public health concern.
• Not only are women affected by poor mental health but impacts are felt directly by their partners, family, friends and community. When left untreated, mental illness can have a direct impact on early childhood development outcomes.
• Exposure to Adverse Childhood Experiences (ACES), of which parental depression is one, can result in high levels of toxic stress on a child’s developing brain that can result in a greater likelihood of poor mental and physical health outcomes later in life.

BACKGROUND
Many mothers experience a perinatal mood and anxiety disorder. In 2017, a study in the Canadian Medical association journal looked at suicide among new mothers and found that 1 in 19 maternal deaths in Ontario is attributed to suicide. Making suicide the fourth leading cause of death for perinatal women in Canada. 1 in 19 mothers!

Because of stigma and leaving the onus on the mothers to reach out for help, only 15% of mothers who experience a perinatal mood or anxiety disorder (PMAD) receive professional treatment. Some countries, such as the UK, Australia, USA, all have a Maternal Mental Health Strategy & screening program in place. Canada instead leaves the responsibility on new mothers to reach out for help. They may not know to reach out for help if they do not know they are experiencing a PMAD, or they may be afraid of the stigma associated with a PMAD.

If we want to support children and youth, we must start with mothers and ensure that they are healthy. When moms thrive, babies thrive. If we want to turn the tide on some of our biggest challenges with children and youth we need to focus on preventing them by having a strategy for supporting Canadian mothers and increase maternal mental health.
CONSIDERATIONS
Based on research, current trends, and new knowledge, we need to act now and put a plan in place to screen mothers for PMADs to prevent the loss of life, lessen the effect on children and youth, and decrease the high economical costs for something that can be prevented by early detection, and simple interventions. We need a plan in place to identify the mothers who are at risk and get them into treatment whether that is peer-based support groups, medication, counselling, or hospitalization.

Consider this:
• Maternal depression and anxiety is a stronger risk factor for child behavioral problems than smoking, binge drinking, and emotional or physical domestic abuse.\(^9\)
• More women will suffer PMAD than there are new cases of breast cancer diagnosed annually.\(^{10}\)
• More women will suffer from Postpartum Anxiety and Depression in a year than the combined number of new cases for men and women of Tuberculosis, Leukemia, Multiple Sclerosis, Parkinson’s Disease, Alzheimer’s Disease, Lupus, and Epilepsy.\(^{10}\)
• Depression during pregnancy and the immediate postpartum period is the most concerning time and has the biggest effect on the developing brain.\(^6\)
• It has been estimated that the cost for untreated mother/child unit is up to $150,000 with 72% of the cost allocated to the child.\(^7\) It is estimated 85% of mothers do not receive treatment, so the economic cost to Canada is approximately $11 billion dollars. This can be reduced to approximately $5,000 if we screen and treat.\(^8\)

NEXT STEPS
This needs to start with the provinces. The provinces, which are extremely important, will know the needs of their communities, and can put a realistic budget of what it will cost in place. So, we are suggesting a bottom-up process. We need the provinces to make this a priority, go to the federal government as a unified voice, and ask for funding with budget allocations for each province.

Saskatchewan has had a Maternal Mental Health Strategy for 10 years and Northern Ontario Postpartum Mood Disorder Strategy published and launched in 2015. We will use these two Canadian strategies as guidelines, amend them to apply to other provinces, and create a national strategy for recommendations for PMAD informed communities and the development of a menu of services for each Province (including but not limited to universal screening) for pregnant and new mothers.

We will develop an All Canadian PMAD Strategy by integrating the community development methodology and work of the two existing Strategies into a total federal coordinated effort that is inclusive of all of Canada.

Once funding has been approved, the provinces need to work with advocates, mothers with lived experience, the Perinatal Mental Health Coalition Canada and Life With A Baby to execute the strategy so no mother is left behind.

REFERENCES
8. Patterns of Depression and Treatment in Pregnant and Postpartum Women Angela Bowen, RN, PhD1; Rudy Bowen, MD, CM, FRCPC2; Peter Butt; MD, CCFP3; Kazi Rahman, MBBS, MS (PhD Candidate)4 ; Nazeem Mubairane, PhD5, 2012
2.1 Embedding Cultural Safety in Core Curriculum

Resolved that, all Indigenous people deserve to receive care from practitioners who are self-reflective/self-aware regarding their position of power and the impact of this role in relation to patients to ensure people feel and are respected and safe. All Provinces, Territories and the Federal Government support Indigenous communities in co-designing a mandatory national education program/curriculum that promotes cultural safety for all health providers, volunteers and students.

SUBMITTED BY
Maryanne D’Arpino, Senior Director, Safety Improvement Projects, Canadian Patient Safety Institute and
Markirit Armutlu, Patient Safety Improvement Lead, Academic Faculty Development, Canadian Patient Safety Institute

PURPOSE
Primum non nocere – First, do no Harm. This issue brief addresses the long-standing concerns of Indigenous people experiencing harm while trying to access services in healthcare. Patient safety is already embedded in most health professional curricula, thanks to several national health organizations and faculties who have taken on the mantle and inserted patient safety content into their standards and educational outcomes. However, Patient Safety Curricula must include the concept of Cultural Safety and embedding cultural safety in health professional curriculum is one important way forward. This important work is in its early stages in Canada, with some jurisdictional health authorities, universities, medical and nursing associations collaborating with Indigenous communities to co-create training resources. The Indigenous Cultural Safety (ICS) Online Training Program provided by the Provincial Health Services Authority of British Columbia and the Southwest Ontario Aboriginal Health Access Centre is such a program that is currently available. However, a sobering reality is that most provincial and territorial jurisdictions do not have similar programs. A clear majority of the health professions graduates remain ill prepared to address the needs of our diverse Indigenous populations. The existing biases of healthcare providers can unintentionally contribute to harming Indigenous patients they are intending to help. Therefore, supporting Indigenous communities in co-designing a mandatory national education program/curriculum that promotes cultural safety for all health providers, volunteers and students will help reduce the risk of harm to Indigenous people when accessing health care.

