ICES 20TH ANNIVERSARY MAGAZINE

TWENTY

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INSTITUTE FOR CLINICAL EVALUATIVE SCIENCES 1992-2012

9

WELCOME

SINCE 1992, ICES HAS CONDUCTED RESEARCH AIMED AT IMPROVING ONTARIO'S HEALTH CARE SYSTEM AND PROMOTING BETTER HEALTH FOR ALL ONTARIANS.

TO MARK OUR 20TH ANNIVERSARY, WE'VE LOOKED BACK AT THE GROUNDBREAKING, EVIDENCE-BASED INSIGHTS UNCOVERED BY OUR SCIENTISTS AND STAFF AND THE IMPACT THEIR WORK HAS HAD ON SERVICE DELIVERY AND THE QUALITY OF CARE – ACROSS ONTARIO AND AROUND THE GLOBE. OUR STORY INVOLVES COMPLEX RESEARCH METHODS AND THE CHALLENGES OF MANAGING THE WEALTH OF DATA ENTRUSTED TO US. BUT OUR ULTIMATE GOAL CAN BE STATED SIMPLY: TO HELP PEOPLE LEAD HEALTHIER LIVES. WE HOPE THAT CLARITY OF FOCUS COMES THROUGH IN THE FOLLOWING PAGES.

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Cover illustration by Mike Ellis



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LOOKING BACK, LOOKING FORWARD

LOT HAS CHANGED DURING OUR FIRST 20 YEARS, BUT THE FUNDAMENTALS THAT DEFINE ICES REMAIN THE SAME.

Since ICES was founded in 1992, the challenges of health services delivery have only grown more complex, as have the methods by which we investigate them. At the same time, through two decades of constant change, we've maintained a clear sense of continuity.

The goals of the visionary founders of ICES (recalled in these pages by David Naylor, our original CEO) remain as relevant as ever: to create knowledge that will make the health system more effective, and to promote better health for all Ontarians. In fulfilling that mandate, ICES scientists have helped to map the landscape of health care in Ontario – beginning with our pioneering research atlases – and established the boundaries for an entire field of inquiry.

The challenge in trying to sum up their collective achievements is that it quickly turns into a very long list of landmark studies and influential reports – which is why we're marking our 20-year milestone with this publication. It provides a welcome chance to survey the extraordinary depth and diversity of research that has been conducted under the ICES banner, and that continues today.

All of this great work has a common foundation: the vast data holdings entrusted to our stewardship. So in this retrospective we also explore the challenges of managing this vital data, and the leadership role ICES has taken in protecting information privacy. As well, we focus on some of the many health care challenges – from wait times to the diabetes epidemic – for which ICES research gives policy makers the evidence-based insights they need to shape equitable, cost-efficient solutions.

Yet even as we take this opportunity to look back, in the spirit of ICES we're also looking forward. Our growing network of satellite campuses now connects centres of research excellence across Ontario. We continue to forge new partnerships – joining, for example, the Métis Nation of Ontario and the Chiefs of Ontario in their quest for health services that reflect the needs of Aboriginal communities. And, looking toward the horizon, we plan to extend our data repository by integrating additional key public services such as education and social services.

If we had to distill two decades of remarkable effort down to a single word, it would be *impact*. In countless ways, ICES research has changed how, where and why health services are delivered – across Ontario and well beyond its borders. This collective achievement could not have happened without the steadfast support of the Ministry of Health and Long-Term Care, our close friends at Sunnybrook Health Sciences Centre, our many partner organizations, our dedicated Board of Directors and, of course, our own talented and tireless staff. Everyone who has been part of the ICES story can feel proud of that legacy. And I know we're all eager to see how this unique institution will continue to evolve over the next 20 years. Thank you for being part of our celebration – and for sharing our commitment to improving the future of health care.

David Henry President and CEO

The Toronto Blue Jays win a second consecutive World Series title.



ICES, with eight faculty members, moves into the renovated G-wing on Sunnybrook campus and produces about 30 research papers.

In partnership with the Cardiac Care Network of Ontario, ICES produces report cards analyzing hospital surgical outcomes.

"Making Health Services Relevant" symposium attracts 350 delegates.

1993



A SELECTION OF MILESTONES FROM THE PAST TWO DECADES HIGHLIGHTS THE MANY DIMENSIONS OF A CONSTANTLY EVOLVING RESEARCH MANDATE – AND SHOWS HOW FAR ICES HAS COME.

THE

20

FIRST

YEARS

1992

ICES opens its doors on the campus of Toronto's Sunnybrook Hospital on April 1.

Dr. David Naylor is the first CEO.

Dr. John Evans is founding Chair of the fourmember Board of Directors.



Patterns * _ Health Care * Ontario

1994

The first ICES practice atlas is published. Patterns of Health Care in Ontario provides a "bird's-eye view of the health care system," raising public awareness of the challenges in delivering a wide range of health services.

Dr. Jan Hux receives the first Adam Linton Fellowship, named for the late physician and Ontario Medical Association president who played a key role in the founding of ICES.

ICES launches *informed*, a quarterly newsletter for physicians.

Nelson Mandela is elected President of South Africa.



The Quebec sovereignty referendum yields a slim decision in favour of federalism.



The Research Transfer Unit is established under the leadership of Cathy Fooks to help disseminate ICES research findings to clinicians and

Patient information brochure on PSA screening for prostate cancer is developed in partnership with the Canadian Cancer Society.



government.

Publication of Cancer Surgery in Ontario atlas.

Partnership with the Heart & Stroke Foundation of Ontario is formed to advance research on cardiovascular health and services.

Patient decision-making aids are produced for women facing breast cancer treatment and considering hormone replacement therapy.

ICES releases Waits and Rates: The 1997 ICES Report on Coronary Surgery for Ontario, which results in recommendations to the MOHLTC for improved cardiac care.

1997



ted as the

The euro is officially adopted as the new pan-European currency.

Cardiovascular Health and Services in Ontario Atlas, in partnership with the Heart & Stroke Foundation, is published.

ICES appoints its first privacy officer, **Pamela Slaughter.**

A new series of atlas reports is launched, beginning with Supply of Physicians' Services in Ontario.

1999

1996

The ICES website is launched.

Sore Throat Scorecard co-developed by ICES researchers leads to a 25% reduction in unnecessary antibiotic prescriptions.

ICES helps develop HEALNet (Health Evidence Application

and Linkage Network) to connect more than 75 researchers in 17 Canadian universities.

Guidelines for the treatment of uncomplicated hypertension are distributed to practicing physicians.

Ontario round table on Appropriate Prescribing (ORTAP) is officially launched.

1998

Dr. David Naylor steps down. Dr. Jack Williams, deputy director of research since 1992, is appointed President & CEO by an expanded 10-member Board.

ICES has two dozen faculty researchers, 50 staff members and 30 graduate students.

A publication by Dr. Lorraine Ferris defines doctors' mandatory responsibilities with patients who pose a potential threat to others, which sets an international precedent and results in changes to the provincial Medicine Act.

Arthritis and Related Conditions Atlas, in partnership with the Arthritis Society of Ontario, is published.

2000

First annual ICES/CIHI/ MOHLTC data symposium, "Health Care Data: Research, Planning and Decision-making," is held.

Dr. Andreas Laupacis assumes the role of President & CEO; Dr. Peter Glynn becomes Chair of the Board.





Al-Qaeda terrorists attack the U.S. on September 11.

With new funding from the Canadian Foundation for Innovation, along with renewed support from the MOHLTC, **ICES can undertake a significant expansion** of its databases and physical space.

ICES researchers help **develop the Registry of the Canadian Stroke Network** and evaluate a new strategy for stroke care in Ontario.

The Canadian Cardiovascular Outcomes Research Team (CCORT) is formed.

2001



A new report entitled Access to MRI in Ontario: Addressing the Information Gap provides hospitals with practical, evidence-based guidance for ensuring accessibility and managing wait times.

The first **Canadian Cardiovascular Atlas** is the **most extensive study of its kind**, thanks to an unprecedented level of collaboration across the country.

ICES launches At A Glance, a monthly e-bulletin highlighting recent evidence-based health services research for a national and international readership.

2003

Hurricane Katrina ravages New Orleans in late August.



Access to Health Services in Ontario is a key information resource for the major transformation in Ontario health care this year, evaluating quality of access in terms of wait times, service provision rates, appropriateness, unmet needs and other factors. Findings help shape the provincial government's landmark Wait Time Strategy.

An **ICES study** correlates the number of fast-food outlets in a region with the rate of heart disease and mortality.

2005



2002



Among many **new initiatives** announced for the **10th anniversary year of ICES** are three cancer studies focusing on delays in diagnosis and potential barriers to treatment.

Health Technology Assessment of Positron Emission Tomography marks the first time the Ontario government makes the implementation of a new technology contingent on data demonstrating its real-world effectiveness.

An evaluation of the burden of diabetes across the province culminates in publication of **Diabetes in Ontario** – one of the most in-depth ICES research projects to date – and among the **most comprehensive in the world.**

With the **launch of EFFECT:** Enhanced Feedback for Effective Cardiac Treatment, the CCORT research team undertakes the world's largest randomized study of cardiac report cards.

2004

In response to publication of EFFECT study findings, 54% of surveyed physicians introduced quality improvement initiatives at their hospitals.

Arthritis and Related Conditions Atlas (2nd edition) proposes strategies to meet the growing demand for case and treatment.

The new social network website Facebook launches in February.



2006

ICES expertise on patterns of health care delivery is applied by the Ontario government to define the boundaries for the 14 Local Health Integration Networks (LHINs).

The second edition of **Access** to Health Services in Ontario focuses on changes in rates of service and wait times by age, gender, socio-economic status and selected outcomes.

Primary Care in Ontario provides a comprehensive look at changes in services over the previous decade and highlights the need for policy makers to ensure there will be sufficient numbers of general/family practitioners to meet future needs.

Dr. Brian Golden becomes the Chair of the Board.

Senior scientist **Dr. Jan Hux** is named interim **President & CEO.**



Dr. David Henry is the new President & CEO. ICES has 85 research scientists, 90 research staff, 51 student trainees and 30 major research partnerships.

ICES@Queen's is established

as the first in a series of satellites in partnership with Ontario universities.

A new drug safety study

correlates the use of selective serotonin reuptake inhibitor (SSRI) antidepressants with suicides of patients. Other areas of research focus include quality of care and the management of chronic conditions such as asthma, diabetes and cardiovascular disease.



An ICES study reveals that **nearly a third of two-year-old children** in Ontario have **not received the recommended immunizations** for their age, placing them at risk of contracting and spreading vaccinepreventable diseases.

A study of ambulance use in Ontario finds that **highly trained paramedics** in vehicles equipped for 911 emergency calls **spend 80% of their time making routine, non-urgent patient transfers.**

ICES research continues to explore the socio-economic dimensions

of health care. For example, well-off Ontarians were found to be more likely to receive MRI scans than those who are less fortunate, and people who are chronically ill and poor are the least likely to benefit from new investments in health care.

The **EFFECT study** is selected by the CIHR Institute for Health Services and Policy Research as the **"best health policy research study"** published by Canadian researchers.

2009

The federal Conservative government wins a majority in the May election.



ICES appoints **28 new adjunct** scientists.

The constantly expanding ICES data repository adds 93 new holdings, including the Ontario Vital Statistics death register, and repositories of social data managed by Citizenship and Immigration Canada and Ontario's Ministry of Community and Social Services.

Wide-ranging research yields over 225 new projects, 318 peer-reviewed papers and six investigative reports.

2011

2008

The MOHLTC incorporates the findings of the groundbreaking atlas, Neighbourhood Environments and Resources for Healthy Living – A Focus on Diabetes in Toronto, into a new province-wide Diabetes Strategy. The 2007 atlas clearly linked the risk of developing type 2 diabetes with specific city neighbourhoods and patients' socio-economic status – and sparked widespread public interest, including a front-page story in the Toronto Star.

Scope of ICES research expands – physicians' reporting of unfit drivers, sleeping pill dependency among the elderly, shortcomings in cervical cancer screening among recent immigrants, increased burden on emergency departments from gun-

and knife-related injuries and more.



Barack Obama is elected president of the United States.

2010

ICES forges new partnerships with the Chiefs of Ontario and the Métis Nation of Ontario as part of a renewed focus on studying chronic disease and other health care issues among Aboriginal peoples.

The Ontario Cancer Data Linkage

Project – known as cd-link – is an innovative first step toward wider distribution of de-identified ICES data.

An ICES team develops the LACE index – gauging length of stay,

acuity of admission, comorbidity and emergency room use – for quantifying the risk of death or unplanned readmission within 30 days after discharge from hospital.

ICES@uOttawa opens, continuing the ICES satellite expansion program.

Delegates from across Canada attend the 11th annual ICES/CIHI/MOHLTC data symposium.

