Evidence with Impact

A selection of recent projects that illustrate the combination of ideas, insight and rigour driving ICES research.

MAKES POLICY BETTER

MAKES PEOPLE HEALTHIER

MAKES HEALTH CARE BETTER

Responding rapidly to the **COVID-19 pandemic using ICES data and analytics**

Early in 2020, a global pandemic wreaked havoc around the world. COVID-19, an infectious disease caused by a newly discovered novel coronavirus, spread like wildfire. In Canada, the first case was confirmed in Ontario in late January. By March 11, Ontario had reported its first death attributed to COVID-19, and by March 17, a state of emergency had been declared and all non-essential businesses and schools were closed. As of September 9, 2020, the number of confirmed COVID-19 cases in Canada had reached 134,000, with more than 9,000 COVID-related deaths. Globally, the number of cases surpassed 27 million with the death toll at more than 900,000.

Areas of impact:

Makes policy better

Makes health care better

ICES Research

ICES staff and scientists responded to this pressing health issue by rapidly mobilizing cross-departmental resources. This included working with data partners to add to and enhance important core data resources, while also receiving them more rapidly, in order to report real-time information about COVID-19 testing and test recipient characteristics to decision makers at the **Ontario COVID-19 Command Table.** Epidemiologists, data analysts and scientists at ICES along with the leadership team continue to meet multiple times weekly to prioritize and streamline the rapidly expanding number of data sources and lab results to ensure that data quality standards are observed, and that data are promptly made available to knowledge users and researchers.

The first publicly available **report** was developed as part of a multipronged strategy to provide timely and meaningful data on COVID-19 testing in Ontario to decision makers at the Ontario Ministry of Health (MOH) and Public Health Ontario (PHO), as well as clinicians, researchers and others interested in the characteristics of individuals tested and confirmed positive for COVID-19 in Ontario. The second public **report** focused on patterns of testing and test results for immigrants and refugees in Ontario from the initial phases of COVID-19 testing through to June 13, 2020. This was the first analysis of its kind in Canada.

> **"This was an all-hands-on-deck effort across the entire institute. At the same time as we shifted the entire institute to work from home, our staff and scientists pulled together to respond to a public health emergency in a way ICES had never done before. Our work around COVID-19 shows that we can mobilize rapidly and effectively, and the entire team deserves recognition for their hard work."**
>
> Dr. Michael Schull, CEO at ICES

How this work is **having impact**

- Through partnerships at the provincial and national levels, ICES rapidly added near-real-time COVID-19-relevant data sets to its collection of linked health data.
- ICES' response to one of more than 20 COVID-related Applied Health Research Questions (AHRQs) helped inform PHO on which elective procedures could be postponed in order to make ICU beds available for COVID-19 cases.
- More than 40 COVID-19 research projects were launched by ICES scientists.
- ICES built and shared its **code** for mining COVID-19 lab test results under an open source license. This code was developed through a collaborative effort by ICES and the MOH to identify COVID-19 cases in Ontario lab data consistently and accurately.
- COVID-19 testing **dashboards** using multiple comprehensive data sources were published and updated by ICES on a weekly basis.
- ICES was the first organization to report on COVID-19 testing and cases in individual long-term care facilities.
- Daily reports on COVID-19 testing in long-term care and retirement homes were provided to PHO and MOH beginning April 17, 2020.
- Multiple public health units, including those in London, Niagara, Durham, Sudbury and Toronto, use the COVID-19 testing data supplied by ICES in their public facing dashboards.
- ICES is a key partner in the MOH's **Ontario Health Data Platform**. The OHDP will provide researchers with secure access to Ontario health data for COVID-19-related research projects, including on the ICES platform.
- The ICES Indigenous Portfolio reports COVID-19 testing data to various indigenous partners and organizations.

Pragmatic trials: **real-world settings, real-world solutions**

Randomized controlled trials (RCTs) are considered the gold standard for studying the safety and efficacy of new or existing health interventions like drugs, devices or technology. However, traditional RCTs test these interventions under optimal conditions, so that the findings of these RCTs may not be true when these interventions are applied in usual care, in non-research settings or to patients' everyday lives. Attempts to address this have led to pragmatic trials, which are designed to evaluate the effectiveness of interventions in routine practice and are critical to inform decision-making by patients and their families, physicians, administrators and policy-makers in real-world settings.