ISSUE
The health status of Indigenous Peoples is below the national average (Shah, Svoboda & Goel, 1996), and their experiences with the mainstream health care system has been negative, often due to cultural differences. Frequently, cultural differences and the inability of health providers to appropriately address these differences have contributed to high rates of noncompliance, reluctance to seek healthcare even when service is needed, and feelings of fear, disrespect and alienation (NAHO, 2003, pp. 39-41). Adopting a culturally safe approach to health care can benefit individuals, providers and health care systems. When culturally appropriate care is provided, patients respond better to care.

Cultural Safety has moved from the periphery to the forefront of healthcare in Canada over the past decade. Every healthcare provider needs to be able to First, do no Harm. They need to provide care and to improve care to ensure that all patients, regardless of their cultural, religious and ethnic backgrounds, receive safe, high quality care. Yet, despite a growing recognition of the need to embed cultural safety in every aspect of healthcare education, approaches to teaching healthcare students and providers are inconsistent, insufficient, and the effectiveness of the education that is given is open to debate. Though pockets of improvements in cultural safety education have been made, our collective wisdom tells us there is much more to be done; we have a very long way to go to incorporate cultural safety into all health professionals’ curricula. This shortfall continues to place Indigenous patients at risk during their care, e.g. preventable harm in hospitals, home care, etc. Healthcare providers go to work trying to do their very best for the patients they serve, but we will not serve them well if they are not prepared with the basic knowledge and skills in cultural safety to ensure safe care.

Everyone within healthcare is responsible for cultural safety, but who is responsible for what gets included in curricula and licensing requirements? Who is assessing whether academia is actually providing this training? The Canadian Patient Safety Institute believes the key to professional excellence is in mandated standards to get cultural safety education firmly established in colleges and universities in the health professions. Any one of a number of levers can be used to push cultural safety competencies in the health professions — from regulation, accreditation of programs, professional
certification and licensure, as well as collaboration with provincial and territorial ministries of education (through health professions legislation) and provincial quality councils. Only through a combination of mandated requirements and moral suasion can the effectiveness of education and training in cultural safety be measured and ultimately tested. Like seatbelt and bicycle helmet legislation, goodwill can only get you so far.

The inaugural honorary witness to the Truth and Reconciliation Commission, the Right Honourable Michäelle Jean spoke “I call on Canadians – elders and youth, Aboriginal or not – to commit to reconciliation and breaking down the wall of indifference.” It is very clear that Indigenous people across this country have worse health outcomes than nonindigenous individuals. This is partially due to the impact of the social determinants of health, but an additional major influence is the manner in which Indigenous people receive care. Mr. Brian Sinclair did not die of a bladder infection because health professionals did not know how to care for him. He died because he was largely ignored for 34 hours, because providers assumed he was sleeping off drunkenness. Cultural safety is patient safety.

All people should expect to feel respected and safe when they interact with the health care system. In recent years there has been a growing number of training activities by multiple organizations and associations that focuses on cultural safety. This proposal recommends the development of a mandatory program that would be standardized across the country and would allow for local contextualization. A mandatory national program would also address topics of and cultural sensitivity, cultural competency and trauma informed care. The eventual platform should enable knowledge dissemination but also offer mechanisms for the celebration of advances in the care of Indigenous clients. Central coordination and standard curriculum offers the opportunity to promote a solid foundation upon which perspectives and biases can be addressed. The health system, the academic curriculum, and professional associations must acknowledge and address racism, stereotyping and discrimination. When people have a voice and a relationship with providers they are more willing to engage in discussion about their care and are more likely to raise concerns which will improve patient safety.

The 2018 NHLC conference takes place in the City of St. John's in Newfoundland (NFL), situated on the ancestral homelands of the Beothuk. These lands are home to a diverse population of Indigenous and other peoples, including the Mi'kmaq, Innu, Inuit, and South Inuit of NFL. A Cultural Safety training program in NFL may address the history and customs of the Beothuk, Mi'kmaq, Innu and Inuit Nations. Each people have their distinct history and culture. Cultural Safety results from cultural awareness and cultural sensitivity. Healthcare providers need to acknowledge the diversity within Indigenous cultures across Canada and be sensitive and respectful of their histories.

BACKGROUND
Cultural safety emerged in the context of Maori health in Aotearoa (New Zealand) in the 1980s, finding its way into the standardized nursing curricula of New Zealand by the 1990s. Developed by Dr. Ihirapeti Ramsden, a Maori nurse, cultural safety was first imagined as a model for nursing practice with Maori peoples in response to the egregious health disparities faced by Maori peoples, emphasizing the importance of recognizing the colonial, historical, and sociopolitical context in which these disparities had been created, and the ongoing racism and poor health care treatment in which they were maintained (Allan, B. & Smylie, J., 2015).

