

# Supporting Indigenousled use of ICES data and methods to answer important health questions in First Nations communities

For several years, ICES has worked closely with First Nations, Inuit and Métis communities and organizations to develop partnerships guided by the principles and values of each partner. In 2017, ICES formalized the creation of an Indigenous Portfolio with dedicated staff, establishing a commitment to make Indigenous health an ongoing research priority. In 2018, the portfolio added a project navigator to support Indigenous communities in their work with ICES. Through partner engagement, ICES is raising awareness of how data can be used to address Indigenous priorities, enabling Indigenous partners and communities to guide and access research that is of importance to them.



### **ICES Research**

At the All Ontario Chiefs Conference in 2013, a resolution was passed mandating the Chiefs of Ontario to work with ICES to produce a report examining trends in prescription opioid use in Ontario First Nations communities. Completed in 2019, this work has led to ongoing partnerships between the Ontario Drug Policy Research Network and the Chiefs of Ontario to support ongoing, First Nations-led opioids research. Other reports prepared in partnership with the Chiefs of Ontario include a study on aging among First Nations people.

ICES also supports First Nationsled research in Ontario through its work with the Mamow Ahyamowen ("Everyone's Voices") research partnership, a collaboration of dozens of First Nations-governed health service organizations in Northern Ontario, which consulted with ICES to acquire data and research evidence to help answer community questions and work toward health equity. The first of the Mamow Ahyamowen reports was completed in 2019, focusing on trends in time and cause of death and chronic conditions at the time of death. A total of 59 communities opted in to this study. Additionally, ICES has a close partnership with one of the Mamow Ahyamowen First Nations partners, the Weeneebayko Area Health Authority (WAHA), with two embedded staff under the guidance of WAHA.

# How this work is having **impact**

(Recommendation 10) ...that Indigenous Services Canada work with First Nations and provinces and territories to develop and implement an integrated data collection protocol specific to the health and well-being of First Nations; and that this data be used to inform the provision of evidence-based health services on reserves.

The Challenges of Delivering Continuing Care in First Nation Communities, Report of the Standing Committee on Indigenous and Northern Affairs, 2018.

# **Supporting Community-Level Advocacy**

- The 2019 Chiefs of Ontario opioid report produced with the support of ICES is being distributed among First Nations to support community-level responses. The project was also approved by Kenora Chiefs Advisory and Grand Council Treaty #3, which received reports specific to its communities.
- The first Mamow Ahyamowen report, released in 2019, includes 68 tailored reports at the community, partner and overall level. One partner agency shared findings from its partner-level report at a media event to raise awareness of the causes of death within its community.
- The Chiefs of Ontario study on aging in First Nations, supported by ICES and released in 2017, provided evidence to advocate for improved resources, such as seniors' housing on reserves. ICES was called to present the results of the study at a 2018 House of Commons Standing Committee on Indigenous and Northern Affairs, helping to inform the Committee's report.

# **Setting an Example for Collaborative Work with Indigenous Partners**

- Recommendation 10 of the 2018 Report of the Standing Committee on Indigenous and Northern Affairs states "...
  that Indigenous Services Canada work with First Nations and provinces and territories to develop and implement an integrated data collection protocol specific to the health and well-being of First Nations; and that this data be used to inform the provision of evidence-based health services on reserves."
- ICES scientists are collaborating in a cross-Canada data platform partnership aimed at achieving these goals, and helping to spread the use of a new research framework that enshrines respect for the Indigenous ownership of data, or data sovereignty, at all stages of research.

# Electronic "second opinion" helps ER doctors decide if low-risk heart failure patients can be safely sent home

An important goal in medicine today is the ability to more accurately predict the outcomes of illnesses, treatments and surgeries in advance, so that patients and their care providers can make informed treatment decisions that are customized to their individual risk. A potential revolution in predictive medicine has become more possible as massive collections of real-world health data, such as the unique and robust data held at ICES, become available. These data can be used to create predictive algorithms that are based on the realworld experiences of thousands, or even millions, of patients. As data sets grow bigger and more complex, prediction tools are able to zoom in even more tightly on an individual's personalized risk; in other words, more data means more precision.