Areas of impact:

Makes policy better **Makes health care better** **Makes people healthier**

ICES Research

A team led by ICES Western scientist Dr. Merrick Zwarenstein developed a **tool** for designing randomized trials that would be more pragmatic. The tool, PRECIS-2, guides trial designers in building randomized trials whose findings are more relevant to decision makers. The tool uses nine domains—eligibility criteria, recruitment, setting, organization, flexibility (delivery), flexibility (adherence), follow-up, primary outcome and primary analysis—each ranked on a scale from 1 (explanatory, or "ideal conditions") to 5 (pragmatic, or "real world"). Using the tool helps ensure trials are designed so that their results are relevant to, and used by, patients, clinicians and policy makers. In the early 2000s, no pragmatic trials were being done in Ontario. Twenty years later, dozens of pragmatic trials using PRECIS-2 and data available at ICES have been conducted, combining the benefits of pragmatic attitudes with randomized trials and vast administrative data sets.

Researchers have found a substantial benefit to conducting pragmatic trials using ICES databases. Instead of identifying and testing an intervention on a small sample of people with a particular condition, researchers are able to look at the data on everyone with the condition in Ontario and conduct the trial on all of them very cheaply because data collection costs are low. These pragmatic trials are both less expensive than traditional RCTs and more comprehensive.

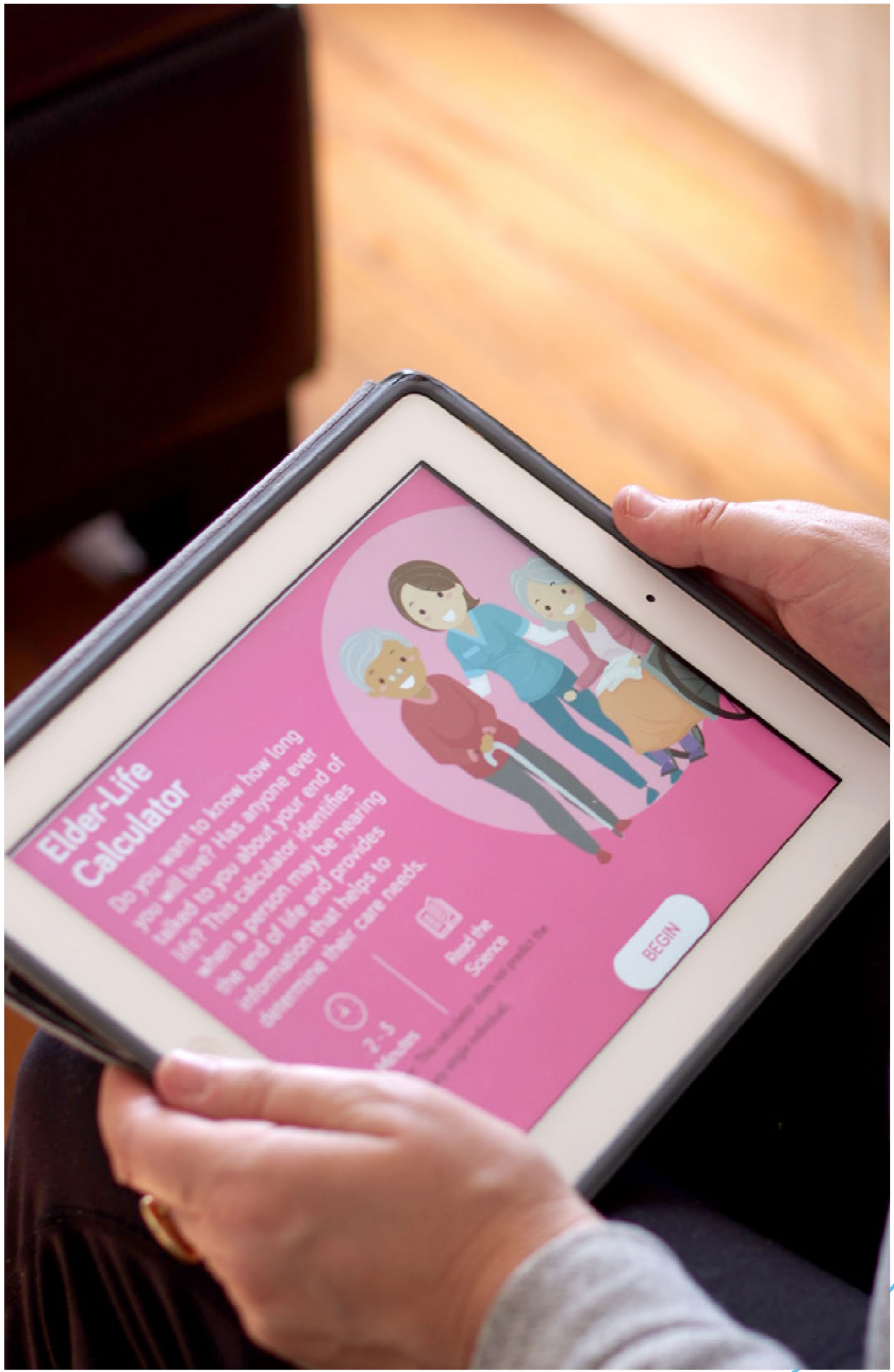
> **"Unfortunately, most traditionally designed randomized controlled trials have small samples because recruitment and data collection are expensive. Also, their findings are difficult to apply to real-world questions as patients, clinicians and settings are highly selected. Because ICES data are easily and cheaply accessible and represent all Ontarians, they can be used to conduct precise, widely applicable and low-cost pragmatic RCTs that provide policy-relevant answers on the effectiveness, safety and efficiency of many clinical, public health and social policy choices."**
>
> Dr. Merrick Zwarenstein , Senior Scientist at ICES Western