Cultural safety emphasizes explicit attention and action to address power relations between service user and service provider, charging the service provider with the responsibility to consider and address the role of their professional and institutional power in contributing to culturally safe or unsafe care. Addressing the power imbalance between service provider and service user requires the following:
1. that the service user’s way of knowing and being is valid;
2. that the service user is a partner in the health care decision making process; and
3. that the service user determines whether or not the care they have received is culturally safe or not (Health Council of Canada, 2012; DeSouza, 2008).

CONSIDERATIONS
The argument for a standard education program can be countered by arguments that one size does not fit all, that the creation of local programs enables great local co-design and that health is a provincial responsibility. Cultural safety has been endorsed and adopted by multiple health professional organizations, health professional training programs and health service organizations in Canada as a step towards addressing the health inequalities of and inequitable access to health care experienced by Indigenous peoples. Data challenges pose a significant barrier to improving Indigenous health generally and for understanding the impact of racism specifically. The available population health data for Indigenous peoples in Canada is a patchwork, drawing largely on sources with significant limitations. The
need for meaningful data is critical to understanding and addressing the role of racism in creating and sustaining the health disparities experienced by Indigenous people in Canada.

NEXT STEPS
A commitment to action is required. CPSI recognizes the interplay between cultural safety and the impact on patient safety outcomes. CPSI is committed to working with system partners, regulators, and policy decision makers to ensure that cultural safety becomes an accreditation standard for health professions programs within Canada.

CPSI is committed to working with its Indigenous partners and stakeholders to update the Safety Competencies Framework; and in doing so - to integrate within each of the existing six domains the concept of Cultural Safety. This framework will provide the essential requirements for integrating cultural safety into undergraduate, graduate, college, and professional education.

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This brief was prepared in collaboration with Maryanne D’Arpino / CPSI, Wayne Miller / CPSI, Katie Procter / FNHA, and Dr. Arika LaFontaine / AHS.
2.2 Indigenous Health

Resolved that, in order to understand and address the patient safety incidents experienced by Indigenous (First Nations, Metis, and Inuit) people, Canadian healthcare leaders and Indigenous communities will jointly develop a meaningful consultation process that respects diverse, holistic approaches to health, and recognizes the importance of strengthening health literacy and patient engagement as critical conditions for patient safety.

SUBMITTED BY
Jan Byrd, Patient Safety Improvement Lead, Canadian Patient Safety Institute

ISSUE

- In Canada, patient safety incidents are the 3rd leading cause of death - behind cancer and heart disease - with around 28,000 deaths each year (Risk Analytica, 2017). There is a preventable adverse event in Canada every 1 minute and 18 seconds, and a resulting death every 13 minutes and 14 seconds (Risk Analytica, 2017). The definition of Patient Safety Incidents (PSIs) is based on a preventable, unintended outcome of care caused by medical management or complication rather than by the underlying disease itself, resulting in prolonged healthcare, disability or death.

- Clear health communication is essential for promoting patient safety, yet breakdowns in communication among health care providers, patients, and families are common, and are a leading root cause of patient safety incidents. Improving communication is a low cost, high yield intervention across healthcare; perhaps even more so for Indigenous patients.

- Low health literacy is risky, and certain communities are at greater risk. Yet, there has been little attention paid to how socio-cultural factors impact health literacy in Indigenous communities in Canada. Addressing and improving health literacy, and thus patient empowerment, in Indigenous populations is critical in order to prevent patients from experiencing patient safety incidents. In addressing patient safety incidents in Medicare, we always seek to empower patients. Due to the effects of colonization and differences in how Indigenous vs non-Indigenous patients access care, empowerment will be both similar and different for Indigenous patients.

- In Canada, health literacy is defined as “the ability to access, comprehend, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course (PHAC2018). 60% of adults and 88% of seniors in Canada are not health literate (PHAC2018), putting them at risk of experiencing a patient safety incident. Health literacy and patient safety are closely linked. Health literacy impacts how patients engage with the health system, navigate its barriers and respond to adverse events. Reframing current investments towards health literacy as a primary outcome, versus a secondary outcome, could help to improve the impact of current initiatives.

- Social determinants of health and socio-cultural factors contribute to how well individuals can receive, manage and act on the health information they receive. In Canada, it is known that significant health disparities exist between Indigenous and non-Indigenous Canadians, and these “health disparities are directly and indirectly associated with or related to social, economic, cultural and political inequities; the end result of which is a disproportionate burden of ill health and social suffering on the Aboriginal populations of Canada (Adelson, 2005)”. Unwinding this complex, multi-stakeholder issue requires a consistent frame of reference; patient safety may be a more effective frame.

- Low health literacy is consistently associated with poorer health outcomes, poorer use of health care services, more hospitalizations, greater use of emergency care, poorer ability to demonstrate taking medications appropriately, poorer ability to interpret labels and health messages, and, among elderly persons, poorer overall health status and higher mortality rates (Berkman et al. 2011; Wolf & Cooper Bailey, 2009). Low health literacy has also been repeatedly linked to problems with the use of preventive services, delayed diagnoses, understanding of one’s medical condition, adherence to medical instructions, and self-management skills (Wolf & Cooper Bailey, 2009). It follows that individuals with lower health literacy are at a greater risk for experiencing patient safety incidents. This is not an Indigenous patient specific issue, but due to other mitigating factors likely has a greater impact on this demographic of patients.
Health literacy is a concept that is frequently applied to the patient's ability to find and understand health information. However, recent literature has also described the role of health care providers in supporting the level of health literacy achieved by individuals and populations (Kidd et al., 2018). The impact that health providers can have, and the ways that health systems can support health providers in this pursuit, cannot be underestimated.