Mark Rochon is the new Chair of the Board.

2012

ICES@UofT opens its doors, with ICES@Western soon to follow.

ICES now has a total of 161 core and adjunct scientists supported by a research staff of 152 and adds a sixth program of research – Kidney, Dialysis and Transplantation.

ICES marks its 20th anniversary with a series of special publications and events while continuing an ambitious research agenda that spans the spectrum of health service issues – all aimed at furthering the Institute's strategic vision:

- Expand access to data
- Engage new partners
- **Enrich** capacity through enhanced funding and operational capacity.

THE ORIGINS OF ICES

IN THE FIRST ICES ANNUAL REPORT, INAUGURAL CEO **DAVID NAYLOR** INTRODUCED STAKEHOLDERS TO A NOT-FOR-PROFIT CORPORATION DEDICATED TO RIGOROUS, EVIDENCE-BASED HEALTH SERVICES RESEARCH.



he goal of this independent institute was ambitious: "to promote effective, efficient and equitable medical care." Twenty years on, Dr. Naylor, now President of the University of Toronto, reflects on the impact of the organization he helped to found and shares some details of how it all began...

HOW WOULD YOU SUM UP THE VISION THAT SHAPED ICES?

The vision was simple. With the emergence of clinical epidemiology as a discipline, we had more and more evidence about what did and didn't work in a clinical research setting. But we still had only a limited understanding of the epidemiology of the health care system itself, including how best to translate evidence into effective and efficient front-line services.

Other jurisdictions were clearly trying to fill that gap. The momentum was strongest in the U.S., where health services research was a well-established field. A number of pioneers, such as Jack Wennberg of Dartmouth Medical School and Bob Brook of UCLA and RAND, were deploying research evidence and rigorous quantitative methods to understand and improve decision-making in the health realm. However, Canada was lagging.

I moved to Sunnybrook Hospital in 1990 with a clear plan to build a new multidisciplinary unit that would bridge clinical epidemiology, health services research and policy formulation. With the development of ICES in 1992, we were able to scale up that hospital-based operation dramatically into a provincial centre of excellence that had tremendous access to data and strong ties to providers, administrators and policy makers alike.

TO WHAT EXTENT WAS ICES THE PRODUCT OF A PARTICULAR TIME AND POLITICAL CLIMATE?

First, the public honeymoon with universal health care had clearly ended by the early 1990s. Second, a previous Liberal government in Ontario had already recognized that the system could not be managed simply by pulling big fiscal levers. They had worked with the Ontario Medical Association (OMA) to set up a Task Force on the Use and Provision of Medical Services, chaired by a former deputy minister of health, Graham Scott. I was involved with that collaborative initiative and it served as important groundwork, in a practical and political sense, for the creation of ICES.

Third, a new NDP government was elected in September 1990 and soon found itself in negotiations with the OMA. Both sides recognized that, with resource constraints, the only way forward was through a more substantial collaboration between the primary funder and health care providers. ICES was in meaningful measure a by-product of the bargaining process in the spring of 1991, which in turn reflected a unique context and history. Its creation was also tied to the emergence of a new Joint Management Committee that brought together the OMA and the Ministry of Health with a view to promoting more effective, efficient and equitable health care in the face of the deepening recession.

HOW DID THE VISION EVOLVE AS ICES GAINED TRACTION?

In those early years we stayed very close to the plans that were drafted in 1991. One clarification had to do with the expectation that ICES would be a guidelinewriting factory. Of course we developed some guidelines and decision aids for providers and patients. But, as I wrote in 1995, many other bodies were "already developing and disseminating guidelines. As well, our clinical affiliates [had] often indicated frustration with the form and proliferation of existing guidelines. Thus, from a strategic standpoint, the logical first step was to understand current practice patterns and consider them in light of existing guidelines."

We also had to contain the resources invested in guideline implementation. Our budget simply did not permit us to subsidize a broad-based push on clinical quality through front-line interchanges with institutions and providers. Nor, frankly, was that a sustainable strategy for system improvement. We



In 1993 ICES moved into the newly renovated G-wing on the campus of Sunnybrook Hospital.

needed providers to take ownership of evidence about puzzling variations in care and then evaluate their practices and make changes locally.

Another shift was to draw more heavily on sources beyond the usual administrative databases. We were able to enrich our understanding by using population-level epidemiological data, along with a variety of socio-economic indicators, detailed clinical databases from registries and trials, and various surveys.

Finally, I have to say that we learned – sometimes the hard way – about stakeholder relations, political and professional sensitivities, the quirky world of the mass media, and the challenges of communicating complex information to patients and the wider public. I don't think any of us quite anticipated how important or challenging those activities would be.

WHAT DID IT TAKE TO WIN SUPPORT FOR ICES AND GET IT OFF THE GROUND?

During the late 1980s, leaders in both the OMA and the Ministry of Health had become increasingly keen on the idea of an arm's-length body that would promote evidence-based health care. I'd worked with both sides. As a strategic advisor to the OMA during the 1991 negotiations, I floated a number of the ideas behind ICES, and they were well received. I vividly recall writing them up one weekend – in the basement of our family bungalow in Don Mills, with two toddlers running around!

It was propitious that the new clinical epidemiology unit at Sunnybrook got off to a fast start in 1990–1991 with great faculty, staff and students. Originally located in A-wing, the unit served as a demonstration project for the concept of ICES, albeit one with a strong academic focus. Later in 1991, I polished the material from my weekend writing binge into the final proposal for ICES, and it was formally approved. In hindsight we were very lucky to get so much capital and operating support. But, truth be told, that original \$20-million commitment came quickly and easily. Actually operationalizing ICES, in contrast, was a massive stretch. Scores of individuals pulled together to make it happen. We had to renovate G-wing, an abandoned veterans' facility on the Sunnybrook campus; gain access to very large and sensitive databases; build the capacity to process vast amounts of confidential information; develop secure methods for linking those data; connect with scores of institutions and hundreds of providers; manage endless political issues and media traffic; and reconcile the priorities and needs of clinical and non-clinical faculty, a varied and very talented staff, and rapidly growing numbers of students and postdoctoral trainees. Many of us were on a steep learning curve for a very long time – no one more than me!

WHAT ROLE DID DR. ADAM LINTON PLAY IN THE FORMATION OF ICES?

Adam Linton and I met at Victoria Hospital in London, Ontario, where I was a medical resident – later chief resident – and he was completing a distinguished run as chief of medicine. He was a fabulous clinician and a remarkable character with a wicked sense of humour. We shared a belief in the need for physicians to take a much stronger role in promoting efficient resource allocation, effective clinical practices and smart public policy formulation.

Adam and I worked together on various ideas and issues starting in 1984. Once he left clinical administration, he rose quickly through the leadership ranks of the OMA and was a key champion of the creation of the Joint Management Committee (JMC) and ICES. Tragically, as he prepared to assume the OMA presidency in 1991, Adam was diagnosed with inoperable pancreatic cancer. When I saw him last in December 1991, I outlined how all the plans and funding for ICES had come together. He could not have been more pleased but also said, simply and sadly, "I am sorry that I won't be there to see it all happen." He died a few days later, on January 3, 1992. I firmly believe that he would be very proud of what ICES has accomplished over the last two decades.

66 There is no question that ICES over the past 20 years has had a local, provincial, national and international impact.

HOW WOULD YOU CHARACTERIZE THE ORIGINAL RELATIONSHIP BETWEEN ICES. THE OMA AND THE MINISTRY OF HEALTH?

From the outset I made it clear that ICES had to operate at arm's length. The title page of the 1991 proposal includes this subtitle: "An Independent Research Body Sponsored by the Ontario Ministry of Health and the Ontario Medical Association." The proposal set out mechanisms to safeguard the academic freedom of faculty members for two purposes: to ensure recruitment and retention of the best and brightest researchers, and to maintain the credibility of the new organization.

My rule of thumb was that one-third of ICES work would be investigator-driven and leveraged through support from peer-reviewed funding; one-third would be driven by stakeholder concerns; and one-third would be undertaken in direct response to issues raised by the JMC. Unfortunately, the deepening recession strained relations between the OMA and the government. The JMC collapsed, leaving us with more freedom to operate but less receptor capacity for our findings. To their great credit, both the OMA and the government sustained their commitment to the fiduciary governance of ICES. Later we made the transition to a more traditional board with additional representatives, again with excellent support from our original co-sponsors.

HOW WOULD YOU SUM UP THE IMPACT OF ICES?

Two factors strike me as important to the success of ICES. One is a culture that blends ideas and insights from different disciplines; ICES has always welcomed a wide range of practising health professionals and full-time researchers with varied backgrounds. The other factor is the coexistence of research projects that range from highly pragmatic to rigorously fundamental. That range of approaches leads, in my view, to creative tension and ultimately to the conceptual fluency that is a hallmark of ICES research.

There is no question that ICES over the past 20 years has had a local, provincial, national and international



ICES was a new multidisciplinary unit bridging clinical epidemiology, health services research and policy formulation.

impact. The intellectual footprints of the people who have worked at and with ICES can be seen clearly in every clinical realm, in public health and health care policy-making, and in the global uptake of countless new research ideas and methodologies. And arguably the biggest impact of ICES has been on the education of scores of researchers who have gone on to make their own marks across Canada and around the world.

I can't begin to tell you how blessed we were to have such great faculty, staff, trainees and students in those early days. And thanks to a succession of excellent leaders, ICES has continued to grow and thrive. I remain deeply grateful to the wonderful people with whom I worked in the early years and am humbled by the brilliance and commitment of all those who, over the course of two decades, have nurtured ICES into the remarkable organization it is today. I learned a long time ago that in life, it is much better to be lucky than smart. I will always count myself incredibly lucky to have been part of all that creative energy with so many wonderful people, first in A-wing and later in G-wing at Sunnybrook.

FOCUS ON: **DIABETES**

THE **GROWING DIABETES EPIDEMIC** WILL CHALLENGE CANADA'S HEALTH CARE SYSTEM. ICES RESEARCHERS HAVE RESPONDED WITH POPULATION-BASED EVIDENCE DETAILING THE SCOPE AND IMPACT OF THIS WIDESPREAD CHRONIC DISEASE AND ITS COMPLICATIONS – WITH THE GOAL OF BETTER INFORMING POLICY DEVELOPMENT, RESOURCE PLANNING AND CARE DELIVERY.

Defining the magnitude of the problem

An ICES diabetes study led by Dr. Jan Hux in 2002 linked three types of administrative health data – physician service claims, hospital discharge abstracts and public health insurance records – to yield richly detailed information about prevalence, incidence, mortality and complication rates in Ontario. Dr. Hux's team devised case definitions for diabetes that were subsequently validated at ICES and adopted by other jurisdictions across Canada.

The study's findings were published in Diabetes in Ontario: An ICES Practice Atlas, which provided important baseline data to measure progress in meeting the diabetes challenge. This report, which also outlined potential policy options, contributed to the establishment in 2004 of a provincial task force looking at the organization of diabetes care across Ontario and how it could be better coordinated. The conclusions of the task force in turn led to the implementation in 2008 of the Ontario Diabetes Strategy, a major public investment - totalling \$700 million - that built on internationally accepted best practices and a growing body of evidence guiding the organization of health care around chronic disease.

Identifying populations at risk

Dr. Richard Glazier led a 2007 ICES study that examined relationships between neighbourhood characteristics and the prevalence of diabetes, using geographic methods to measure patterns across 140 unique areas of Toronto. The study team used two tools to measure relevant neighbourhood characteristics. The Activity-Friendliness Index gauged how conducive various parts of the city were to walking, bicycling and other types of physical activity. The Healthy **Resources Index quantified local** availability of health care resources, including access to diabetes treatment and education. Using these tools, the researchers were able to better understand how the urban environment influences lifestyle choices and therefore can have a potential impact on diabetes.

In addition to urban dwellers, ICES studies have investigated the incidence of diabetes among the poor, children and youth, seniors, new Canadians, and First Nations and Métis communities. Some of the findings:

- Younger, low-income Ontarians with diabetes have a greater risk of death than their high-income counterparts.
- South Asian, black and Chinese populations develop diabetes at a higher rate, at an earlier age and within lower ranges of body



mass index (BMI) than their white counterparts.

- Women with diabetes have more Caesarean sections and experience more fetal complications.
- Pregnant women with mildly abnormal blood sugar levels are at higher risk of developing type 2 diabetes later in life.
- Rates of diabetes are significantly higher among the Métis than in Ontario's general population.
- Youth with diabetes are more likely to be hospitalized when transitioning to adult care.

Monitoring frequency and access to care

A 2012 study led by Dr. Gillian Booth mapped patterns of diabetes prevalence, health outcomes and service availability in Ontario communities between 2006 and 2011. The ICES and St. Michael's Hospital research team compared these indicators across regions, sub-regions and communities. A key finding: while the concentration of diabetes programs and services was greatest in urban centres, existing service capacity was likely insufficient – and the rising numbers of people living with diabetes would create an increasing demand for more services.

