

HEALTH LAW IN CANADA



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UNIVERSITY OF TORONTO
DALLA LANA SCHOOL OF PUBLIC HEALTH

Health Data Protection Law in the Era of Big Data:

Risks and Opportunities for Modernization

Conference: 8:30 am – 5:00 pm

Cocktail Reception: 5:00 pm – 6:00 pm

Location: University Club of Toronto, 380 University Ave.

Conference Objectives:

The integrated single payer health system model in Ontario and other Canadian provinces can be the foundation for world-leading learning health care systems bolstered by advanced analytics, including AI. In the era of big data, many individuals and organizations are calling for greater access to data including health care providers, researchers, patients, private sector organizations and policy and decision makers. Key questions include: How can we increase the benefits derived from data while maintaining strong privacy protections and public trust? What can we do already (under existing legislation)? How could the *Personal Health Information Protection Act, 2004* (PHIPA) and the *Freedom of Information and Protection of Privacy Act* (FIPPA) be modernized for the benefit of the patient? This conference will bring diverse experts together for structured dialogue aimed at articulating a way forward for modernization of Ontario's data protection legislation.

Please tweet using our hashtag: #ONDATALAW

PROGRAM

8:30 - 9:00 AM Breakfast and Registration

9:00 - 9:10 AM Welcome and Review of Objectives for the Day

Rosario G. Cartagena, Deputy Editor-in-Chief, *Health Law in Canada*; Adjunct Lecturer, University of Toronto's Institute of Health Policy, Management and Evaluation; and Chief Privacy and Legal Officer, ICES

Alison Paprica, VP, Health Strategy and Partnerships, Vector Institute, Assistant Professor (status), IHPME

9:10 - 9:30 AM Opportunities for Improving Health Data Governance in the Era of Big Data – A Canadian Perspective

Eric Sutherland, Executive Director, Data Governance Strategy, CIHI

9:30 - 10:00 AM Summary of Preliminary Findings from MOHLTC Engagement with Stakeholders on Data governance and Privacy

Introduction: Gillian Kafka, Managing Editor, Health Law in Canada

Michael Hillmer, Executive Director, Information Management, Data and Analytics, Ministry of Health and Long-Term Care

10:00 - 10:20 AM Morning Health Break

10:20 - 10:50 AM Data Access: Moving Towards an Integrated Future

Introduction: Maria Eugenia Brunello, Managing Editor, Health Law in Canada

John Roberts, Chief Privacy Officer and Archivist of Ontario, Ministry of Government and Consumer Services

10:50 - 11:10 AM What We Can Do Now: (i) Harmonization of Data Sharing Agreements and (ii) De-Identified Sample of a Data Set Concept

Introduction: Michele Warner, Managing Editor, Health Law in Canada

Alison Paprica, VP, Health Strategy and Partnerships, Vector Institute

11:10 - 11:40 AM IPC perspective on Data Integration

Introduction: Simmie Palter, Managing Editor, Health Law in Canada

David Goodis, Assistant Commissioner (Policy and Corporate Services), Office of the Information and Privacy Commissioner of Ontario

11:40 AM - 12:40 PM Lunch Break

12:40 - 1:20 PM Case Study 1 – Using Prescribed Entity and Prescribed Registry Data for Health Care Delivery or Public Health Management

Moderator: Jennifer Gibson, Director, University of Toronto Joint Centre for Bioethics Sun Life Financial Chair in Bioethics

Amit Garg, Professor, Medicine, Epidemiology & Biostatistics, Western University

Michael Bowmile, Senior Legal Counsel, CCO

Craig Lindsay, Patient Advisor

1:20 - 2:00 PM Case Study 2 – Partnering with the Private Sector to Provide Patients with Access to Their Own Data

Moderator: Michael Schull, CEO ICES

Huda Idrees, Founder & CEO, Dot Health

Bonnie Freedman, Counsel, BLG

Sachin Aggarwal, CEO, Think Research

Tara Kiran, Family Physician, St. Michael's Hospital Academic Family Health Team and Fidani Chair in Improvement and Innovation, University of Toronto

Frank Gavin, Board Member, Citizen Engagement Council at CHILD-BRIGHT National SPOR Network, Canadian Institute of Health Research

2:00 - 2:40 PM Case Study 3 – Hospitals Sharing Real Time Data to Enable AI Studies That Involve More Than One Site

Moderator: Lydia Lee, Partner and National Leader, CIO Advisory Services and Digital Health, KPMG

Muhammad Mamdani, Director, Li Ka Shing Centre for Healthcare Analytics Research and Training (CHART)

Mary Jane Dykeman, Partner, DDO Health Law

Emily Nicholas, Director of Health Engagement and Communications at Reframe Health Lab

2:40 - 3:00 PM Afternoon Health Break

3:00 – 3:40 PM

Case Study 4 – Involving Regulators, Researchers and Care Providers in Developing and Refining Adaptive Regulation for New Technologies

Moderator: Carole Piovesan, Lawyer, AI Lead and Co-Lead of the National Cybersecurity, Privacy and Data Management Group, McCarthy Tetrault LLP