BACKGROUND

- Literacy is one of the major influences of health status (Korhonen, 2006). Lower levels of education are correlated with poorer health for Aboriginal people in Canada (PHAC, 2008). Patients with low health literacy have a difficult time being engaged patients. Engaged patients take a more active role in maintaining their health and are often more satisfied with their care and have positive feelings of overall health. (Health Council of Canada, 2011). Empowered patients are engaged.

- Indigenous people in Canada face disparities in multiple domains: poverty, unemployment, substandard housing, and lower levels of education. The impacts of colonization and residential schools are deep, yet these impacts have not led to a trauma-informed understanding of the experiences of healthcare. Indigenized concepts of literacy have not been appreciated in mainstream frameworks of health literacy measurement nor in patient engagement models. Health systems still require Indigenous patients to change the way they frame and access care to achieve equitable health outcomes, while health systems reframe the way they provide care for other patient demographics to achieve equitable health outcomes. A shift from a patient burden of health literacy towards a shared system-patient burden for health literacy will better reflect a more patient-centred care approach.

- Despite the high prevalence and significant health impacts on patients with low health literacy, few Canadian health care providers or organizations are adequately responding to this issue. Furthermore, as many provinces and territories are moving care into the community, there are many risks as families become caregivers. Gaps in care, failures in communication and lack of care continuity will further aggravate existing inequities in care.

- One of the biggest patient safety risks related to limited health literacy is the risk of medication errors. Numerous studies have found low health literacy to be significantly associated with a poorer understanding of medication names, indications, and instructions and adherence to treatment regimens (Wolf & Cooper Bailey, 2009).

- Responding to the Truth and Reconciliation Commission calls to action to identify and close the gaps in Indigenous health, and to the UN Declaration on the Rights of Indigenous Peoples, this motion seeks to create a deeper understanding of experiences of harm from patient safety incidents in healthcare within Indigenous communities, and to support the communities to co-design culturally relevant health literacy strategies that will improve health literacy and increase engagement, decrease the rate of patient safety incidents, and ultimately improve health outcomes and health equity.

- If this resolution is not adopted, harm from patient safety incidents will continue to negatively impact communities who are at risk due to lower levels of health literacy. Over the next 30 years in Canada, there could be roughly 400,000 average annual cases of PSIs, costing approximately $6,800 per patient and generating an additional $2.75 billion (estimated in 2017) in healthcare treatment costs per year (Risk Analytica, 2017). There is a shared responsibility between patients and the health system to remediate this issue.

- In the 2018 HealthcareCAN document, Bringing Reconciliation to Healthcare in Canada, the authors underscore many wise practices related to meaningful community engagement with First Nations, Metis and Inuit communities. The report highlights a set of critical issues to close the health gap between Indigenous and non-Indigenous communities; this guide will frame the issue for broader consultation towards next steps that are Indigenous community-informed and to ensure that further action is co-led by the health system and the patients affected.

- Current approaches to increasing health literacy and engaging patients value biomedical knowledge, while deprecating social contexts, patient experience and medical knowledge from non-biomedical sources. This results in interventions being “done to” communities rather than co-designed together with communities.

- Harm in healthcare from patient safety incidents is preventable. Patients, who have strong health
literacy, are able to be engaged, and who feel understood by their health providers will be safer. Strengthening health literacy and improving patient engagement will lead to improved patient safety in Indigenous communities.

CONSIDERATIONS
- More than 1 in 9 emergency department visits are due to drug-related events.
- More than half of Canadians are using prescription drugs at any given time.
- 23.6% of adverse events are medication errors (Canadian Adverse Events Study, 2004).
  Cost per event = $4,208
  Total system cost = $400 million/year

- With a growing population, care being offered and sought increasingly in community, widening health disparities and resultant costs, greater health literacy will prevent patient safety incidents.
- A better understanding of Indigenous patients’ health literacy is required before health literacy interventions can be designed to improve Indigenous health outcomes.
- Research is needed to explore the cultural relevance of existing measures of health literacy and to work with communities to create a baseline regarding health literacy among Indigenous people.
- The new model developed will acknowledge and integrate culturally congruent socio-political contexts for health literacy, with recognition that many Indigenous people do not have English as a first language, not a biomedical worldview (Vass et al., 2011).
- As a designated World Health Organization Collaborating Centre for Patient Safety and Patient Engagement, the Canadian Patient Safety Institute is well positioned to partner in this important work.
- Cultural safety within a First Nations, Inuit and Métis context means the practitioner, whether Aboriginal or not, can communicate competently with a patient in that patient’s social, political, linguistic, economic, and spiritual realm. (NAHO, 2009). Cultural safety analyzes power imbalances, institutional discrimination, colonization, and colonial relationships as they apply to health care and health education (NAHO, 2009).