How this work is **having impact**

- Papers describing the suite of tools for designing randomized trials to be more pragmatic have been cited over a thousand times and are widely regarded as the standard descriptions of the pragmatic approach to randomized trial design.
- Between them, Dr. Zwarenstein and Dr. Baiju Shah have led five large-scale pragmatic randomized trials using ICES data to evaluate the effect of knowledge translation interventions on patients of Ontario primary care physicians and home care providers. These studies found that at a large scale, different kinds of printed educational materials did not improve family physician adherence to evidence-based care guidelines, and that care pathways for home care provision did not improve care outcomes for a number of conditions.
- The **ISLAND trial**, led by Drs. Noah Ivers and J.D Schwalm, showed that interventions like mail-outs and phone calls encouraged more patients to adhere to their cardiac rehabilitation program after a heart attack.
- The **MyTEMP** trial, led by Drs. Ahmed Al-Jaishi and Amit Garg, is examining the effect of patients being provided a personalized dialysate temperature during each dialysis session on their risk of cardiovascular-related death or hospitalization.
- The **CHOICES trial**, led by Dr. Jay Udell, uses a multicomponent intervention and implementation approach that includes audit and feedback reports for family physicians and educational materials and tools for patients to help increase the use of cholesterol-lowering statin medications.

A tool using novel data approaches helps patients and caregivers **make decisions about end-of-life care**

When surveyed, **most Canadians** express a desire to die at home. However, Canada has one of the highest rates of inpatient hospital deaths among member countries of the Organisation for Economic Co-operation and Development, **with 52% of Canadians with cancer** dying in hospital compared to 22% of Americans. In Ontario, **75% of people with heart failure** die in hospital. Although recent research shows that providing end-of-life care doubles the likelihood of dying at home, only **one in three** homecare clients will receive palliative care. In the institutional setting, half of all people entering long-term care homes in Ontario will die within 18 months of admission, but doctors and families alike find talking about palliative or end-of-life care difficult.



Elder-Life Calculator

Do you want to know how long you will live? Has anyone ever talked to you about your end of life? This calculator identifies when a person may be nearing the end of life and provides information that helps to determine their care needs.