## **ICES Research**

The Emergency Heart Failure Mortality Risk Grade (EHMRG) Calculator is an important ICES-developed risk prediction tool that is growing in international reputation. Not intended to replace a doctor's judgement, the tool acts as a sort of clinical "second opinion," helping to ensure that patients receive the most appropriate care. An online questionnaire that works on emergency doctors' computers and smartphones, the calculator is used in the emergency department when a patient arrives with heart failure, to help estimate severity and whether the patient needs to be admitted to hospital, or if they

can be safely sent home with followup care. Doctors enter their patients' vital signs and other information into the calculator, and the calculator estimates the risk of whether this patient might die within seven days.

A follow-up study has shown that the EHMRG tool could be better than physicians' estimates at predicting risk. Early results from a subsequent large ICES-led trial, called the COACH trial, show that when the EHMRG tool is used in conjunction with a rapid follow-up clinic program, it is a safe and effective way to reduce unnecessary hospitalizations.



# [The EHMRG tool] illustrates the potential for the novel use of data for health-care innovation.

**2018 report** prepared by the Expert Panel on Timely Access to Health and Social Data for Health Research and Health System Innovation for the Council of Canadian Academies.

# How this work is having **impact**

## **Clinical Adoption**

- Estimates of cost savings and safety from the nearly complete COACH trial using the EHMRG calculator are so compelling that several hospitals in Ontario plan to fund the program after the trial ends.
- In the U.S., Saint Luke's Health System, which includes four hospitals with emergency departments in Kansas City, added the EHMRG tool as a mandatory element of its electronic medical records system, following a trial of the tool's effectiveness and safety.

# **Endorsement by Professional Organizations**

- In a 2018 report, an expert panel of the Council of Canadian Academies cited the EHMRG tool as a cutting-edge model that "illustrates the potential for the novel use of data for health-care innovation."
- In 2017, the European Society of Cardiology Acute Cardiovascular Care Association published a position paper that singled out the EHMRG tool as a promising support for physician decision-making, with ongoing development and validation.
- An expert panel appointed by Health Quality Ontario and the Ministry of Health and Long-Term Care reviewed the EHMRG calculator in the 2013 clinical handbook for congestive heart failure and recommended that "the physician community needs to adopt this tool or a risk-stratification method to guide decisions."

# Better access to health care and mental health supports for Canada's military families

Canada's military families face extra hurdles in getting health care. Members of the Canadian Forces have health care provided by military physicians, but their family members must access care through the civilian system. Frequent relocations mean that each time a family is transferred to a new city or province, the spouses and children of service members must find new family doctors and specialists, including mental health care providers, and often encounter long wait lists. Continuous access to high-quality medical care is often mentioned as one of the top concerns for military families when assigned to a new posting. A 2013 report from Canada's Military Ombudsman highlighted gaps in research and the need for objective data to support the creation of evidencebased policy to improve the well-being of Canadian military families.



### **ICES Research**

Ontario has led the way among Canada's provinces and territories in considering and addressing better health transitions for military families. About 10 years ago, Ontario began adding administrative codes that tag the health records of spouses and children of active Canadian Forces members, as part of the process to waive the 90-day waiting period for public health insurance eligibility. Other provinces and territories have followed suit. The existence of these data tags has made it possible for ICES researchers to securely and anonymously track military families within ICES' extensive data holdings

and better understand how they access the civilian health system. The work is the first of this kind in the world, providing real-world evidence about how Canadian military families use the health care system, how long they wait for health services, the prevalence of physical and mental health problems, and how their health needs may differ from those of civilians. With 40 percent of Canada's military families living in Ontario at some point, this work is fundamental to Canada's response to the problem of poor access to health care for military families.

# How this work is having **impact**

[This work] helps fill a knowledge gap resulting from the fact that there had previously been no population-based Canadian data describing patterns of mental health services use in older dependents and spouses of active service personnel in the Canadian Armed Forces.

**2018 announcement** of the Colonel Russell Mann Military Family Health Research Award to Dr. Alyson Mahar by the Vanier Institute of the Family.

# **Evidence for Funding and New Programs**

- In 2018, ICES researchers published the first large-scale quantitative Canadian study of how military families access health care following a new military posting. This work highlighted challenges that were previously unrecognized by many Canadians, including those who operate the health system.
- ICES research on mental health services use by children and youth in military families was used by the Military Family Resource Centre in Trenton in 2018 to secure additional funding for youth mental health needs.
- In 2018, Canada's Department of National Defence (DND) launched Seamless Canada, a program to improve military family relocation transitions. Researcher Alyson Mahar was invited to present ICES' findings at a planning meeting with representatives from every province and territory.
- In 2018, ICES was contracted to contribute to Canada's Comprehensive Military Family Plan as part of the DND's Secure and Engaged Canadian Defence Policy.