NEXT STEPS
The next steps could include:
- Form a working group
- Ensure a meaningful consultation process.
- Co-design an approach for better measuring and improving health literacy and an Indigenized model for patient engagement.
- Review current literature and identify gaps that need more inquiry, or cultural relevance
- Seek to understand the work done in other places, e.g., Australia
- Co-design a new framework of indicators for measuring health literacy that is not based on a solely biomedical model or English as a first language.
- Recognize diversity even among First Nations, Metis and Inuit communities in terms of health literacy levels and needs.
- Trial the approach in community with leaders.
- Understand the baseline then co-design interventions to improve health literacy and strategies for engagement.
- Talk about patient safety and what it means. Tell stories about what has happened.
- Re-conceptualize engagement in a way that takes into account language and world view
- Spread successes recognizing not one size fits all but share principles learned. Decolonize educational approaches for Indigenous patients and be open to new ways of knowing.

The consultation process will ensure meaningful engagement with Indigenous communities, honoring the tradition of listening and sharing stories, with recognition that many socio-cultural factors influence experiences of health: language, level of education, poverty, unemployment, age, housing concerns, remote locations, and community wellness. A new model and framework, respecting indigenous ways of knowing will be developed.

Supported by CPSI – a designated World Health Organization Collaborating Centre for Patient Safety and Patient Engagement - the consultations will culminate in an Indigenized approach to health literacy
and patient engagement that are culturally competent. Patients with strong health literacy, who are engaged on their care, whose culture is respected and understood, are empowered and safer patients.

**Stakeholders:**
- First Nation communities and their political advocacy organizations
- Inuit communities and their political advocacy organizations
- Metis communities and their political advocacy organizations
- Canadian Patient Safety Institute
- Patients for Patient Safety Canada
- Canadian Foundation for Healthcare Improvement
- National Health Leadership Conference Delegates
- Public Health Agency of Canada
- NHLC Co-Sponsors - HealthCareCAN and the Canadian College of Health Leaders
- Provincial and Territorial governments
- Patients for Patient Safety Canada

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This brief was prepared in collaboration with Dr. Aïka Lafontaine and CPSI.
THE CANADIAN HEALTHCARE DEBATE

THEME: SENIORS HEALTH

3.1 Family Caregivers of Seniors

Resolved, that Canadian healthcare leaders recognize and embrace family caregivers of seniors as valued members of the healthcare team by committing within the next two years to changing the culture in the healthcare system to actively involve family caregivers in care settings and by educating healthcare providers on the value of respecting and acknowledging the crucial role family caregivers play.

SUBMITTED BY
Dr. Anwar Haq - Covenant Network of Excellence in Seniors’ Health and Wellness and Dr. Jasneet Parmar, Medical Director, Convenant Network of Excellence in Senior's Health and Wellness

ISSUE
Family caregivers are the backbone, “the shadow workforce” of our society and the healthcare system and vital to its sustainability. As primary caregivers, they offset costs and capacity in our health system and they provide ongoing care and assistance to help Canadian seniors stay in their homes and communities. However, family caregiving is often provided at a great cost.

In 2016, Statistics Canada estimated that there were approximately 10.1 million family caregivers in Canada. Statistics predict that the need for family caregivers will increase dramatically in the future. By 2036, 1 in 4 Canadians will be over the age of 65. More than a quarter of Canadian seniors will be living with at least four chronic conditions. The increasing number of seniors, over 80 years old, experiencing declining physical and/or cognitive functioning will need to be supported to live in their homes.

There is a high burden associated with providing care. In addition to their caregiving role, family caregivers’ responsibilities often include earning a living, raising a family and taking care of their own personal health. Many family caregivers describe high levels of stress, depression and difficulties in their caregiving role. Current reports suggest that 28% of caregivers find providing care to be stressful; 19% indicate that their physical and emotional health suffers. There is also a financial burden placed on family caregivers who often spend $100-$300 per month on expenses directly related to caregiving.

Despite the critical role family caregivers play in the health and well-being of seniors, they remain largely invisible and inadequately recognized and valued within the healthcare system. Conversely, healthcare providers are given little or no education or training on how to better support family caregivers.

BACKGROUND
The Change Foundation defines family caregivers as family, friends, or neighbours who provide critical and often ongoing personal, social, psychological and physical support, assistance and care, without pay, for people in need of support due to frailty, illness, degenerative disease, physical/cognitive/mental disability, or in end-of-life circumstances. While family caregiving is not a new concept, in recent years the role has become much more complex. A rapidly aging population has greatly increased the numbers of seniors who want to age at home. Increased life expectancy means that seniors require care for a longer period of time. More seniors are living with chronic illnesses, functional impairments and/or dementia and require more complex care. All of these factors lead to greater dependency upon caregivers – particularly the family caregivers.

Family caregivers often interact with healthcare providers in many settings – acute care, long term care and home care. To date, there has been a significant lack of awareness and support for family caregivers within the healthcare system. While there have been efforts to help foster resilience in family caregivers, the support system surrounding them has been neglected. The knowledge family caregivers have about the person in their care is often not recognized or respected and they are seldom included as part of the care team. Family caregivers are also challenged with navigating the system on their own and searching for resources to support them. Educating and training healthcare providers to support family caregivers has been a missed opportunity.

While there has been some progress in providing education and training for healthcare providers in Canada, there is a lot more that could be done. Some examples include:

- Alzheimer Society Canada has a webpage with information and resources to help physicians provide early diagnosis and to help healthcare providers support individuals and their families through the continuum of the disease.
• Caregivers Alberta provides a navigator workshop that trains healthcare professionals to better support family caregivers and a caregiver support team where healthcare providers can network to increase knowledge about community resources available to family caregivers.