Measuring the economic cost

In a 2009 study, an ICES and St. Michael's Hospital research team found that blood glucose test strips represented the third largest cost to the Ontario Public Drug Programs in fiscal year 2007–2008, accounting for \$100 million, or 3.3% of drug expenditures.

The researchers projected that the total cost of test strips for older Ontarians would exceed \$500 million between 2009 and 2013. They also found that nearly half of individuals prescribed test strips were at relatively low risk for drug-induced hypoglycemia and might not benefit from routine monitoring.

The study's cost analysis found that by implementing policies to focus test strip use among those patients most likely to benefit, the provincial government could reduce overall costs by at least \$26 million and by as much as \$302 million over the five-year study period. These savings could be redirected to more effective interventions for patients with diabetes.

Predicting future diabetes risk

A 2010 investigative report by Dr. Doug Manuel and his colleagues estimated, for the first time, Canadians' future chances of developing diabetes based on current levels of obesity and other risk factors. Findings were generated using the Diabetes Population Risk Tool (DPoRT), which the ICES study team designed, validated and calibrated by integrating national population health surveys with diabetes databases in Ontario and Manitoba. The report presented two case studies that illustrated how the DPoRT could be used for population health planning.■

Ontario Diabetes Database

The Ontario Diabetes Database (ODD), which is housed at ICES, employs a validated algorithm to identify people with diabetes based on records of hospitalizations and physician visits.

The database includes all individuals who have one or more hospitalizations or at least two physician services claims involving a diagnosis of diabetes within a two-year period. The algorithm is highly sensitive and specific in identifying patients whose diabetes diagnosis has been recorded in primary care charts.

All individuals included in the ODD remain in the database until death or until they relocate outside of Ontario.



SINCE ICES FIRST BEGAN PUBLISHING REPORTS IN ATLAS FORM IN 1994, THESE PIONEERING RESEARCH COMPENDIUMS HAVE MADE VITAL INFORMATION MORE IMMEDIATELY ACCESSIBLE, HELPING POLICY MAKERS IDENTIFY ISSUES OF CONCERN WHILE ENSURING THAT NEW INITIATIVES ARE FIRMLY GROUNDED IN THE REALITIES OF ONTARIO'S HEALTH CARE LANDSCAPE.

etting evidence-based knowledge into the hands of decision makers has been central to the mandate of ICES since its inception. By providing unbiased scientific findings to key stakeholders in the Ontario health system – including policy makers, administrators, planners and practitioners – the earliest ICES researchers believed they could have a positive influence on clinical practice and public policy affecting all aspects of health care delivery.

In its first full year of operation, ICES fulfilled that objective by publishing approximately 30 research papers, including many that illuminated important issues and stimulated debate across the health sector and in the media. But already, researchers were considering alternative ways to broaden the reach and impact of their findings.

Dr. Vivek Goel, who worked with CEO David Naylor and other ICES scientists on those early publications, remembers the impetus for moving beyond the traditional research-paper format: "We'd started to generate enough reports to show variations in treatment processes and outcomes. We felt it was important to show the general themes that were coming out of our reports, and to create a comprehensive resource for decision makers in hospitals, government and other settings." A diverse team of ICES researchers began to explore how they might reformat their findings into more accessible documents providing quickly digestible overviews of province-wide trends. The result was an entirely new genre of evidence-based reporting: the research atlas.

A NEW WAY TO SHARE INFORMATION

The first ICES publication to adopt the new model was *Patterns of Health Care in Ontario*, released in 1994. This pioneering research atlas covered a wide range of system-related and disease-specific topics, including cancer surgery and hysterectomy rates, variations in physician billing patterns, and access to services based on patients' location and socioeconomic status. The atlas highlighted regional patterns in health care delivery and provided recommendations to help guide quality improvement, resource allocation and future decision-making. One of the first publications of its kind anywhere, it roughly coincided with the inaugural U.S. health care atlas produced by what is now The Dartmouth Institute for Health Policy and Clinical Practice.

The favourable response to *Patterns of Health Care in Ontario* far surpassed expectations. The atlas raised public awareness of key health care delivery issues, prompting hospitals to launch internal audits of Caesarean sections, appendectomies and other procedures, and inspiring the creation of a coalition task force on the use of hysterectomies across the province.

The second edition of *Patterns of Health Care in Ontario*, published in 1996, updated regional analyses and hospital performance metrics while providing new research on community health indicators, mental health services, pediatrics and provincial prescribing trends. Both editions were widely cited during this period, as the government of former premier Mike Harris undertook a hospital restructuring program aimed at meeting the demands of a health care system undergoing profound change.

LOOKING AT THE DATA

To help stakeholders digest the latest atlas findings and see how they could be applied, ICES initially set up workshops and other information-sharing meetings with representatives of the Ministry of Health, as well as physicians, hospital staff, members of the Ontario Hospital Association and various advocacy groups. In hindsight, though, it's clear that these publications would not have had the same level of impact were it not for their use of maps, charts and other visual templates. As Dr. Goel recalls, "We wanted stakeholders to be able to look at health care information across the regions of Ontario in the same way you look up information in a traditional atlas."

The atlases' data-rich maps pointed out variations in health care delivery from county to county, while bold graphs summarized resource utilization by hospital, region and varying patient demographics. This highly visual approach proved especially valuable for Ministry staff and other management professionals. "Policy makers and bureaucrats are very busy, so it's helpful for them to see a diagram or chart and then read a description of what that graphic means in the big picture," explains Karey Iron, an original ICES staff member and currently director of data partnerships and development. "We wanted to help them understand how individual pieces of the health care system were working and how they could apply the findings to their sphere." What's more, Iron points out, over time the atlases helped to foster a more nuanced understanding of how different stakeholders could combine their efforts to improve health care delivery in Ontario.

FOCUSING ON KEY ISSUES

In 1997, ICES released its first topic-specific atlas, *Cancer Surgery in Ontario* – an in-depth look at surgical practices, and one of the first steps in a broader provincial initiative to reorganize and improve cancer care. "Patients told a review committee about the difficulties of manoeuvring through the cancer care system, the gaps in service and the difficult transitions from one service to another," explained Dr. Neill Iscoe, a former ICES adjunct scientist involved in the project. "We set out to determine what was occurring in cancer surgery in order to identify where we might need to build bridges, fill in gaps and make changes to provide better patient care." The atlas provided crucial data and guidance for the regional integration and rationalization of cancer services.

Arthritis and Related Conditions, published in 1998, was a collaborative effort between ICES, the Ontario division of The Arthritis Society, and the Arthritis Community Research and Evaluation Unit. The atlas was an important stepping stone toward the formation of a provincial task force on arthritis management. In 1999, ICES scientists, with support from the Heart and Stroke Foundation of Ontario, produced Cardiovascular Health and Services in Ontario – the most extensive study of its kind to that point. Another team produced Supply of Physicians' Services in Ontario, which addressed the availability, geographic distribution and comprehensiveness of care provided by doctors across the province.

The 2005 ICES atlas Access to Health Services in Ontario proved to be a key information resource for the ongoing transformation of the provincial health care system. This landmark report identified the volume and associated wait times for key health services defined in the Ontario government's Wait Time Strategy. Patients, health care providers and policy makers could determine wait times in their local areas – as well as in other parts of the province – for cancer, cataract and cardiac surgeries, and hip and knee replacements. The second edition, published a year later, provided important data for the government's strategy to reduce wait times in areas that were flagged in the first edition.

A 2008 atlas entitled Neighbourhood Environments and Resources for Healthy Living – A Focus on Diabetes in Toronto, jointly developed by researchers at ICES and St. Michael's Hospital, studied the risk of developing type 2 diabetes across 140 Toronto neighbourhoods. Researchers found that in urban neighbourhoods characterized as poor but also comparatively walkable – with well-lit streets and easy access to medical services, healthy food options and recreational facilities – there was a significantly lower incidence of diabetes. This seemed to indicate that better planning of cities and community services could mitigate some of the damaging health effects associated with low incomes.

The findings of the Toronto atlas, along with those of *Diabetes in Ontario* (2003), were subsequently incorporated into the province's Diabetes Strategy, 66 In the context of fairness – the idea that service delivery should be the same across the province – maps and graphs that show regional variation certainly evoke a strong response and have an impact.

> – JAN HUX, ICES INTERIM PRESIDENT AND CHIEF EXECUTIVE OFFICER, 2006-2007



which sought to establish standardized levels of care across all jurisdictions. The success of the Toronto diabetes atlas was multiplied when the Canadian Diabetes Association funded ICES research into the same kinds of neighbourhood causal links in other Ontario regions.

Subsequent atlases reported on the use of health services across the continuum of care, investigating emergency department challenges, the delivery of mental health services, and children's inpatient, day surgery and outpatient care. All provided essential information for health services planners and decision makers.

THE WAY FORWARD

In recent years ICES researchers have continued to publish a series of thematic and topic-specific atlases and investigative reports. All are aimed at providing pragmatic, accessible research for a health care system challenged by resource allocation issues and a growing, rapidly aging population base. ICES has also worked diligently to update atlas data on a regular basis – a task that, until 2010, was managed by the Monitoring and Reporting Department.

Other new atlases, currently in progress, are investigating public health questions such as the needs of Aboriginal communities, issues in women's health and patterns of mental health delivery – along with diabetes, cardiovascular disease, cancer and other emerging challenges in clinical care.

ICES scientists and staff are also exploring the research possibilities of the province's electronic health records initiative, which will move patient information collected by primary physicians into a centralized database. Since its founding, ICES has relied primarily on hospital and health insurance data, which is gathered for administrative purposes, yet is rich in research potential. With the eventual adoption of electronic health records, researchers will gain access to even more in-depth, de-identified patient information, including clinical status, prescriptions, physicians' follow-up reports and other critical data.

Looking back over nearly two decades of research atlases, Dr. Goel is quietly proud of the breadth and quality of information that ICES researchers have provided to decision makers: "The most important overall impact is that people are really paying attention to the findings and developing their measuring systems accordingly...whether it's at the hospital boards, the boards of health, the Local Health Integration Networks or the Ministry."



THE FOUNDERS OF ICES UNDERSTOOD FROM THE OUTSET THAT A RESEARCH INSTITUTE GRANTED UNIQUE ACCESS TO VAST AMOUNTS OF PERSONAL HEALTH DATA WOULD HAVE TO TAKE A RIGOROUS APPROACH TO PROTECTING INFORMATION PRIVACY.

n the early 1990s, as the quality and efficiency of health care in Ontario were coming under increased scrutiny,

provincial officials saw the value of a new type of research institute that would provide evidence-based insights on system performance. But before the government could give its full support to ICES, there were two hurdles to overcome. First, ICES scientists needed to explain precisely what kind of data they were seeking, and why. Second, the new organization had to formulate a set of privacyprotective ground rules - at a time when jurisdictions around the globe were taking the first steps toward creating regulatory frameworks to safeguard personal data.

EXPLAINING THE NEED

Historically, data on the effectiveness of medical treatments and practices had been derived from clinical trials, whose inclusion and exclusion criteria were often not reflective of the general population. A study of a new cardiovascular surgery technique, for example, to keep its findings clear might exclude patients with diabetes – when in reality many such patients were likely to be candidates for the procedure.

The alternative was to study the entire population, differentiating key subsets – by age, say, or type of illness – and cross-referencing them to find meaningful patterns. But to do this, researchers needed access, from multiple databases, to the personal data of everyone who used the health care system, along with the ability to link subsets at the individual level.

The proposal from the original ICES team – led by founding CEO David Naylor and his colleague (and successor) Jack Williams – was that the Ontario Ministry of Health could gain these kinds of population-based findings from the administrative data routinely collected in providing health services to Ontarians. Strengthening their case was the fact that the Ontario Health Insurance Plan (OHIP) had recently begun issuing individual cards to every eligible resident, replacing the earlier family cards. This would vastly enhance researchers' ability to study specific types of patients – pinpointing, for instance, users of cholesterol medications, or children in a particular age range for a pediatric study.

"There was a lot of discussion about who exactly would have access to the data," recalls Pam Slaughter, an early team member who became the first ICES privacy officer. "We needed to put strict administrative policies in place, and the data would have to be housed in a locked-down facility with physical barriers, as we didn't have the software we do now to protect data."

REACHING AN AGREEMENT

After considering the implications of

redirecting personal health information to a secondary purpose, government officials agreed that the benefits to Ontarians far outweighed the potential risks. "It was a tremendous achievement for David Naylor," Slaughter says, "gaining access to all of that information. And it was a tremendous show of faith by the Ministry, which was understandably concerned about disclosing data outside its walls."