Areas of impact:

Makes policy better **Makes health care better** **Makes people healthier**

ICES Research

In 2015, a team of researchers at ICES Ottawa published **a study** demonstrating the high cost of end-of-life health care, with most of the costs incurred from acute care hospitalization in the last three months of life. The study, which received **national media coverage**, highlighted the need for a prognostic tool that would help clinicians and caregivers begin a conversation with patients about palliative care. This would potentially shift care from costly acute care settings to community settings where most people prefer to be when they are dying.

In 2019, the research team led by Drs. Amy Hsu, Peter Tanuseputro and Douglas Manuel, in collaboration with health care organizations Bruyère and The Ottawa Hospital, developed a tool to predict who needs end-of-life care. The web-based calculator called **RESPECT** (Risk Evaluation for Support: Predictions for Elder-life in the Community Tool) uses big data available from ICES to develop precision health algorithms that can accurately calculate how long a person has to live based on their responses to questions about the diseases they have and their ability to care for themselves.

The researchers created the tool to be easy to use so that the results would enable patients and their caregivers to make informed decisions customized to their needs.

> **"We need to normalize dying and death because they are a part of life. We need to create a palliative care system that is based on a strong prognostic tool to make those who are dying as comfortable as they can be. RESPECT provides the average person with the tools they need to plan their death."**
>
> Dr. Peter Tanuseputro, one of the ICES scientists who helped create the RESPECT calculator

How this work is **having impact**

- Supported by the team's research, in 2019 the Ontario Ministry of Health introduced a Quality Improvement Plan (QIP) indicator that helps health care organizations estimate the need for palliative care among their clients and identify individuals who may benefit from a palliative care approach.
- The Windsor-Essex Compassion Care Community initiative began using the RESPECT calculator in 2019 to match more than 100 people with frailty to the community services they need.
- The Champlain Local Health Integration Network's palliative home care program is planning a pilot project that will use the RESPECT calculator to support service delivery in retirement homes in Ottawa.
- The research team is currently working with the Champlain Long-Term Care Community of Practice, which consists of medical directors of long-term care homes in Ottawa, to use the RESPECT calculator to guide advanced care planning and goal-of-care discussions with residents and their families.
- The research team has been working with the sub-acute care sector through a pilot program in the complex continuing care setting at Bruyère.
- A **video** about the calculator was released in 2018 and has been viewed nearly 30,000 times.

Using administrative data to identify homelessness and **improve health outcomes for a vulnerable community**

People experiencing homelessness face substantial barriers in accessing health care including but not limited to medical and surgical care, mental health care, prescription medications, eyeglasses and dental care. To provide care to this underserved group, researchers and policy makers alike have struggled to measure the homeless population. The most common way is through point-in-time estimates that measure the number of people sleeping in shelters or on the streets on a given night.

It is a costly approach that requires significant human resources yet will miss people (particularly some women and families) who do not stay in shelters, as well as individuals who are couch surfing, living in the rough or homeless only some of the time. Not being able to accurately measure this vulnerable population means programs and funding cannot be adequately allocated or evaluated.

Areas of impact:

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ICES Research

Dr. Stephen Hwang and his team recruited study participants in Toronto and Ottawa who were experiencing homelessness and obtained their permission to link their records to ICES data to track their health care use. The cohort was followed for four years and has been used in multiple studies, including a paper on the effects of housing on health care encounters and costs that will be published in Medical Care.

In 2019, using administrative data held at ICES, a team of researchers at ICES Western led by Lucie Richard and **Dr. Salimah Shariff** developed an **algorithm** that enabled them to follow individuals experiencing homelessness over time, and provided a reliable and less costly way to identify health needs, services and outcomes for a high-risk and understudied population. To ensure accuracy, the algorithm was validated using the homeless cohort created by Dr. Hwang's team.