• The Change Foundation has implemented a five-year strategic plan the focuses on improving the experiences of family caregivers as they move across Ontario’s healthcare system.

• Pallium Canada provides a series of courses for healthcare providers caring for patients with life-threatening and progressive life-limiting illnesses.

• Covenant Health Network of Excellence in Seniors’ Health and Wellness has held a series of symposia on Supporting Family Caregivers of Seniors in Care.

• Many healthcare settings across Canada have introduced a mandatory assessment of caregiver stress and burden.

CONSIDERATIONS

• Most seniors (93%) in Canada live at home and want to stay there as long as possible.9

• Currently there are approximately 10.1 million caregivers in Canada – 28% of the population.1

• The number of caregivers will rise substantially in the future – it is estimated that by 2036, 1 in 4 Canadians will be over the age of 65.8

• Family caregivers contribute $25 billion in unpaid labour to our healthcare system.10

• An increased population of seniors in their 80s and 90s living with chronic diseases, functional impairments and dementia raises questions about the ability of family caregivers to provide care for seniors in their own home.7

• There is increasing evidence that caregiving is being provided at significant physical, emotional and financial costs to family caregivers. They are often stretched beyond their capacity and report high levels of distress – 40-50% of seniors with high needs have distressed caregivers.3

• The burden and distress is ever increasing; 1 in 10 family caregivers provide more than 21 hours of care a week and many support seniors experiencing depression, moderate to severe cognitive decline and aggressive behaviours.7,11

• If the situation worsens for family caregivers and they are unable to support seniors ageing at home the resulting stress on the healthcare system could cause it to fail.

Multiple Canadian national reports emphasize the issues that need to be addressed to better support family caregivers:7,9,13-12

• educate healthcare providers and the healthcare system to recognize and include family caregivers as an integral part of the care team

• minimize excessive financial burden

• improve access to caregiver and patient care resources, support services, and respite

• provide comprehensive caregiver assessments that address individual needs and timely follow-up where necessary

To begin the shift to improved support for family caregivers, Canadian healthcare leaders need to recognize and embrace family caregivers of seniors as valued members of the healthcare team by committing within the next two years to changing the culture in the healthcare system to actively involve family caregivers in care settings and educating healthcare providers on the value of respecting and acknowledging the crucial role family caregivers play.

If the healthcare system does not take on this opportunity to better recognize and support family caregivers and start to ease the burdens and challenges they face, there may be substantial personal and economic consequences. As levels of stress and burden increase, family caregivers will no longer be able to provide care for Canadian seniors who will require additional home care to remain in their homes or need to be moved to more costly long-term or supportive care. Family caregivers’ health may deteriorate to the point where they become patients of an already burdened healthcare system.

NEXT STEPS

In the province of Alberta, multiple symposia were held to identify key areas of focus that would better support family caregivers: culture change; improved communication between healthcare providers and family caregivers; assessment of family caregiver needs; help to navigate the healthcare system and better access to resources; and increased organizational and leadership support. A collaborative follow-up meeting was held to focus specifically on education and training for healthcare providers – what it might look like and how it could be implemented and sustained. Next steps initiated from that meeting include:

• Creation of an academic stakeholder group to develop educational materials for healthcare provider trainees and students

• Creation of interactive training modules that could be used in acute, home care and supportive living healthcare settings for frontline staff
Integration of a caregiver assessment tool in acute, home care and supportive living healthcare settings
Creation of awareness campaigns for health care providers that identify the resources and supports available for family caregivers
Identifying a platform to host and support an already established inventory of caregiver resources and supports

In addition, a cross-ministerial working group has recently been established to review current caregiver supports, focusing on the impacts, gaps and opportunities to better support family caregivers.

In Alberta, there are a variety of stakeholders involved in moving this work forward:
- Provincial policy and decision makers
- Healthcare leadership, managers and frontline workers
- Seniors and family caregivers
- Academics
- Senior’s service organizations
- Caregiver organizations

The provincial connections have already been made and there are connections being made with those involved in similar work in other Canadian provinces. The opportunity is there to expand the collaboration to a national level and implement measures that will spread and sustain this initiative.

REFERENCES


This brief was prepared in collaboration with Dr. Jasneet Parmar, Dr. Anwar Haq and Elaine Hoogewooodink – Covenant Network of Excellence in Seniors’ Health and Wellness.
THEME: SENIORS HEALTH

3.2 Advanced Care Planning

Resolved, that Canadian health-care leaders and provincial and territorial Ministries of Health commit within the next two years to adopt routine, early integration of Advance Care Planning (ACP), as an enabler for person-centred care, into the care of capable seniors in all care settings, by development of policies, care processes, training programs, funding models and a registry to boost ACP awareness and enhance the capacity for consistent initiation of ACP conversations, documentation storage and access throughout the health system.

SUBMITTED BY
Eman Hassan and Kathleen Yue - BC Centre for Palliative Care

ISSUE
Canadian seniors deserve person-centred care that aligns with their wishes and goals. Unfortunately, this is not currently the case; a multi-centre Canadian study revealed that the health-care wishes of hospitalized elderly patients match with their documentation in medical records only 30% of the time. A 2013 public poll showed that only around half of Canadians have shared their health-care wishes with family members, and far fewer (10%) have discussed their wishes with their health-care providers.

These gaps can be remedied through coordinated provincial and territorial efforts to promote and enable effective communication between health-care providers and patients or families about the patient’s health-care wishes, a process called Advance Care Planning (ACP). Documentation of patient’s health-care wishes needs to be readily accessible to health-care providers to inform care in various care settings.