The agreement stipulated that only a handful of named individuals at ICES would have direct access to the Ministry of Health databases. Sophisticated algorithms would be used to de-identify data, removing all personal attributes that were not necessary to the work at hand. The data would then be stored on a closed server system with access granted only to authorized researchers and analysts who were physically present in the secure ICES facility. There were even rules governing the minimum number of data points that must appear in a single cell of a results table, out of concern that smaller numbers might be too easily traced back to specific individuals. When the complex agreement was signed in 1997, ICES researchers - who up to that point had been conducting more limited analyses - could begin digging into the repository of administrative data, making links that shed light on every aspect of health services delivery. Meanwhile, growing public concern over the protection of personal data was bringing a new dimension to the Canadian privacy landscape: regulation.

ESTABLISHING BETTER RULES

The Personal Information Protection and Electronic Documents Act (PIPEDA), passed by Parliament in 2000, was the first legislation in Canada designed explicitly to ensure data privacy. Superseding earlier, less comprehensive federal privacy laws – and influenced by pioneering legislation enacted by several European countries during the 1990s – PIPEDA was a regulatory landmark.



66 We were extremely sensitive to privacy concerns. ICES helped to shape legislation that protected personal health data while allowing valuable research to proceed.

- JACK WILLIAMS, ICES PRESIDENT AND CHIEF EXECUTIVE OFFICER, 1998-2000

For health researchers, however, the new law had an immediate, unintended effect. In a strict application of PIPEDA, it was no longer possible for organizations collecting Canadian population data – including Health Canada and public health agencies – to access the personal information of any individual without obtaining his or her express consent – and that

could be a burdensome, costly and often fruitless undertaking. Deeply concerned by the new law's unforeseen potential to hinder essential evidence gathering, representatives of the health research community approached the Office of the Privacy Commissioner of Canada and received a sympathetic hearing. But because health care is not a federal responsibility, a remedy could only come through new provincial legislation that was "substantially similar" to PIPEDA in the spirit of privacy protection but took priority over the federal law with regard to the use of health information.

In Ontario, the answer was the Personal Health Information Protection Act (PHIPA), which authorized the use of data from the provincial health care system - deemed to have been collected with "implied consent" - in research undertaken for the public good. Representatives of ICES, among other organizations, provided input to the draft bill, meeting frequently with lawmakers to brief them on evidencebased health research and the steps taken to ensure personal data remained securely protected. "Just as we had to get our minds around how the law worked," Pam Slaughter recalls, "they had to understand how the science worked."

The version of PHIPA ultimately passed in November 2004 benefited from these and similar consultations across the scientific community. With this, ICES gained the welcome certainty of being authorized to use health data as a "prescribed entity" governed by PHIPA. (For more on the data security aspects of ICES research, see "It's All About Data," page 42.)

BALANCING PRIVACY AND THE PUBLIC GOOD

An acute awareness of privacy implications shapes every aspect of the work carried out at ICES, from the protocols around specific data queries to the ethical framework guiding research generally. Certified privacy experts assist scientists and monitor work in progress, maintaining the standards that ICES has helped to set for health services research globally.

For every proposed project, researchers must complete a Privacy Impact Assessment Form. If a study requires that patient data include, for instance, postal codes so that it can be linked to regional census data, there must be a clear justification for this level of specificity before ICES analysts will create the data set.

"I never liked the concept of being a privacy cop," says Pam Slaughter of her role as chief privacy officer, which she held until her retirement in 2011. "I preferred to simply meet with scientists whenever they were doing something that might be pushing the envelope, to make absolutely sure that they needed to do what they wanted to do, and that they were aware of the ramifications, and work mutually to find solutions. It was a matter of underlining what was acceptable and what was not."

Indeed, awareness of the issues is as critical to privacy at ICES as technology measures such as moated servers and encrypted lines. No researcher can gain access to the system without first signing a confidentiality agreement and participating in privacy awareness training.

Equally important is ensuring that privacy policy is communicated to the public. The ICES website includes detailed explanations of how personal data is protected, as well as the valuable insights it yields. With stories appearing regularly in the media about organizations that have mishandled confidential information, it's vital to reinforce the benefits of allowing access to data that has been de-identified.

"You have to be very careful to protect the privacy interests of the people whose data you hold," Pam Slaughter says. "But you also don't want to slow down legitimate and valuable work that is in the public interest."

FUTURE PRIVACY CHALLENGES

As the ICES research enterprise continues to grow in scope, there are inevitably new challenges to maintaining the protection of information privacy. The most obvious is the expansion of the ICES satellite network (see page 30).

"Since the introduction of satellites, we've been operating in a more complex, dynamic environment," explains Laura Davison, ICES chief privacy officer since August 2011. "Protecting information is not quite so simple when it's no longer contained within our four walls. Our satellites are partnerships between ICES and the host institutions, so achieving our shared privacy goals depends on collaboration and open dialogue."

The privacy agenda has become even more complex as ICES builds partnerships with organizations whose data protection practices are similarly strict but governed by legislation other than PHIPA. Many federal departments, for example, are accountable to the Office of the Privacy Commissioner of Canada. "There are a lot of common themes," Davison says, "but a lot of differences as well. This will add to the complexity of safeguarding privacy going forward."

The evolution of ICES is unfolding against a backdrop of increasingly sophisticated data security threats that require constant vigilance. However, the solution cannot be to retreat into insularity: "There's a growing desire to leverage new technology and make the data available to the widest research community possible," Davison says. "We're developing new methods of delivering information as we continue moving away from the model of having researchers sit at terminals in our facility. We want to create online spaces where they can securely access data - within our IT environment, even though they're physically outside it. As we continue on this journey, looking at all the exciting ways we can improve ICES, privacy absolutely has to be at the centre of every decision."

FOCUS ON: Drug Safety

BY LINKING MULTIPLE SOURCES OF REAL-WORLD HEALTH DATA, ICES STUDIES HAVE IDENTIFIED MANY **DANGEROUS DRUG SIDE EFFECTS AND INTERACTIONS** OVER THE YEARS. HERE ARE JUST A FEW EXAMPLES:

Anti-inflammatory drug linked to risk of heart failure

Rofecoxib, a non-steroidal anti-inflammatory drug (NSAID) marketed in Canada as Vioxx, gained rapid acceptance in clinical practice as a treatment for osteoarthritis because of its lower risk of gastrointestinal bleeding a common side effect of NSAIDs. A 2004 ICES study led by Dr. Muhammad Mamdani found that of 45,000 Ontario seniors prescribed rofecoxib, 80% had an increase in hospital admissions for heart failure, while patients using other NSAIDs had a 40% increase. Although the absolute risk for heart failure was less than 1%, this finding subsequently published in The Lancet - was significant, given that more than a fifth of Ontario seniors were taking these medications. Vioxx was withdrawn from the market later that year.

Antibiotic linked to potentially fatal blood sugar abnormalities

A 2006 study led by Dr. Laura Park-Wyllie showed that gatifloxacin, a commonly prescribed antibiotic marketed as Tequin, could cause potentially life-threatening blood sugar abnormalities. The investigation revealed that patients treated for low blood sugar levels were more than four times as likely to have received gatifloxacin as other common antibiotics, while those hospitalized with high blood sugar levels were nearly 17 times as likely to have been treated with the medication. Within two months of the study appearing in the *New England Journal* of Medicine, the drug's manufacturer announced it was halting production.

Diabetes drug study influences safety guidelines

The widespread use of a popular class of oral diabetes drugs that included rosiglitazone (brand name Avandia) became controversial following the publication of ICES research linking them to an increased risk of heart failure and heart attacks. A 2007 study led by Dr. Lorraine Lipscombe found a 60% relative increase in heart failure and a 30% increase in mortality among Ontario seniors who were taking at least one medication in this class of drugs. ICES scientist Dr. David Juurlink subsequently joined forces with the advocacy group Public Citizen to insist that the U.S. Food and Drug Administration (USFDA) halt an international clinical trial comparing rosiglitazone and pioglitazone (Actos). Dr. Juurlink's research showed that rosiglitazone was associated with a higher risk of heart failure and death than pioglitazone, making it unethical to proceed with the trial.



Increased cardiovascular risk with clopidogrel-PPI combination

The medication clopidogrel (brand name Plavix) is used to reduce blood clotting in patients with heart disease. Dr. Juurlink and his colleagues found that among patients who'd had a previous heart attack and were taking clopidogrel in combination with a proton-pump inhibitor (other than pantoprazole), the risk of another cardiovascular event within 90 days was 40% greater than for those taking clopidogrel only. This 2009 study contributed to decisions by the USFDA and the European Medicines Agency to discourage the clopidogrel-PPI combination.

Antidepressant blocks life-saving benefits of breast cancer drug

A 2010 ICES study led by Drs. Juurlink and Lawrence Paszat confirmed that paroxetine (brand name Paxil) – a commonly prescribed antidepressant – could nullify the effects of the cancer drug tamoxifen if taken by women with breast cancer. The risk of death from breast cancer increased in proportion to the length of the time that use of the two drugs overlapped. The study also found that several other antidepressants in the same class of drugs did not impair tamoxifen's effectiveness. An editorial accompanying the paper in the *BMJ* recommended that physicians avoid co-prescribing the two drugs to women with breast cancer, and that regulators insist on stronger warnings on drug labels.

Varying rates of multiple drug therapies in long-term care facilities

The use of multiple, concurrent drug therapies is a concern in long-term care settings where frail older adults are at risk for adverse events. A 2011 ICES study led by Dr. Susan Bronskill found that almost 16% of long-term care residents received nine or more drug therapies, and 2% received 13 or more. The wide variation in polypharmacy rates across nursing homes – from 8% to 26% – suggests that this measure should be factored into drug policy reviews at the facility level.

Opioids and the treatment of non-malignant chronic pain

Since 2008 ICES research teams have conducted several studies with the Ontario Drug Policy Research Network (ODPRN) on the use of opioids in the province, investigating utilization patterns, escalating doses and opioidrelated mortality. Some key findings:

 Following the introduction and extensive marketing of long-acting oxycodone in 1991, the incidence of opioid-related deaths doubled in Ontario, rising from 13.7 per million that year to 27.2 per million in 2004.

- Opioid-related deaths are concentrated among the patients of doctors who regularly prescribe these drugs. Researchers found that the 20% of Ontario family physicians who prescribed opioids most frequently issued prescriptions 55 times more often than the 20% who prescribed opioids least frequently.
- Among Ontario patients receiving continuous methadone maintenance therapy, 18% had overlapping prescriptions for other opioids (most commonly codeine and oxycodone), often for extended periods.
- Ontario patients receiving an opioid prescription within seven days of low-risk surgery were 44% more likely to become chronic opioid users within one year.

ICES scientist Tara Gomes, project lead, ODPRN, sees important work ahead in this high-profile area of drug safety: "We plan to continue monitoring the use and abuse of opioids, to evaluate the effectiveness of Ontario's Narcotics Strategy, and to determine the impact of newer opioid formulations on prescribing and abuse of these drugs. Because we interact directly with the province's Narcotics Advisory Panel, we can contextualize our research to ensure it addresses the key issues that policy makers are grappling with."

TWO DECADES OF IMPACT



THE TOP TEN AREAS WHERE ICES RESEARCH HAS MADE A DIFFERENCE TO PATIENT OUTCOMES AND THE EFFECTIVE DELIVERY OF HEALTH SERVICES – IN ONTARIO AND BEYOND.

THE OVERRIDING CHALLENGE TO....ICES IS TO ENSURE THAT THE RESULTS OF RESEARCH DO NOT LANGUISH ON LIBRARY SHELVES BUT ARE PROMPTLY TRANSLATED INTO CHANGES IN HEALTH POLICIES AND PRACTICES FOR THE BENEFIT OF ALL ONTARIANS.

- DR. JOHN EVANS, FIRST ICES ANNUAL REPORT, 1992

or 20 years, ICES researchers have been providing timely, evidence-based papers and

reports that serve as signposts for health care policy and help practitioners deliver more effective services to patients. ICES recommendations have assisted health care providers across Ontario to identify and narrow variances in practice patterns and patient outcomes. The following is a selection from this vast body of work, grouped into ten key areas of inquiry where ICES has had an impact:

1

HEALTH SYSTEM MEASUREMENT, ACCOUNTABILITY AND PLANNING

In 1994 ICES released its first practice atlas, *Patterns of Health Care in Ontario*, which raised awareness of the challenges facing the province's publicly funded system – and set the standard for future reporting and accountability in this sector. The publication of the atlas (and an updated edition in 1996) contributed to several key initiatives:

- Internal audits were implemented at Ontario hospitals for procedures such as Caesarean sections and appendectomies.
- A multi-stakeholder task force was formed to review hysterectomy practices.

 Recommended hospital closures and consolidations were implemented during the largest hospital restructuring in Canadian history, beginning in 1996.