# **Informing National Recommendations on Care for Military Families**

- The College of Family Physicians of Canada collaborated with Military Family Services in 2017 to publish a **Best Advice guide** for family doctors about health care issues specific to military families, and is developing extended learning programs for other specialties. The guide and curriculum use ICES research.
- In 2018, the Vanier Institute of the Family presented Alyson
   Mahar and her research team with an award for ICES research
   into how military spouses and older dependents use mental
   health services.

# Using ICES data to help Ontario communities deal with the opioid crisis

Ongoing public health concerns about opioidrelated harms, including overdoses and deaths, has led to changes in drug policy and clinical guideline recommendations. In 2017, Ontario's Strategy to Prevent Opioid Addiction and Overdose included a policy to remove a class of opioids deemed to be high-strength and long-acting (for example, fentanyl, morphine and hydromorphone) from the Ontario **Drug Benefit** formulary. The policy was revised with analyses done at ICES in partnership with the **Ontario** Drug Policy Research Network (ODPRN). The revisions included changes to the use of these high-strength, long-acting opioids specifically in end-of-life care, responding to the need expressed by the palliative care community and patients. The policy was further modified to allow nurse practitioners to prescribe controlled drugs and substances, a change applauded by stakeholders.



### **ICES Research**

In 2018, using data from ICES, the ODPRN released the **Ontario Prescription Opioid Tool**, an interactive, web-based tool that provides public access to information about opioid and naloxone prescribing in Ontario from 2012 to the present, with quarterly updates. Prior to the tool's release, webinars were held to get stakeholder input from Public Health Units, Local Health Integration Networks and other organizations. Based on the feedback from these stakeholders, the tool was refined to include indicators that would be useful for informing local strategies that target safe and appropriate opioid use in Ontario.



# This work has directly impacted Ontario's evidence-based opioid strategy.

Dr. Dirk Huyer, Chief Coroner for Ontario

# How this work is having **impact**

# **Increasing Capacity for Timely Response**

- The delisting policy has been evaluated every six months since it was announced and implemented to inform better alignment of the policy with a tailored response to the opioid crisis on a regional level.
- Ontario's Public Health Units continue to request updated or additional analyses from ODPRN and ICES to inform their regional programs and strategies.
- This research is informing the development of educational and training materials for naloxone programs, along with the Community Drug Strategy for the implementation of these programs, and the expansion of existing programs. For example, in July 2018, the Toronto Police Service announced that its officers would carry naloxone.
- In 2017, the Office of the Chief Coroner for Ontario started the
   Opioid Investigative Aid, which captures detailed information
   around the circumstances of opioid-related mortality. This
   ensures that timely and real-world data are available
   to inform this research and various strategies aimed at
   addressing the opioid crisis.

# **Engagement with People with Lived Experience**

 This program of research is regularly engaging with patients with lived opioid experience to gain their perspectives and understanding of emerging priorities.

# Strong Engagement among Health Units

- In 2019, the team hosted a webinar to demonstrate the capabilities of the prescription opioid tool. Over 200 representatives attended from various stakeholder groups, including Ontario Public Health Units and LHINs, Health Canada, the Registered Nurses Association of Ontario, the Centre for Addiction and Mental Health, and the Canadian Centre on Substance Use and Addiction.
- In its first nine months online, the prescription opioid tool was viewed more than 14,000 times. Public Health Ontario has highlighted the tool's usefulness and will include the tool as a resource at an integrated workshop.

# ICES data and methods uniquely positioned to support Ontario's health transformation

The Government of Ontario is restructuring the province's health care system to make it easier for patients, families and caregivers to navigate and transition between health care providers, as well as making these providers more accountable for the quality, cost and outcomes of that care. Soon to be reorganized into Ontario Health Teams (OHTs), many health care providers—from family doctors and specialist physicians to hospitals, community care agencies and multidisciplinary health professionals—will operate and be funded and held accountable within coordinated OHT units, with each team providing a full continuum of care for an assigned population.

The OHTs will replace a system of care that has been organized through 14 geographically determined Local Health Integration Networks (LHINs). LHIN boundaries for planning and funding do not address the fact that many patients access care across regions, often through piecemeal referrals to doctors and specialists. For example, a patient might drive from their rural home region to a city hospital for specialist appointments, returning to their own LHIN for home care. This fluidity of movement between LHINs has made it difficult to assign health dollars and bottom-line accountability to the quality and effectiveness of care.