Pam Snively, VP, Chief Data & Trust Officer, TELUS

Sheryl Groeneweg, Director General, Innovation, Science and Economic Development (ISED)

Frank Rudzicz, Associate Scientist, Vector Institute

3:40 - 4:30 PM

Case Study 5 – Learning from New Brunswick’s Success With Legislation That Allows for the Collection and Use of Health AND Non-Health Data

Moderator: Terry Sullivan, Professor and Senior Fellow, IHPME, DLSPH, University of Toronto and Adjunct Professor in the Department of Oncology at McGill University

The Success Story

Ted McDonald, Director of NB-IRDT, Professor in Economics and Academic Director of the New Brunswick Research Data Centre

James Ayles, Director Health Analytics, New Brunswick Department of Health

John Calhoun, Economist, Policy, Research and Labour Market Analysis, Department of Post-Secondary Education, Training and Labour, New Brunswick

Implementation in Ontario

Daniel Fabiano, Partner, Fasken Martineau DuMoulin LLP

Charles Victor, Senior Director, Strategic Partnerships and External Services, ICES

Kaelan Moat, Managing Director, McMaster Health Forum

4:30 - 4:50 PM

Lessons Learned, Way Forward and Closing Remarks

Lessons Learned Today

Adalsteinn Brown

Dean and Professor, Dalla Lana School of Public Health

A Way Forward

Dr. Sacha Bhatia, Cardiologist

Director, Women’s College Hospital Institute for Health System Solutions and Virtual Care

4:50 - 5:00 PM

Closing Remarks

Eric Sutherland & Rosario G. Cartagena

5:00 PM

Cocktail Reception

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Details:

Our goal is to bring policymakers, healthcare professionals, data holding organizations, regulators, academics, lawyers, trainees and other stakeholders together to learn through presentations and case studies and have structured dialogue about modernizing Ontario's data protection legislation. Attendees at the conference will represent key stakeholders in the province.

This event is by invitation only. There is no registration fee. Individuals requesting a certificate for six (6) hours of continuing legal education will be charged \$200. We are unable to reimburse travel costs.

If you would like Continuing Legal Education (CPD) credit, please purchase a ticket at:

<https://www.eventbrite.com/e/health-data-legislation-in-the-era-of-big-data-tickets-55141590983>

To contact us:

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CONFERENCE ACKNOWLEDGEMENTS:

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The goals of Health Law in Canada are to:

- (1) increase diversity in authorship and encourage collaborations;
- (2) encourage diverse readership across healthcare, legal and government/policy sectors;
- (3) stimulate innovation in the health sector;
- (4) ensure relevance to the health sector; and
- (5) include content that is current, forward thinking and that shapes the future of health law in Canada.

For more information about *Health Law in Canada*, or to view our board members profile, please visit:

<http://ihpme.utoronto.ca/research/research-centres-initiatives/health-law-in-canada-journal/>

SPEAKER BIOS



Sachin Aggarwal

Sachin Aggarwal is the chief executive officer of Think Research which builds knowledge-based tools for clinicians. He joined the team in 2010 as executive vice president and chief operating officer.

He is a co-author of the Centre for International Governance Innovation's 2018 special report, "Data Governance in the Digital Age."

Prior to joining Think Research, he served as the deputy chief of staff for the Office of the Leader of the Opposition, where he managed six departments, including the leader's executive team.

Mr. Aggarwal was chosen as one of the recipients of the 2017 Canada's Top 40 under 40 Award. He currently sits on the Board of the Council of Canadian Innovators (CCI) and has served on the Board of Directors for numerous community outreach programs, including Dixon Hall Neighbourhood Services and the Toronto People with AIDS Foundation.

He was called to the Bar in Ontario and in New York after earning a law degree from the University of Toronto. He holds a MBA from the Rotman School of Management and a BSc. from McMaster University.

James Ayles

Forthcoming



Sacha Bhatia

Dr. R. Sacha Bhatia is the FM Hill Chair in Health Systems Solutions and the Founding Director of the Institute for Health System Solutions and Virtual Care (WIHV) at Women's College Hospital. He is also a staff cardiologist and UHN and WCH. He is the national evaluation lead of the Choosing Wisely Canada campaign, a scientist at the Institute for Clinical Evaluative Sciences, and an Assistant Professor at the University of Toronto. He has been published in international peer reviewed journals like the New England Journal of Medicine and JAMA Internal Medicine. He has been a commentator on Bloomberg News, CTV News and the CBC, and has been asked to give over 80 presentations internationally, nationally and regionally since 2013.

He is a recipient of the American College of Cardiology's Young Investigator Award, the American Society of Echocardiography's Arthur E. Weyman Young Investigator Award, and most recently the Goldie Award for Quality and Innovation at the University of Toronto. He sits on the boards of the Heart and Stroke Foundation and DREAM Global REIT, a publicly traded company listed on the TSX.

Previously he worked as a clinical and research fellow in cardiology at Massachusetts General Hospital and Harvard University. Dr. Bhatia received his medical degree and MBA at McGill University and his internal medicine and cardiology training in Toronto.