The Enhanced Feedback for Effective Cardiac Treatment (EFFECT) project – the world's first randomized trial of report cards measuring hospital performance – was launched in 2002 under the guidance of Dr. Jack Tu. The result was a new set of benchmarks for cardiac care, which has led to changes in service delivery and an overall reduction in mortality rates arising from cardiac incidents.

An ICES research team has also verified that patients treated at hospitals with higher spending levels have lower death rates, readmissions and repeat cardiac events. And another team has been instrumental in the implementation of mandatory public reporting on *Clostridium difficile* rates at Ontario hospitals – a policy associated with a subsequent 27% reduction in infections.

2 HEALTH SYSTEM FUNDING

Research and analyses conducted by ICES scientists have helped policy makers negotiate the challenges of maximizing the value of funding dollars and human resources across Ontario's health care system. Researchers have examined the impact of varying payment plans on primary care delivery and looked at how different payment models, based on medical specialty, contribute to cost increases.

ICES scientists and their counterparts at the Ministry of Health and Long-Term Care provided the first accurate picture of Ontario doctors' income levels and how they vary according to medical specialty – information that will help the government better assess remuneration levels.

3 PUBLIC HEALTH

ICES research has contributed to the development of public health policies aimed at protecting and promoting the health of Ontarians while reducing inequities in service delivery.

 A pivotal study on the links between cell phone use and motor vehicle collisions helped lay the groundwork for legislation banning driver cell phone use in Ontario and many other jurisdictions. This work has saved lives and prevented injuries to tens of thousands of drivers – and in Ontario it has yielded

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an estimated direct cost savings exceeding \$200 million since the legislation was introduced.

- The groundbreaking research collected in Neighbourhood Environments and Resources for Healthy Living – A Focus on Diabetes in Toronto demonstrated the impact of local environmental factors – including access to health care, public transit and nutritious food options – on diabetes rates within specific demographic groups such as recent immigrants and the unemployed. Less than a year after the atlas's publication in 2007, the findings were incorporated into a new Ontario Diabetes Strategy.
- In a series of widely referenced papers, ICES scientists documented the varying prevalence of cardiovascular risk factors across a range of community groups, including immigrants, the young and those with low socio-economic status.
- ICES researchers are currently working with Ontario's First Nations and Métis communities to carry out the first comprehensive analysis of health profiles for those communities.

4 APPROPRIATENESS OF CARE

Studies by ICES scientists and their research partners have clarified understanding around the safety, effectiveness and appropriateness of certain medical conditions and procedures. One such study identified which angioplasty patients benefit from drug-eluting stents and which do not – findings that were the basis for Ontario's current restricted coverage policy on stents. Another ICES report highlighted the substantial cost savings that would result from curtailing the excessive use of blood glucose testing strips by individuals with type 2 diabetes.

WAIT TIMES AND PATIENT ACCESS

In 1995, ICES scientists led a landmark study of hospital wait times for coronary artery bypass surgery and their impact on coronary patients. This and other investigations of patient access and processing influenced the implementation of Ontario's Wait Time Strategy, a province-wide initiative to reduce delays in accessing various types of surgeries, as well as hospital emergency services and diagnostic imaging (MRI and CT scans).

ICES researchers have also authored several studies demonstrating the link between socio-economic status and access to health services. Key findings include:

- Ontario infants with complex chronic conditions living in the lowest-income neighbourhoods had a 1.26-fold higher mortality risk and a 1.24-fold higher hospitalization rate than those living in the highest-income neighbourhoods.
- Despite universality of access, cardiac procedures are more readily available to patients of higher socio-economic status.
- Similarly, while access to MRI scans has improved over time, higherincome patients are more likely to receive them.

These studies have provided the necessary quantifiable evidence for policy decisions aimed at improving health care access for marginalized Ontarians.

6 PATIENT SAFETY

ICES researchers have shed light on a range of factors suspected of contributing to unnecessarily high patient mortality rates. One frequently cited study showed that patients with serious medical conditions admitted on weekends were more likely to die in the hospital than those admitted on a weekday. Another study of mortality rates among patients requiring cardiac surgery showed that people waiting for valve operations have a higher risk of death than those waiting for isolated coronary artery bypass graft (CABG) surgery. This led to the creation of provincial guidelines to promote safer queuing policies for non-CABG cardiac procedures.

7 EMERGENCY DEPARTMENT CARE

ICES researchers have helped support the Ontario government's ongoing efforts to improve emergency department (ED) care by studying key performance indicators such as wait times, patient demographics and geographic availability of services.

One study drawing on ICES data showed that lower-volume EDs are twice as likely to overlook acute myocardial infarctions as their highest-volume counterparts. This and subsequent studies highlight 678910

the need to ensure uniform quality across EDs. ICES researchers have also explored the impact of patients with comparatively minor medical concerns on wait times and overcrowding in EDs. What had been a controversial issue was largely resolved when the findings showed a negligible increase in time to first physician contact, as well as length of overall stay for ED patients with more serious conditions.

Another important ICES study examined the impact of overcrowding by studying outcomes on ED shifts with longer wait times, as reflected in longer mean lengths of stay. It demonstrated that among patients deemed well enough to leave the department, shortterm mortality and readmission rates were higher on overcrowded shifts.

8 CHRONIC DISEASE

Comprehensive ICES studies have helped to enhance service planning and improve care delivery for chronic conditions such as asthma, diabetes, arthritis and cardiovascular disease. The value of this type of research will continue to grow as Ontario's aging population puts increased pressure on costly health care resources.

Diabetes has been the focus of many ICES studies, as well as two comprehensive research atlases. These have provided evidence and recommendations critical to the government's efforts in combating what has become a growing diabetes epidemic in Ontario and across Canada. One study pointed to the importance of treating a range of diabetes risk factors – beyond blood sugar control – to help prevent coronary disease. And an influential article revealed that age- and sex-adjusted diabetes prevalence increased by 69% in Ontario between 1995 and 2005.

A series of papers by ICES researchers measured the impact of heart failure on Ontario's health care system and explored factors that contribute to poor patient outcomes after discharge from EDs. These studies influenced the development of practice protocols to help reduce unnecessary hospital admissions for heart conditions.

9

HEALTH TECHNOLOGY

New and evolving medical technologies offer great promise for patients, but they can also be expensive and challenging to implement. Research conducted under the aegis of ICES has helped to measure the clinical effectiveness of several key technologies, shedding light on the clinical contexts in which they are deployed and their geographic dispersion across the province.

In collaboration with the Cardiac Care Network of Ontario, ICES researchers have conducted extensive analysis on the use of implantable cardiac defibrillators (ICDs), drawing on the Ontario ICD registry, which is maintained at ICES. These studies have shown a higher rate of post-implementation complications than were reported in clinical trials. Another study of positron emission tomography (PET) scanning raised doubts about the technology's value and led to the drafting of a published report for the provincial health ministry's Committee on Technical Fees. This report influenced the government's subsequent decision to collect appropriate data on clinical effectiveness before deciding if a new technology should be implemented.

10 DRUG SAFETY AND EFFECTIVENESS

Drug therapy continues to be one of the fastest-rising health care expenditures in Ontario. ICES researchers have investigated the utilization patterns and potential risks of many prescription drugs after they've been introduced to the public, providing policy makers with vital evidence-based insights. Key findings include the following:

- Spironolactone, a diuretic drug prescribed to treat heart failure, was found to greatly increase the occurrence of a dangerous blood electrolyte abnormality in patients who began treatment therapy without special attention to risk.
- Bisphosphonates a class of drugs sold as Fosamax, Actonel or Didrocal – are effective in preventing osteoporosis-related hip fractures. However, women taking these medications for more than five years were found to have a 2.5-fold increased risk for rare fractures of the femur than short-term users.

For more examples of ICES research in this area, see "Focus on Drug Safety" on page 24.



ICES SATELLITES: GROWING THE RESEARCH NETWORK

ith the opening of its first satellite site at Queen's University in 2007, ICES extended its geographical reach, giving more researchers access to valuable health system data while gaining their unique expertise and additional sources of information. That evolution has continued, as two more satellites have joined the network – and others are on the way.

To analyze how effectively health services were being delivered across Ontario, the first cohort of ICES scientists had unique access to a wealth of administrative and diagnostic data collected at a secure site in Toronto. For many years, however, no researchers working in other parts of the province could tap into that rich repository of information.

Strict data security and privacy policies, established in consultation with the Ministry of Health and Long-Term Care, dictated that all ICES databases had to be housed and accessed at a single facility on the campus of the Sunnybrook Health Sciences Centre in north Toronto. Even as its vast holdings of deidentified health records grew into one of the largest such collections in the world, ICES could not share data with researchers beyond its physical campus.

SHARING A VALUABLE RESOURCE

In the early 2000s an initiative to expand data access geographically, spearheaded by then-CEO Andreas Laupacis, proposed the establishment of secure ICES satellite sites at strategically selected locations across Ontario. In this new model, researchers at remote sites would be able to launch unique studies and collaborate with colleagues at the main ICES facility and other satellites. The expanded structure would build greater capacity for policy-relevant health services research throughout the province. It would also support the development and mentoring of more research fellows and students in the field.

This vision of a broader, more inclusive ICES was made possible by changes to the *Personal Health Information Protection Act* (PHIPA), which had been passed by the Ontario government in 2004 to set parameters for the use and distribution of health-related data. With subsequent amendments to the law, ICES, under specifically defined circumstances and with proper security protocols in place, could now share its data holdings with approved stakeholders.

In the spring of 2006, as part of its contract renewal discussions with the provincial government, ICES proposed to establish satellite sites at each of



Ontario's six medical schools. The Ministry of Health and Long-Term Care endorsed the proposal in principle, and planning got under way to establish the inaugural ICES satellite at Queen's University.

LAUNCHING THE FIRST SATELLITE

At every step in the journey to creating a new remote facility, the ICES team consulted closely with the Office of the Information and Privacy Commissioner/ Ontario. "We engaged with commission staff throughout the process," recalls Terri Swabey, now senior director of research delivery at ICES. "We gave regular presentations on planning, technology and security specifications to ensure that the implementation was done in a manner that met their requirements. It was more than just setting up a secure, private facility; we had to create an environment that replicated ICES best practices. That meant ensuring that the satellite building didn't allow any unrestricted access. It also meant hiring and training staff who met ICES standards, and making sure that local administration procedures were aligned with our policy requirements."

Those requirements dictated that ICES could not duplicate its data holdings at the satellite location but instead would offer access through secure lines via specially equipped workstations. Not only does this arrangement greatly reduce the security risks associated with data transfer, it also ensures that researchers are always working with the most accurate and up-to-date information.

When the new satellite - dubbed ICES@Queen's opened in 2007, researchers at one of Canada's leading universities welcomed the immediate access to a rich reserve of data that they previously could only access by visiting Toronto. Today ICES@Queen's has 10 data terminals linked directly to the main server at ICES headquarters (now called ICES-Central) on the Sunnybrook campus. The 15 scientists at the Queen's satellite represent a broad range of interests and disciplines, and their collective efforts - supported by a cadre of staff and students - have greatly enriched research output while contributing to the wider discourse around health services policy and practice. For instance, in 2011 Dr. Christopher Simpson, an ICES@ Queen's scientist, was named chair of the Wait Time Alliance, a national group of 14 medical and surgical specialty societies who have come together to reduce delays in access to patient care.

EXTENDING THE IMPACT

Two more satellites have since been added to the ICES network: one at the University of Ottawa (ICES@ uOttawa) in 2010, and another at the University of Toronto (ICES@UofT) two years later. A fourth site at Western University (ICES@Western) is scheduled to open by the end of 2012, and discussions are well under way to add a fifth at McMaster University in 2013. These additional satellites will further extend the breadth of research opportunities and areas of specialty across the ICES network (see sidebar on page 33).

Terri Swabey has seen the synergies grow quickly between the various sites: "As we engage scientists across our network, we have more opportunities to bring together different types of data and to encourage valuable partnerships and research collaborations." At the same time, the move to a multi-site model has presented a few challenges. Scientists and staff have worked hard to ensure that researchers at the satellites and ICES-Central are fully collaborating and not working in silos. Research proposals must be shared across all sites to avoid duplication and ensure optimum allocation of resources.

"Many of our scientists were working together at centres and institutions across Ontario long before ICES physically connected them, so they're used to working together," Swabey explains. "But we have to ensure that our operational processes are seamlessly supporting all work, no matter where researchers are in the province."

ICES planners are building on that past experience as they explore other possible satellite sites – including a potential expansion into northern Ontario, where researchers are often isolated by geography. Wherever ICES extends its network next, there will be further opportunities for learning. "Every time we work with a new partner, we think in a different way about how we do business," says Swabey. "That process helps us raise the bar a little higher for everybody."