> "There's a cost to doing nothing. The status quo that allows people to be chronically homeless has a cost to it, and it's borne by the health care system, the justice system and the shelter system. There's a cost to providing affordable housing, but it results in cost offsets or cost savings and that is something we are able to demonstrate using ICES data."
>
> Dr. Stephen Hwang , Senior Adjunct Scientist at ICES Central

How this work is **having impact**

- The homeless cohort can be linked to ICES data to examine the impact of health care interventions on homelessness.
- The researchers are currently examining the Housing First model, which involves rapid access to housing using a rent subsidy and to mental health and social supports that enable the person to make a successful transition from homelessness to housing.
- The algorithm is being used to evaluate how Ontario's new **heat warning system** has changed the way the homeless population uses health services during a heat wave; those findings will be presented at a workshop with stakeholders later in 2020.
- The researchers are working with teams across Canada to cross-validate the algorithm for national use.
- The algorithm is being used to understand the health impacts of COVID-19 among the homeless.
- The federal government's **COVID-19 Immunity Taskforce** is including homelessness in its reporting.

A First Nations-led diabetes report supports the development of effective health policies and programs

Diabetes is one of the leading chronic health conditions impacting First Nations peoples in Ontario, according to the **First Nations Regional Health Survey**. The First Nations have long recognized that individual and community health and well-being are linked to factors that are rooted in their historical, political, geographic, environmental, economic, cultural and social foundations. These factors contribute to inequity and marginalization, which are connected to high rates of diabetes, lack of access to care and poor diabetes-related outcomes.

For several years, Indigenous (First Nations, Inuit and Métis) communities in Ontario have collaborated with ICES to develop unique partnerships that include data governance and data sharing agreements, which have enabled Indigenous-driven analyses using ICES data.

Areas of impact:

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The 2019 report **First Nations and Diabetes in Ontario** is an example of how meaningful collaboration using First Nations population data can be achieved. This work is in response to the calls to action contained in the **2015 report** of the Truth and Reconciliation Commission of Canada. The report followed the First Nations' Ownership, Control, Access and Possession (OCAP®) **Principles** that highlight the necessity of First Nations' engagement and governance. The report, a first-of-its-kind, First Nations–specific study of diabetes in Ontario, found the prevalence of diabetes among First Nations people was 16.6% compared to 8.1% among other people in the province. It is the result of a collaborative project between the Chiefs of Ontario (COO), ICES, and other First Nations and academic partners.

Over three years, the project team worked with a six-member patient advisory group to better understand First Nations people's experiences with diabetes and diabetes-related health services in Ontario. All members of the advisory group are living with type 2 diabetes or know of someone living with type 2 diabetes, and reside in Ontario First Nations communities.

The study was supported by a grant from the **Ontario SPOR SUPPORT Unit**, which is funded jointly by the Ontario Ministry of Health and the Canadian Institutes of Health Research. Honouring the principles established to observe First Nations data sovereignty and employing approaches from community-engaged participatory research, the report examines the prevalence and incidence of diabetes, as well as health outcomes and service utilization of people with diabetes.

> **"Our Elders remind us to think seven generations ahead, which means these findings are particularly concerning to us. Our children are experiencing rising rates of diabetes, we need to look to their future and use this research to improve prevention for them now and for future generations and early support prior to complications of diabetes."**
>
> RoseAnne Archibald, Ontario Regional Chief, Chiefs of Ontario

How this work is **having impact**

- This project was the first to be reviewed by the COO First Nations Data Governance Committee which informed application and review processes for future research requests.
- The report is an example of relationship-building, illustrating how research teams and communities can work together to co-create evidence in a timely manner.
- The findings are being used to inform community diabetes programming.
- The findings from the report were presented to the COO Health Coordination Unit and at the COO Health Forum attended by health directors from First Nations communities.
- In 2019-2020, the research team published a series of 12 peer-reviewed papers, one for each of the report's content areas, in the journals of the Canadian Medical Association.
- The project has informed the analysis that Mamow Ahyamowen, a partnership of more than 70 First Nations communities, is conducting with ICES data and has increased awareness in the communities about the availability of ICES data.
- The researchers are currently working on a People's Report for the COO, which will integrate the findings of the quantitative report with a qualitative report; the report will be released in 2021.