BACKGROUND
As patients age or are diagnosed with a serious illness, the potential burdens of a treatment can increase, while benefits can decrease. Trade-offs between benefits and burdens are a very individual decision, with treatments that are right for one patient being wrong for another. If conversations with patients around their health-care wishes have not been initiated before they lose their decision-making capacity due to aging or a serious illness, unwanted treatment may be the result. At present, approximately 20% of health-care costs are spent during the patient’s last year of life, with many of these costs associated with increased use of aggressive treatments that are often unwanted or unbeneﬁcial. Higher costs have also been associated with worse quality of death.

A growing body of evidence indicates that integration of Advance Care Planning (ACP) into the health-care system increases the congruence between patient’s wishes and the care they receive, improves quality of life for patients, reduces stress on families, and reduces costs to the health-care system.

ACP is a communication-based intervention that enables person-centered care by helping capable adults reflect on their personal values, goals and preferences regarding future medical care, and share this information with their families and health-care providers. Routine early initiation of ACP is important in elderly patients because the risk of becoming unable to make decisions for themselves doubles every five years after the age of 65. Within a large multi-centre survey, hospitalized, elderly patients and their family caregivers rated end-of-life care conversations as among the most important and yet least addressed topic in the provision of their care.

Improving care for Canadian Seniors is only going to become increasingly relevant as the population ages; by 2030 almost a quarter of Canadians will be aged 65 or older, up from approx. 15% in 2013. With the recent passage of the federal bill C-277 Providing for the Development of a Framework on Palliative Care in Canada, a call for national and jurisdictional endorsement and support for early integration of ACP within the health-care system is relevant and timely. As a key enabler of a palliative approach to care, integration of ACP is essential to the successful implementation of Bill C-277.

Several initiatives have occurred aiming to integrate ACP at local or regional levels. Without ACP policies and a registry to access documentation, individual health-care institutions are left to develop their own policies and processes, resulting in inconsistent or inadequate access to information about
patient’s care preferences. The lack of national and jurisdictional full endorsement and support has been observed as a barrier to the effective and widespread implementation of these initiatives.\textsuperscript{12}

CONSIDERATIONS

This issue can be addressed through coordinated, system-wide implementation of ACP. System-level interventions have shown results in other jurisdictions.\textsuperscript{5-12} Barriers to ACP adoption have been identified, and include patient barriers, health-care provider barriers and system-level barriers. Patients lack awareness and knowledge of ACP; health-care providers lack the communication skills and conversation aids required to have these discussions; the health-care systems lack processes that enable consistent initiation of ACP conversations and access to ACP documentation that informs care in various settings.\textsuperscript{12} 13-18 Individual interventions and approaches have each shown success in addressing individual barriers;\textsuperscript{9-10} so use of this knowledge in the implementation of a system-wide approach has high chances of success.

The implementation of ACP does not need to be onerous or burdensome; for example, the median conversation length using the Serious Illness Conversation Guide, a structured approved developed by Ariadne Labs at Harvard Medical School, assists in identifying goals and priorities, trade-offs and implications for care in the context of a prognosis disclosure is around 15 minutes.\textsuperscript{19}

The most successful approaches to ACP include:\textsuperscript{5}

- **Awareness and education programs** for seniors about ACP process and its benefits.  
- **Policy and process development** to provide guidance and leadership for ACP. Of particular importance, this would provide clarity around roles and responsibilities, and enforce consistency across different service providers/initiatives.  
- **Sufficient infrastructure** for identification, receipt and storage of ACP documents, to ensure they are accessible when they are needed. This includes infrastructure that allows transfer of ACP documents between and within health-care sectors and regions, such as through a registry of ACP documents that can be accessed by all health-care providers, but the ownership of documents is still in the hands of the patient.  
- **Training Programs** to equip health-care providers with the required communication skills for conducting ACP conversations. The education programs don’t need to be time or labour intensive; for example, the Serious Illness Conversation Program training takes just 2.5 hours.\textsuperscript{19}  
- **Funding Models** to provide sustainable adequate funds and resources for the ongoing implementation of ACP. This would include back-fill for health-care provider education, and funding for health-care provider time to conduct the conversations, including (but not limited to) billing codes for primary care physicians.

NEXT STEPS

Stakeholders that should be involved:

- Health-care leaders: mobilize health authorities and organizations, promote spread effective ACP implementation programs and policies.  
- Provincial and territorial Ministries of Health: create ACP registries, resources and funding allocation, and other infrastructural foundations.  
- Health-care professional bodies: create professional standards of care for ACP; provide health-care provider education and training to members; promote conversation aids and resources.  
- Community organizations providing services for seniors and patients with serious illnesses: provide ACP education and awareness programs with their clients/patients.  
- Patients, seniors and caregiver representatives: to provide end-user perspectives.

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This brief was prepared in collaboration with the Canadian Hospice Palliative Care Association.
2018 THE CANADIAN HEALTHCARE DEBATE

THEME: SENIORS HEALTH

3.3 High Quality Palliative Care

Resolved, that recognizing access to high quality palliative care is an important issue for Canadians, health care leaders promote Palliative Care Matters, adopt the Collective Impact Framework (CIF) and work together toward a framework for an integrated approach to funding and delivery of palliative care.