David Henry, who became president and chief executive officer of ICES as the first satellite got up and running, emphasizes the broader impact of moving to a multi-site model: "We've got this extraordinary, world-beating concentration of scientific talent in Ontario, but in the past they had to come to Toronto and camp out here at ICES, often staying in a hotel for a few days, just to get a piece of work started. The implementation of satellite sites, by increasing the number of scientists and the breadth of scientific expertise, greatly expands the capacity of ICES to conduct research that contributes to the effectiveness, quality, equity and efficiency of health care and health services across Ontario."



"HAVING WORKED OR STUDIED AT FIVE ONTARIO MEDICAL SCHOOLS, I UNDERSTAND THE PERSPECTIVE OF RESEARCHERS WHO NEED REMOTE ACCESS. THE ORIGINAL ICES MODEL WAS JUSTIFIED AT THE BEGINNING, BUT ADDING SATELLITES HAS MADE IT A TRULY PROVINCE-WIDE INSTITUTION."

> - ANDREAS LAUPACIS ICES PRESIDENT AND CHIEF EXECUTIVE OFFICER, 2000–2006

THE ICES SATELLITE NETWORK

ICES@Queen's

Opened 2007 Director: Dr. Ana Johnson Queen's University campus 15 scientists + staff Areas of focus:

•Cancer

- Population health
- Pharmacoepidemiology
- Cardiovascular disease

ICES@uOttawa

Opened 2010 Director: Dr. Carl van Walraven Civic Campus of The Ottawa Hospital 8 scientists + staff Areas of focus:

- Population and public health • Vaccination
- Capacity building
- Pediatric and prenatal healthBehaviour change in health
- care providers

 Large-scale intervention
- studies

ICES@UofT

Opened 2012 Director: Dr. Geoff Anderson University of Toronto, St. George Campus 25 scientists + staff

Areas of focus:

- Nursing
 Capacity building
- Health human resourcesHealth technology assessment

ICES@Western

Opening late 2012 Director: Dr. Amit Garg Victoria Campus of

- Western University 4 scientists + staff Areas of focus:
- Kidney, dialysis and transplantation
- Surgical outcomes
 Methodology trials and
- biostatistics • Health care management
- Mental health

ICES@McMaster Scheduled for 2013



THE VALUE OF NETWORKING

Researchers across the ICES network have produced ground-

breaking work. A good example is a recent project led by Dr. Doug Manuel, senior scientist at ICES@uOttawa, in collaboration with Public Health Ontario and The Ottawa Hospital Research Institute. The study, which gained national media attention, found that 60% of deaths in Ontario can be attributed to smoking, unhealthy alcohol consumption, poor diet, lack of physical activity and stress. Researchers concluded that overall, Ontarians would gain 7.5 years of life expectancy if everyone were in the healthiest category for all five behaviours.

FOCUS ON: HEALTH EQUITY

ACCORDING TO THE INVERSE CARE LAW FIRST PROPOSED BY BRITISH PHYSICIAN JULIAN TUDOR HART IN 1971, THE **AVAILABILITY OF QUALITY CARE** TENDS TO VARY INVERSELY WITH

THE NEED OF THE POPULATION SERVED. UNFORTUNATELY, ONTARIO HAS NOT BEEN AN EXCEPTION TO THE RULE. Significant health-related inequities persist across Ontario's diverse population, placing a significant burden on patients, their families and the health care system. Most of these differences are related to social factors such as income, education, gender, ethnicity and immigration status.

To address the challenges of inequity, ICES researchers in the early 1990s began using Statistics Canada's National Population Health Survey to link behaviours such as smoking to patterns of health. Statistics Canada subsequently developed a method of dividing Ontario's population into five equal-sized groups by income, ranging from lowest to highest. Using these income quintiles, researchers were able to identify clear socio-economic gradients in terms of access to care, use of services and health behaviours.

In the years since, innovative ICES studies have explored health inequities in relation to a wide range of social determinants, providing evidencebased guidance to policy makers on opportunities for intervention and improvement. A few examples of the work accomplished to date:

Income and Education

 Low-income patients are more likely than their high-income counterparts to be hospitalized for mental health issues, to visit emergency departments for non-urgent issues, and to remain in acute care hospital beds while awaiting transfer to more appropriate levels of care in the community, such as nursing homes.

- According to a 2009 study, if all Ontarians had the same health status as those with higher incomes, 318,000 fewer people would be in fair or poor health, 231,000 fewer people would be disabled, and 3,373 fewer deaths would occur each year in metropolitan areas.
- In the lowest income range, 26% of women and 41% of men die before age 75 – compared to 19% of women and 28% of men in the highest income group.
- In low-income neighbourhoods, children with inflammatory bowel disease (Crohn's disease and ulcerative colitis) are 17% more likely to be hospitalized and up to 80% more likely to undergo surgery.
- While mortality in Ontario diabetes patients declined by more than 30% between 1995 and 2006, people from lower-income neighbourhoods experienced a significantly smaller improvement in comparison to those with greater financial means.
- Socially disadvantaged Ontarians are being prescribed opioids, such as morphine and oxycodone, on an ongoing basis and at doses that far exceed Canadian guidelines. These



drugs can cause death, particularly in high dosages or when taken with alcohol or sedating medications.

- Rates of cardiovascular disease, despite an overall decline in Canada, are increasing among adults under age 50 and those of lower socioeconomic status.
- Although Ontario wait times for magnetic resonance imaging (MRI) have improved since 2004, an ICES study found that wealthy Ontarians are 38% more likely to receive MRI scans than poorer citizens.
- Highly educated Ontarians are more likely to get referred to a psychiatrist than those with less formal education.

Ethnicity and Immigration Status

- Women who have immigrated to Ontario from the Caribbean, Hispanic America or Sub-Saharan Africa face triple the risk of serious preeclampsia during pregnancy than women from industrialized nations.
- Immigrant women have a 24% higher rate of diabetes than their Ontarioborn counterparts.
- Rates of gestational diabetes mellitus (GDM), a common form of pregnancy-related diabetes, are significantly greater among immigrant women from the Middle East and North Africa (1.7-fold), East Asia (2-fold) and South Asia (3.5-fold), compared to Canadian-born women.

- Recent immigrants to Ontario have a 30% lower risk of stroke than longterm residents – which suggests that people who choose to immigrate tend to be healthier.
- One in three South Asian, West Asian and Arab women say they have trouble accessing a doctor to address urgent health concerns. More than 50% indicate that they've not visited a dentist in the previous 12 months.
- In Toronto, only 37% of recent female immigrants receive Pap smears to screen for cervical cancer, despite recommendations that all women aged 18 to 69 be tested every two years.

Gender

A research initiative called POWER (Project for an Ontario Women's Health Evidence-Based Report) - led by Dr. Arlene Bierman, an ICES adjunct scientist and a physician at St. Michael's Hospital - brought a gender-based perspective to examining access, quality and outcomes of care across the province. The study focused on comprehensive indicators for the leading causes of disease and disability and looked at how they varied by sex, income, ethnicity and place of residence. "The health care needs of men and women are different," Dr. Bierman notes in summing up the landmark study. "And among women, health needs vary enormously depending on social factors."

The findings of the POWER study echo those of other ICES research across the spectrum of health equity issues. The common thread is a growing recognition that the needs of diverse communities must be considered explicitly by health care policy makers and practitioners, and indeed by all Ontarians.

"The problem is not a lack of evidence," concludes Dr. Richard Glazier, who leads the Primary Care and Population Health program at ICES. "We need to reduce these inequities in our system in order to improve the quality of care we provide."

Until we actually look at social differences among patients, it's impossible to say if care is equitable or if the system has the proper resources to respond to the varied needs it serves.

DR. RICHARD GLAZIER
 ICES Senior Scientist and Program
 Lead, Primary Care and Population Health

HOW WE DO WHAT WE DO



THE FUNDAMENTAL STRENGTH OF ICES, AS AN ENTERPRISE FOCUSED ON KNOWLEDGE-BUILDING, IS THE QUALITY OF ITS PEOPLE.

any of the research scientists at ICES are also practising clinicians who understand the everyday challenges of health care delivery. Others are methodologists and statisticians whose expertise in analytical methods helps drive leadingedge investigations that have global impact. The wide-ranging work carried out by ICES researchers is organized into six major programs, each guided by strategic priorities for the assessment of health care delivery, patterns of service use, health technologies, drug therapies and treatment modalities. Each program also includes highly

skilled research staff who manage projects, compile data from our administrative data holdings, perform complex statistical analyses, and interpret and document the findings.

Of course, an organization the size of ICES also requires extensive infrastructure and support to shape and sustain research initiatives – with skills and expertise ranging from information security and technology, to partnership development and finance, to media relations and human resources. The ICES executive leadership helps direct everyone's efforts toward realizing the collective vision.

RESEARCH PROGRAMS

CANCER

Program leader: Dr. David Urbach **Research focus:** The delivery of cancer services across the continuum of care from screening for breast, cervix and colorectal cancers to to the advancement of palliation and survivorship. Program scientists are deeply engaged in policy-shaping research that supports the mission and activities of Cancer Care Ontario, including the provincial Colorectal Cancer Screening Program, the Cancer System Quality Index and the Surgical Oncology Program, among other initiatives.

HEALTH SYSTEM PLANNING AND EVALUATION

Program leader: Dr. Astrid Guttmann Research focus:

Clinically trained health services researchers join with experts in statistics, economics, finance and policy analysis to study a broad array of issues, including pay-forperformance and public reporting; end-of-life health care spending; and the development of physician networks and integrated care initiatives. Program scientists examine service quality in emergency departments, long-term care, pediatric facilities and chronic care hospitals.

CARDIOVASCULAR AND DIAGNOSTIC IMAGING Program leader: Dr. Jack Tu

Research focus:

Measuring and improving the quality and effectiveness of cardiovascular care in Ontario, including the treatment of strokes. Among the diverse topics currently under study are ST-seqment elevation myocardial infarction (STEMI), congestive heart failure in the emergency room, the appropriateness of angioplasty procedures, management of transient ischemic attacks and strokes, and addressing risk factors in chronic disease.

KIDNEY, DIALYSIS AND TRANSPLAN-TATION

Program leader: Dr. Amit Garg **Research focus:**

To improve health and health care in Ontario, as well as nationally and internationally, by generating new knowledge across the spectrum from preventing serious and progressive kidney disease, to the optimal delivery of dialysis, to solid multi-organ donation and transplantation. Current research is linked across four themes: acute kidney injury, chronic kidney disease, kidney donation and renal replacement therapy.

CHRONIC DISEASE AND PHARMACOTHERAPY

Program leader: Michael Paterson Research focus:

In the chronic disease area, scientists track the epidemiology of illnesses such as diabetes, arthritis, asthma and obstructive pulmonary disease - over time and across diverse regions and population subgroups. Researchers also examine chronic-disease management strategies in Ontario. In the area of pharmacotherapy. epidemiologic methods are used to examine real-world applications and outcomes for a wide range of drug therapies.

PRIMARY CARE AND POPULATION HEALTH

Program leader: Dr. Richard Glazier Research focus:

The accessibility and effectiveness of primary health care, as well as issues in population health. Researchers are currently examining the performance of primary care reform models; the use of electronic medical records for research and quality improvement; mental health and addictions; measuring the population burden of illness; addressing the causes of ill health; the effectiveness of public health interventions; and injury prevention.

SKILLS AND EXPERTISE

ICES' work is supported by staff with a broad range of expertise:

Application development Business and quality assurance

Communications

Contract administration

Data analysis and biostatistics

Data partnership development

Database administration and development

Decision support

Epidemiology

Facility management Financial analysis and operations

Health data quality

Human resources

Information technology

Media relations

Medical geography

Network administration Privacy

Project management and administration

Public relations

Research coordination Security

Sourcing and procurement

Website design and maintenance

FOCUS ON: **KNOWLEDGE TRANSLATION**

EVEN THE MOST POWERFUL **RESEARCH FINDINGS ONLY GAIN** THEIR FULL IMPACT WHEN THEY ARE IN THE HANDS OF PEOPLE WHO CAN PUT THEM TO GOOD USE. THAT'S WHY COMMUNICATION PLAYS SUCH A VITAL ROLE IN THE ICES STORY. OVER THE PAST TWO DECADES, THE INSTITUTE HAS CREATED MANY DIFFERENT VEHICLES FOR REACHING POLICY MAKERS, PLANNERS, PRACTITIONERS AND THE PUBLIC - AND ICES SCIENTISTS HAVE ALSO ENGAGED DIRECTLY WITH DECISION MAKERS AND **CLINICIANS – ALL TO BRIDGE** THE CRITICAL GAPS BETWEEN RESEARCH, POLICY AND PRACTICE.

In the early years ICES and its research partners produced a range of innovative tools and decision aids to help health care providers and the public arrive at informed treatment decisions. A typical example is *Making Choices About the Removal of My Breast Cancer: What Do I Prefer*? Using plain language in an accessible format, the authors offered women a clear understanding of currently available options.