## **ICES Research**

For several years, ICES scientists have applied innovative research methods to ICES' unique holdings of Ontario's health administrative data to reveal networks of self-organizing groups of physicians and hospitals that do not observe geographic boundaries. The research shows that these networks have developed naturally through

long-standing referral patterns, sharing of information and admission of patients to the same hospitals. By following patients through the health system records, ICES researchers have shown that residents cross LHIN boundaries to seek care, especially in large urban areas.

ICES Annual Report 2018/19



Ontario Health Teams will be responsible for the health outcomes of a population within a geographic area that is defined based on local factors and how patients typically access care.

Ontario Health Teams: Guidance for Health Care Providers and Organizations, Ontario Ministry of Health and Long-Term Care

# How this work is having **impact**

# **Laying the Groundwork for Better Analysis**

 ICES research published in 2013, long before the current restructuring efforts, showed that these multispecialty physician networks could form the basis of more formalized care networks serving large numbers of patients, capturing real-use patterns not accounted for when observing geographic boundaries.

## **Creating the Maps for the New OHT Networks**

 The Ontario government has structured the OHT application process by using the existing ICES methodology to identify physician networks, in addition to local considerations, when attributing populations for which the OHTs will be responsible.

# **Assessing Systems of Accountability**

 Once the OHTs are implemented, there will be ongoing work to assess these systems of shared accountability, integration, planning and implementation. The ICES work on physician networks is expected to play a role in the design of these strategies.

# How big data is helping the public understand their health risks

Project Big Life calculators were developed using ICES data to show the public how research and public health policy could affect individuals, their families and their communities. The calculators use big data to develop precision health algorithms that predict the risk of diseases, dying or using health care. There are four calculators: the Life Expectancy Calculator, the Sodium Calculator, the Heart Attack and Stroke Calculator and the Elder-life Calculator.



## **ICES Research**

A team of ICES scientists in Ottawa have used ICES data collected through the province's health system and Statistics Canada to build a series of four online calculators, collectively called Project Big Life. These calculators, or prognostic tools, help patients and their doctors see how their current health behaviours might affect their future health. The first was the **Life Expectancy Calculator**, released in 2012 and based on a report by ICES and Public Health Ontario called **Seven More Years: The Impact** of Smoking, Alcohol, Diet, Physical Activity and Stress on Health and Life **Expectancy in Ontario**. The success

of this calculator led to the creation in 2013 of the **Sodium Calculator**, which was developed by analyzing the sodium levels of more than 20,000 grocery and restaurant food items. The Elder-life **Calculator**, released in 2014, estimates the life expectancy of individuals based on their responses to 25 questions about what diseases they have and their ability to care for themselves. In 2018, the most recent calculator in the series was launched: the Heart Attack and Stroke Calculator provides individuals with their risk of hospitalization or death due to heart disease by considering factors like diet and level of physical activity.

ICES Annual Report 2018/19

# How this work is having **impact**



It took physicians approximately four minutes to discuss the sodium calculator results with their patients, and 75 percent of them found it to be a desirable and feasible intervention to facilitate dietary advice.

Jefferson K. A Feasibility study of an eHealth intervention for dietary sodium reduction in primary care [master's thesis]. Oshawa, ON: University of Ontario Institute of Technology; 2019.

### **Public Use**

- When the Life Expectancy Calculator was released online in 2012, it attracted 50,000 users in the first 30 minutes of going live and caused the host servers to crash.
- There have been over 1.5 million uses of the calculator in over 200 countries.
- Schools in Canada and the United States use the calculators for class projects to illustrate how research can be useful at the individual level.
- At a presentation outside the House of Commons in 2013, members of Parliament lined up to have their sodium levels measured using the Salt Calculator.

# **Use Among Clinicians and Planning Professionals**

- The calculator developers are working with the City of Ottawa to facilitate use of the algorithms in planning tools to support the healthy city initiative and health care planning.
- Canadian dietitians are using the Sodium Calculator as part of the SODIUM-HF clinical trial, which is testing dietary sodium and clinical outcomes in patients with heart failure.
- The Elder-Life Calculator is recommended by the Ontario
   Palliative Care Network.
- Currently set up for use in Canada, the calculators can be adapted for use by any of the 100 countries around the world that collect health survey data.