SUBMITTED BY
Ms. Karen Macmillan, Senior Lead for the Palliative / End-of-life Strategy, Covenant Health and Dr. Konrad Fassbender, Scientific Director, Palliative Institute, Covenant Health

PURPOSE
Death is a certainty for 100% of Canadians - yet 70% don’t have access to regional, comprehensive, coordinated and integrated palliative care. As a death denying society, discomfort in having these conversations play a crucial role in limiting access to high quality palliative care. Evidence suggests for example that only 14% of doctors know their patient’s preference for pain management and location of death. Palliative care is however inherently complex and reform requires coordinated efforts across all stakeholders and settings. Palliative Care Matters is a coalition of 14 national health care leaders who posit that a roadmap and strategy will improve the care and wellbeing for all Canadians at a critical time in their lives.

ISSUE
A majority of 192 recommendations to improve palliative care, contained in 19 national reports over the past 20 years, remain unaddressed. Widely quoted estimates of access to palliative care in Canada range from 16-30%. Downie et al. challenged these numbers but acknowledged that lack of access remains a critical issue. The Employment Insurance Family Caregiver benefit program provides evidence that coordinated and sustained efforts are required to make progress yet lack of public awareness severely limited the effectiveness of this particular legislation. In fact, repeated public polls demonstrate that half of Canadians are not familiar with the term ‘palliative care’. A doubling of seniors and other changes in Canadian demographics over the next quarter century will continue to put demands on scarce healthcare resources and result in increased need for palliative care. Emerging evidence on a ‘palliative approach’ supports the need for palliative care education for general as well as specialized care providers. A palliative approach addressing educational needs can be accomplished through embedding competencies for caring for dying Canadians across all health care disciplines and settings. Finally, the Compassionate Communities movement reinforces the message that caring for dying Canadians requires support beyond the healthcare system.

BACKGROUND
The royal assent of the Canadian federal Bill C-277 An Act providing for the development of a framework on palliative care in Canada highlights the urgent need for improved access for Canadians. Conceived in 2015 and endorsed by the Conference Board of Canada, Palliative Care Matters seeks to engage the public and other key stakeholders through patient-focused and evidence-based action plan building and supporting other national and local organizations working to improve palliative care and impact levels of government. Palliative care is cross-sectoral involving any diagnosis and has the potential to improve care earlier in illness trajectories and therefore requires a wide range of advocates to impact care.

Adding urgency to the matter, legislation supporting Medical Assistance in Dying (MAID) was passed. In other countries, similar legislation afforded a platform for public debate regarding the need for improved access to palliative care. The final Report on MAID in fact compels the health care system to provide access to high quality palliative care to alleviate a person’s suffering. Some provinces are beginning to implement palliative care frameworks, supported by an increase in public, professional, and academic discussions on the importance of high quality and accessible palliative care services. There remains significant work to build comprehensive palliative care programs, inform Canadians about palliative care, why it matters and which services are available.

Palliative Care Matters convened a meeting on February 8, 2018, including 51 individuals representing 33 organizations. The Collective Impact Framework (CIF) was proposed as a vehicle for meaningful action. The Collaborative Impact Framework is defined as “a framework to tackle deeply entrenched and complex social problems. It is an innovative and structured approach to making collaboration work across government, business, philanthropy, non-profit organizations and citizens to achieve significant and lasting social change.” Fatigue for working in isolation and lack of action were lamented. High
participant engagement during the meeting, a post-meeting survey, and subsequent discussions indicated a strong aspiration to move forward with coordinated action. The CIF approach is challenging however as it requires multiple organizations to abandon their own agenda in favour of a common agenda, shared measurement and alignment of effort. Collaboration, evidence, and public engagement will inevitably change the lived experiences and outcomes of dying Canadians and their families.

CONSIDERATIONS
Palliative Care Matters postulates that the Collective Impact Framework\textsuperscript{22} will accelerate improvements to the care of dying Canadians and their families. Securing the attention and commitment for the additional stakeholders cannot be accomplished through simple coalitions and requires the following five key elements\textsuperscript{44}:

1. All participants have a common agenda for change including a shared understanding of the problem and a joint approach to solving it through agreed upon actions.
2. Collecting data and measuring results consistently across all the participants ensures shared measurement for alignment and accountability.
3. A plan of action that outlines and coordinates mutually reinforcing activities for each participant.
4. Open and continuous communication is needed across the many players to build trust, assure mutual objectives, and create common motivation.
5. Backbone organization(s) with staff and specific set of skills to serve the entire initiative and coordinate participating organizations and agencies.

An independent review of the implementation of CIF within the Canadian Patient Safety Institute serves as an exemplar of the development of effective governance structures in large scale change projects.\textsuperscript{18} Application of the CIF cannot be accomplished in a single meeting. Three years are required to harmonize the collective actions and accelerate positive change. A coordinated Palliative Care Strategy would align the delivery of services and programs enabling caregivers and their family members more effective access and supports in end of life planning. Implementation of a shared communications strategy would enable consistent messaging across program delivery partners and increased awareness by the Canadian public of services and supports available to caregivers and their family members.

NEXT STEPS
Application of the CIF was initiated through a survey of PCM’s 14 steering committee members to identify the practical barriers and facilitators for development of an action plan. A formal stakeholder analysis is contemplated as a first step toward a refined understanding of the stakeholders and their individual agendas. This analysis will help PCM to understand the scope and nature of interest facilitating the palliative care conversation and policy formation.

REFERENCES
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