The first ICES researchers also began producing **working papers** to disseminate findings more quickly, and to share research ideas and policy proposals under development. One such paper attracted wide interest by documenting variations in patterns of mammography use by women's age and place of residence.

Early ICES **briefing notes** provided helpful digests of selected technical reports, research projects and working papers. In addition to positioning current research within the immediate health care environment, the notes offered recommendations for further study on topics such as Coronary Surgery Capacity in Ontario, Mental Health Practices of Ontario Family Physicians and Managing Acute Care Resources.

For a few years, the *ICES Ink* newsletter kept researchers, physicians and the public up to date on "who we are, what we're doing and where we're heading." Each issue included profiles of current research publications and work in progress, as well as the perspective of the CEO and general ICES news.

For 12 years the quarterly newsletter informed provided practising physicians with a peer-reviewed synopsis of the latest clinical information and offered evidence-based options for enhancing the delivery of effective patient care. Articles covered everything from corneal abrasions and toddler toilet training to epilepsy and rheumatoid arthritis. "The uptake of informed extended well beyond the original target audience of primary care physicians," recalls Dr. Diane Kelsall, the newsletter's former editor and now deputy editor, clinical practice, for the Canadian Medical Association Journal. "There was a gap in the knowledge required by health care providers, and ICES filled it with informed."

Before the Internet revolutionized communications, ICES used an automated **fax-on-demand** system to provide supplementary information to the articles in *informed*, as well as many other ICES documents, in response to faxed requests from individuals and organizations.

Launched in 1996, the ICES **website** remains an important vehicle for



highlighting current research projects, presenting new initiatives and summarizing recent media coverage. Providing an easily accessible repository of reports and publications, the site is also an important channel for engaging the interest of prospective ICES scientists, staff, graduate students and research fellows.

In 2006 the ICES Monitoring and Reporting group introduced inTool, a web-enabled database query and reporting platform which was so named for providing instant, interactive information on current research and health measures. With inTool, online users could access aggregated health data on a wide range of topics at various levels: province-wide, by Local Health Integration Network (LHIN) or sub-LHIN and, in some cases, by census division or public health unit. Information was presented by age, sex and income level via dynamically generated graphs and tables, as well as static and interactive maps. Owing to a shift in funding priorities, the last inTool update was posted in early 2010; however, all reports are available online and remain valuable tools for local planning and decision-making across Ontario.

Today ICES research is highlighted in **At A Glance**, a monthly bulletin summarizing recent peer-reviewed publications. Each issue showcases five studies, presenting the rationale and basic methodology for each, along with key findings and the implications for health policy and/or practice. At A Glance is distributed to more than 5,000 readers across Canada.

For the past dozen years, ICES, in collaboration with the Ministry of Health and Long-Term Care and the Canadian Institute for Health Information, has hosted an annual data symposium focusing on the use of health administrative data in planning, policy and research. This one- or two-day event offers plenary, panel and discussion sessions featuring prominent subject matter experts from within ICES and across North America. The symposium attracts a wide range of delegates and provides a unique learning experience for those seeking to expand their horizons in health services research.

ICES constantly seeks new ways of engaging with users of research evidence. Information requests can now be submitted via **Applied Health Research Questions** (AHRQs). The responses from ICES experts inform planning, policy and program development, which in turn help strengthen the Ontario health system. At the same time, ICES has worked to reach a broader public audience through extensive **media coverage** – locally, nationally and around the globe. Journalists regularly turn to ICES as a helpful source of authoritative information and expert perspectives on the important health care issues of the day. And in recent years **social media** have begun to play a key role in quickly conveying research findings to a larger audience. ICES currently has over 1,000 followers on Twitter and an active profile on Facebook.

The platforms and channels have changed dramatically since the earliest ICES papers were mailed and faxed to the world, but the goal remains the same: to get evidence-based insights out to where they can have a positive impact on the delivery of health services.

66

Last year, publications by ICES researchers yielded an unprecedented level of public interest, with more than 2,100 media hits in Ontario, across Canada and internationally.

SUSAN SHILLER
 ICES Communications Director

COLLABORATION

THE KEY TO RESEARCH EXCELLENCE

ollaboration is the key to driving successful research initiatives and ultimately achieving positive change. Two relationships have been particularly important: The Ontario Ministry of Health and Long-Term Care has been a major funder of ICES and has managed that relationship over 20 years without seeking to influence the direction or findings of ICES research; and Sunnybrook Health Sciences Centre has been a strong supporter of ICES and has provided us with a home for 20 years.

To expand the scope and impact of health services research in Canada, ICES has forged partnerships across a diverse network of adjunct scientists, stakeholder organizations and representatives of provincial and national health care organizations. In addition, many ICES scientists serve on research committees, programs and task forces at the local, provincial, national and international levels. Some of the ICES partners:

FEDERAL GOVERNMENT

Canadian Institute for Health Information Canadian Institutes of Health Research Health Canada Public Health Agency of Canada Statistics Canada

PROVINCIAL GOVERNMENT

Health Quality Ontario Ontario Ministry of Children and Youth Services Ontario Ministry of Community and Social Services Ontario Ministry of Transportation Public Health Ontario

NATIONAL ORGANIZATIONS

Canadian Diabetes Association Canadian Drug Safety and Effectiveness Research Network Canadian Network for Observational Drug Effect Studies Heart and Stroke Foundation of Canada Networks of Centres of Excellence

PROVINCIAL ORGANIZATIONS

Canadian Cancer Society, Ontario Division Cancer Care Ontario Cardiac Care Network of Ontario Chiefs of Ontario Health System Performance Research Network Heart and Stroke Foundation of Ontario Métis Nation of Ontario Ontario Drug Policy Research Network Ontario Hospital Association Ontario Institute for Cancer Research

LOCAL ORGANIZATIONS

Baycrest Centre for Geriatric Care Centre for Addiction and Mental Health Institute for Work and Health Local Health Integration Networks Ottawa Hospital Research Institute St. Michael's Hospital Sick Kids Research Institute Sunnybrook Research Institute University Health Network University of Toronto Women's College Research Institute

PARTNERING WITH ABORIGINAL PEOPLES

In 2009, ICES began collaborating with the Métis

Nation of Ontario (MNO) to produce a series of chronic disease surveillance reports. These reports gather Métisspecific data on incidence, prevalence, health services use and outcomes for a number of widespread chronic conditions, including diabetes, cancer, and respiratory and cardiovascular diseases. A study on mental illness and addictions is currently under way. The findings are helping to define the health priorities of the Métis people and will inform the creation of health programs tailored to their needs.

More recently, in 2012, ICES entered into a data governance agreement with the **Chiefs of Ontario** (**COO**), a coordinating body for 133 First Nations communities across Ontario. Under this agreement, ICES is empowered to carry out health-related analyses on behalf of the COO and the communities for whom it advocates, collecting and using First Nations data in a manner that respects the fundamental principles of OCAP: ownership, control, access and possession. To date, the partnership has investigated on-reserve incidence and patterns of care for cancer and physical injuries.

"The common thread running through all of our work with Aboriginal communities is trust," says David Henry, chief executive officer of ICES. "We don't unilaterally decide where research should focus, with an eye on future publication. We ask community leaders to tell us what they want to investigate, and together we determine whether the data resources exist to make it happen. Put simply, we're working for them."

FOCUS ON: CARDIOVASCULAR DISEASE

"THROUGH GREAT LEADERSHIP, THE ACADEMIC FREEDOM TO PURSUE A VISION, UNIQUE DATABASES, A DEDICATED TEAM AND MULTIDISCIPLINARY COLLABORATION, OUR **CARDIOVASCULAR DISEASE RESEARCH PROGRAM** HAS HAD A SIGNIFICANT IMPACT ON THE QUALITY OF CARE IN ONTARIO."

– DR. JACK TU

ICES Senior Scientist and Canada Research Chair in Health Services Research

1993: David Naylor's early investigation of wait times for bypass surgery leads to the creation of the Cardiac Care Network of Ontario.

1990s: Confidential and then public "report cards" developed at ICES show hospitals how their patients fare after cardiac surgery. This work is later expanded to include heart attacks and angioplasty.

1999: Dr. David Alter publishes the first study linking socio-economic status with access to specialized cardiac services in Ontario. Higher neighbourhood income levels correlate to shorter wait times for catheterization, increased use of coronary angiography and lower mortality one year after acute myocardial infarction. 2001: The Canadian Cardiovascular Outcomes Research Team (CCORT) is formed. Led by Dr. Jack Tu, it would grow to 30 cardiovascular experts from six provinces. Over the next decade, CCORT's work leads to significant improvements in cardiac care across Canada. Also in 2001, the Registry of the Canadian Stroke Network is developed. Now one of the largest in the world, the registry has helped support the development of the Ontario Stroke System, a network of partners who deliver evidence-based stroke care and prevention programs. 2002-2006: The Canadian Cardiovascular Atlas - compiled from a series of 24 articles by CCORT published in the Canadian Journal of Cardiology - is a comprehensive report card on patterns of cardiovascular health and care delivery across Canada's health regions, investigating geographical variations in everything from cardiac risk factors to survival rates following cardiac surgery. 2004: An influential article by Dr. Tu in the New England Journal of Medicine highlights the need for privacy legislation and policies allowing "minimal risk" observational research and the collection of registry data without written consent.

2005: Enhanced Feedback for Effective Cardiac Treatment (EFFECT) – a population-based, randomized

trial evaluating the "real-world effectiveness" of hospital report cards - demonstrates their value. Among Ontario hospitals that received early feedback in the form of public report cards, more than half launched initiatives to improve the quality of care, and nearly 25% changed their policies to allow emergency physicians to give appropriate patients clot-dissolving drugs rather than waiting for a specialist. 2007: Under the leadership of Dr. Douglas Lee and Dr. Tu, the Ontario Implantable Cardioverter Defibrillator (ICD) Database is established at ICES. Clinical data collected at 18 Ontario centres over a five-year period informs improvements in patient care. 2012: Dr. Lee develops a computerbased algorithm that calculates individual patients' risk of death from heart failure for use in hospital emergency departments. Future mobile and web-based adaptations will help emergency physicians to assess patient risk in real time.

Next: "There are many unanswered questions about cardiovascular care before and after patients leave the hospital," says Dr. Tu, who is working with 21 researchers at five Ontario universities to measure the quality of outpatient cardiovascular care as part of a new CIHR team grant initiative.





IT'S ALL ABOUT DATA

THE ICES DATA REPOSITORY IS A VAST RESOURCE OF DE-IDENTIFIED AND LINKABLE HEALTH DATA THAT SETS A GLOBAL STANDARD FOR QUALITY, COMPREHENSIVENESS, FLEXIBILITY AND SECURITY. IT PROVIDES A CRITICAL SOURCE OF KNOWLEDGE FOR HEALTH SERVICES RESEARCH, AS WELL AS FOR HEALTH POLICY, PLANNING AND EVALUATION IN ONTARIO. **CES is privileged to have one of the world's largest holdings of individual-level**, **de-identified and linkable health and health-related data.** Encompassing the health services records of nearly 13 million people (as of 2012), this vast data resource provides the foundational evidence for vital research in support of more effective health system policy, planning and evaluation.

Most of the core data sets are provided through sharing agreements with three key organizations – the Ontario Ministry of Health and Long-Term Care, the Canadian Institute for Health Information and Statistics Canada – whose willingness to make data available continues to be critical for virtually all ICES research.

ICES is designated as a prescribed entity in Ontario under the *Personal Health Information Privacy Act* (PHIPA). This allows ICES to collect and use administrative data for the purposes of monitoring and evaluating the provincial health system. ICES policies, practices and procedures for using data are reviewed and approved on a regular basis by the Office of the Information Privacy Commissioner/Ontario.



The data made accessible to ICES researchers reflects Ontarians' day-to-day interactions with the health care system. It includes physician billings to the Ontario Health Insurance Plan, drug claims to the Ontario Drug Benefit Program, discharge summaries of hospital stays and emergency department visits, and more. Because these data sets have been gathered for administrative purposes, ICES is spared the prohibitive cost of collecting records from original sources.

LINKING AND SECURING INFORMATION

"What makes ICES unique are our data holdings and the ability to link to data anonymously at the individual patient level," says Karey Iron, director of data partnerships and development. "The linkage of data sets maximizes the questions that we are able to answer."

Linking records is achieved using the ICES key, a unique, anonymous identifier that remains constant across multiple data sets. Analysts can link diverse data to see, for example, how many heart attack sufferers were hospitalized and treated in a timely fashion, as well as who had subsequent appointments with specialists and were prescribed appropriate medications on a follow-up basis. The same study might also integrate updates on outcomes recorded five or 10 years later. "It's that ability to link data and create a story over time that really accounts for the richness of the ICES data resource," says Iron.

All data is de-identified and stored on servers housed within a closed computing system at ICES-Central, on the campus of Sunnybrook Health Sciences Centre in Toronto. Researchers are allowed access to new information only after it has been de-identified.

THE EVOLUTION OF DATA COLLECTION

The biggest challenge in the early days of ICES was the sheer mass of data to be inputted and administered. "We were getting roughly 11.2 million records a year," recalls Don DeBoer, now privacy officer for ICES@UofT, the satellite facility at the University of Toronto. "Today that seems like a small data set, but back then it was quite a challenge to store that much information, and for researchers to access it."

A year's worth of physician claims, for example, would come to ICES on a set of eight 2,400-foot magnetic tapes that had to be entered into the database by specially trained staff members. "If there was a glitch three-quarters of the way through the eighth tape," DeBoer says, "the whole year would be trashed and they'd have to resend it."

In addition to the challenges of those initial years, analysts were not yet able to link different data sets, which meant that researchers could only draw from one database at a time – a cumbersome process that restricted their scope of inquiry. Today, nearly every ICES study draws from multiple data sets.

Although the ICES data resource has expanded significantly over the years, the analytics team has resisted imposing too rigid a structure on the holdings. "The simplicity of our system makes it easier to construct a data set for a research project," says Karey Iron. "Once we know what we want to do, it's not difficult to pull out the data that we want."

ICES analysts have developed programs that standardize ways of identifying groups of patients to ensure that data is clean, accurate and capable of yielding the required information. These programs are applied across research projects to ensure consistency of programming and of concepts drawn from the data.

A CONSTANTLY GROWING RESOURCE

Over the past two decades, ICES has steadily expanded its data resource by collecting additional data sets from organizations such as the Cardiac Care Network of Ontario and Cancer Care Ontario, as well as from hospitals, physicians, laboratories, pharmacies and long-term care facilities.

Data-sharing agreements are developed on an individual basis with other provider organizations, whose new data is de-identified before being integrated and made linkable within the ICES resource. In some cases, new data is collected from scratch or from sources outside the health sector, which requires extra vigilance to ensure that its integration is compliant with Ontario privacy legislation. Expert teams of data quality and data management specialists at ICES work with staff at the partner agency to securely transfer data into the ICES environment.

ICES also participates in health informatics projects for which data is input directly at the bedside. These include Health Outcomes for Better Information and Care (HOBIC); the Dialysis Measurement, Analysis and Reporting (DMAR) system; and the Ontario Implantable Cardioverter Defibrillator (ICD) database. For all such initiatives, data is gathered on the front lines of health care (via the ICES computing environment) and then used by service providers for clinical and quality improvements. As always with ICES, data from these sources is de-identified before being made linkable within the central resource.

This constant expansion in the breadth of data holdings lends an added dimension of relevancy to ICES research, helping to ensure that studies and atlases continue to have a meaningful impact on policy and practice in the Ontario health care system.

APPLYING SCIENTIFIC METHODS

"What sets ICES apart is the availability of large quantities of population-based data, together with a collection of clinically trained investigators asking important, relevant questions for policy-making and clinical practice," says ICES senior scientist Peter Austin.

ICES scientists, analysts and staff apply rigorous scientific methods as they work to provide evidence for improving the effectiveness, quality, equity and efficiency of health care and services in Ontario. "In the past 10 years," Austin says, "there have been two major advances in methodology. The first is the widespread use of propensity score methods for estimating the effects of treatments, interventions and exposures on patient outcomes. And the second is the development of multilevel or hierarchical regression models for analyzing data, in which patients are clustered within hospitals or within physician practices."

OFFLINE CHART ABSTRACTION (OCA)

Some ICES studies require more detailed information, such as laboratory and diagnostic test results, patient clinical health status, well-being and social health determinants, or data on patients with particular health conditions. This detailed clinical information is often found in documents stored at health care institutions or in physicians' offices across Ontario.

Such data is gathered on-site by trained specialists using laptops equipped with an ICES-developed application called Offline Chart Abstraction (OCA). Launched in 2010, OCA uses encryption and other safeguards to ensure that all data collected – whether stored on hard drives or transmitted electronically – is unreadable to anyone but authorized project personnel. ICES professionals are now further developing the OCA application to enhance its efficiency, usability, data integrity and security.

CD-LINK

In 2010, ICES scientist Dr. Craig Earle launched the Ontario Cancer Data Linkage Project, or cd-link, a joint initiative of the Ontario Institute for Cancer Research and Cancer Care Ontario's Health Services Research Program. This technological innovation encrypts relevant data sets onto compact discs that are then shared with investigators at Ontario academic institutions engaged in cancer research and treatment. Approved investigators work with ICES analysts to create de-identified data sets, ensuring the confidentiality of all patient records used in the research process.

WHAT TYPES OF DATA DOES ICES HOLD?

1. HEALTH SERVICES ADMINISTRATIVE DATA

- Physician billings
- Prescription drug claims for those 65 and older
- Inpatient hospital discharges, emergency and ambulatory care visits
- Home care and rehabilitation claims
- Long-term care visits

2. PEOPLE AND GEOGRAPHY

- Population estimates
- Canada census profiles
- Death records
- · All Ontarians eligible for health care benefits

3. SPECIAL COLLECTIONS

- Registries (cancer, stroke, cardiac care)
- First Nations/Métis
- Developmental disabilities
- Federal immigration information

4. DERIVED CONDITIONS

- Diabetes
- Hypertension
- Chronic obstructive pulmonary disease
- Asthma
- Acute myocardial infarction
- Congestive heart failure
- Inflammatory bowel disease

5. SURVEY DATA

Health surveys

6. CLINICAL DATA

- Patient information collected with consent in primary clinical studies
- Supplementary clinical data from individual hospitals and other institutions

7. CHART ABSTRACTION DATA

• Information on processes and quality of care collected directly from patients' charts

FOCUS ON: MENTAL HEALTH AND ADDICTIONS

WHILE STUDIES OF **MENTAL HEALTH AND ADDICTIONS** ARE

NOT NEW TO ICES, THEY GAINED A MUCH STRONGER FOCUS WITH THE LAUNCH OF A FORMAL RESEARCH INITIATIVE IN 2009. THIS COLLABORATIVE EFFORT WILL PURSUE RESEARCH EXCELLENCE IN THE AREAS OF MENTAL HEALTH SERVICES AND POPULATION HEALTH – WITH THE GOAL OF PRODUCING DATA-DRIVEN, EVIDENCE-BASED, POLICY-RELEVANT FINDINGS.

How we got here

Early 1990s: Work on mental health and addictions is spread over several ICES programs and scattered across Ontario. The provincial Ministry of Health and Long-Term Care (MOHLTC) has no information on who is using mental health services. Early research data is gleaned from patient self-reporting.

1996: Scientists Paula Goering and Elizabeth Lin author a chapter in Patterns of Health Care in Ontario (2nd Edition) on levels of need and variations in the use of mental health services. Early 2000s: Through data validation studies, ICES researchers establish that patient visits related to mental health can be identified using data from the Ontario Health Insurance Plan. 2009: The ICES Mental Health and Addictions (MH&A) initiative led by Drs. Paul Kurdyak and John Cairney, is launched to create a strategic collaboration of scientists and define a long-term program of mental health research. In the same year, ICES holds a pivotal symposium to set research priorities among mental health researchers and policy makers. 2010: The MH&A Data Working Group chaired by Drs. Lin and Kurdyak is established to create a compendium of definitions for mental health and addictions research, and to help researchers navigate the Ontario Mental Health Reporting System. 2011: ICES contributes to a key report of the Ontario Mental Health and Addictions Knowledge Exchange Network – Creating Together: Co-Creating a Mental Health and Addictions Research Agenda for Ontario.

Also in 2011, the MOHLTC releases a comprehensive 10-year mental health strategy, *Open Minds, Healthy Minds,* with a special focus on children and youth for the first three years. ICES is commissioned to create an evaluation framework for this child and youth strategy and develop a baseline

outcomes/indicators scorecard. Dr. Astrid Guttmann joins Drs. Kurdyak and Cairney in leading the multidisciplinary Mental Health and Addiction Scorecard and Evaluation Framework team.

Where we are going

"Mental health is not a homogeneous discipline, so our research is appropriately following a more heterogeneous strategy," explains Dr. Lin, a scientist at both ICES and the Centre for Addiction and Mental Health (CAMH). As a rich resource to support emerging themes in mental health and addictions, the research team is developing a Child and Youth Linkable and De-identified Data Repository – an integrated database comprised of record-level data from multiple sectors, including education, and children and youth services.

At the same time, ICES can make important contributions to the larger conversation around policy in this critical area. "When our work shows gaps in quality of care, I would like to see it spark a debate about how best to utilize resources going forward," says Dr. Kurdyak, a psychiatrist and ICES scientist. "I think we need to start pushing the provision of mental health and addiction services into something closer to a system of care."

SOUND ADVICE

THE ICES BOARD OF DIRECTORS BRINGS TOGETHER RECOGNIZED EXPERTS IN HEALTH, LAW, BUSINESS, ACADEME AND OTHER SECTORS TO ACT AS A SOUNDING BOARD AND PROVIDE VALUED COUNSEL ON ALL ASPECTS OF ICES POLICY AND STRATEGY.

ince ICES was founded, the Board has provided leadership and vision to guide the organization's steady evolution and expansion. Board members regularly advocate to

funding agencies and in public forums to help ICES realize its goals. These trusted advisors also oversee and approve major decisions on financial matters and resource allocation, and are accountable to stakeholders for performance.

The Board's responsibilities include establishing broad organizational policies and objectives; selecting, appointing, supporting and reviewing the performance of the CEO; ensuring the availability of adequate financial resources; and approving annual budgets in support of the ICES strategic plan.

The ICES Board meets five times a year, while the Board sub-committees meet on an as-needed basis to focus on priorities such as governance, finance, audit and risk. The Scientific Advisory Committee, launched in 2011, will meet annually to advise on the quality and direction of ICES research.

Directors are selected for their expertise and commitment to the ICES mandate. Current Chair Michael Baker, Professor of Medicine at the University of Toronto, felt "privileged and honoured" to assume the position in June 2012: "I have been well aware of ICES for a long time and have watched it grow into a unique powerhouse and a national treasure."

In the view of its new Chair, the ICES Board has two key strategic goals for the immediate future: to help raise the public profile of ICES in Ontario and across Canada, and to solidify sources of funding to ensure a stable financial platform moving forward.

"Most of our funding is from tax-supported sources," Baker explains. "The more taxpayers and the general public understand the value of ICES, the more elected officials will maintain their support of our work."

ICES BOARD OF DIRECTORS 2012

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TWENTY YEARS FROM NOW, ICES WILL BE ...



...HELPING ONTARIANS CONDUCT THEIR OWN **ANALYSES TO BETTER INFORM THEIR** UNDERSTANDING OF HEALTH."

- David Henry

"....FINDING **INNOVATIVE WAYS** ΤΟ ΜΑΚΕ DATA **AVAILABLE MORE BROADLY – LETTING** MORE BRIGHT **MINDS SHED LIGHT** ON IT." - Ian Hux

"...continuing to be an important contributor to the process by which **Ontario organizes, manages and pays** for health services."

– Jack Williams

'...TAKING RICH SOCIAL DATA - FROM THE JUSTICE SYSTEM, FROM THE SCHOOLS - AND LINKING IT WITH HEALTH CARE DATA."

- Andreas Laupacis

"...looking at the broader determinants of health, such as education, social services, community services, nutrition and the environment." - Vivek Goel

> "...linking additional data sets - census, education. social services, transportation - to become more of a social, health and economic policy shop." - Rick Glazier

"....USING DATA AND **RESEARCH TO HELP FRONT-LINE PROVIDERS UNDERSTAND, IN REAL TIME, THEIR OWN PRACTICES AND THE CARE THEY DELIVER."** - Michael Schull

"...ACCESSING ELECTRONIC **HEALTH RECORDS AND LINKING** TO DATA ON IMAGING, GENOMICS, NURSING, LAB TESTS AND OTHER SOURCES OF RICH CLINICAL **INFORMATION.**"

- Thérèse Stukel

"...EXTENDING PURELY HEALTH SERVICES RESEARCH TO INCLUDE GREATER COLLABORA-TION IN THE SOCIAL SCIENCES. BEHAV-IOURAL SCIENCES AND GENETICS." – Baiju Shah

"...sustaining the underlying spirit of ICES – applying scientific rigour to health policy issues." – Susan Bronskill



"I AM HUMBLED BY THE BRILLIANCE AND COMMITMENT OF ALL THOSE WHO, OVER THE COURSE OF TWO DECADES, HAVE NURTURED ICES INTO THE REMARKABLE ORGANIZATION IT IS TODAY."

- David Naylor, founding Chief Executive Officer

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