Michael Bowmile

Michael is Senior Legal Counsel at Cancer Care Ontario, the Ontario government's advisor on the cancer and renal systems, as well as on access to care for key health services. In this role he works closely with Cancer Care Ontario's Privacy and Security teams as well as the Ontario Renal Network to provide strategic and legal advice covering a range of legal and regulatory issues. Prior to joining Cancer Care Ontario he worked in the Business Law Group at an international law firm.



Adalsteinn Brown

Adalsteinn (Steini) Brown is the Dean of the Dalla Lana School of Public Health at the University of Toronto. Past roles include Director of U of T's Institute of Health Policy, Management and Evaluation, senior leadership roles in policy and strategy within the Ontario Government, founding roles in start-up companies, as well as extensive work on performance measurement. He received his undergraduate degree in government from Harvard University and his doctorate from the University of Oxford, where he was a Rhodes Scholar.



Rosario G. Cartagena

Rosario is the Chief Privacy and Legal Officer at ICES. In her role, Rosario provides strategic advice to the organization related to privacy, legal, risk, compliance and cybersecurity. Previously, Rosario was a member of the Health Law Group at Fasken Martineau DuMoulin LLP. In her role she provided advice on a variety of health and privacy law matters, including corporate governance, public policy, risk management, health regulatory compliance, and health research. She has also worked in the privacy and legal group at Cancer Care Ontario.

Rosario has an LLM from Osgoode Law School (Business Law) and a law degree from the University of Ottawa. Prior to attending law school, Rosario completed a Master in Science, Public Health Sciences in population health from the University of Alberta and was a post-grad intern at the Harvard School of Public Health.



Mary Jane Dykeman

Mary Jane is a founding partner at DDO Health Law, a Toronto boutique law firm, and practises as a health and privacy/AI lawyer. She regularly assists hospitals, long-term care homes and other health sector stakeholders to find practical solutions to legal, clinical, risk, reputation and privacy matters. Mary Jane has extensive experience responding to privacy breaches, advising on the creation of complex shared health information systems, and training (including boards, senior teams, privacy officers and frontline staff) on legal requirements and emerging trends. She routinely conducts privacy impact assessments and provides advice on data sharing within large health sector initiatives. She also works extensively on specialized issues in health research and data use, as well as advising on patient portals, discussion boards, website content and assisting mobile app developers in the health care space. She has authored a number of significant health sector reports, including for the Law Commission of Ontario and the Ontario Mental Health Foundation. Mary Jane teaches mental health in Osgoode's Health Law LL.M. program, is Vice-Chair of the Alzheimer Society of Toronto and Deputy Chair of the Canadian Blood Services Research Ethics Board.



Daniel Fabiano

Daniel Fabiano is a partner with the Fasken Law Firm. His practice focuses on the intersection of privacy, technology and the public sector, with particular emphasis on healthcare. In particular, Daniel advises hospitals, non-profit agencies, regulatory colleges, independent health facilities, pharmaceutical companies, medical device companies, technology providers, insurance companies and other corporate clients on data sharing arrangements, technology services agreements, and consumer-facing portals, apps and devices. Daniel has extensive experience in helping clients manage privacy risk, including conducting privacy impact assessments, and in preventing and responding to privacy breaches. Daniel was recently seconded as General Counsel to eHealth Ontario.



Bonnie Freedman

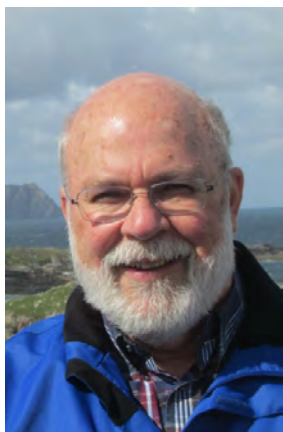
Bonnie Freedman is the regional leader of the Privacy and Data Protection Group and the Life Sciences Group at the Toronto office of Borden Ladner Gervais LLP. She practises corporate commercial law and also works closely with lawyers in the Information Technology Group. Bonnie's expertise lies in the interpretation and application of privacy, information and access to information laws. She has been on the forefront of this evolving area of law and led a project for the Privacy Commissioner of Canada in 2009.

Bonnie advises clients in the private and public sectors on the management of information they collect or create, in a wide range of industries including, financial services, energy, education, health, consumer products and publishing. In addition, Bonnie regularly provides advice to the federal and provincial healthcare and health informatics sectors. She collaborates with all the stakeholders in the industry, including hospitals, clinics, healthcare professionals, registries and other prescribed entities, government and community agencies, industry associations, regulatory bodies, laboratories, pharmacies, pharmaceutical manufacturers and non-commercial providers of information technology services.



Amit Garg

Amit Garg MD, MA (Education), FRCPC, PhD is a nephrologist at the London Health Sciences Centre, where he provides care and conducts research to improve health outcomes for patients with kidney disease including those receiving dialysis or a kidney transplant. He enjoys working with colleagues and trainees in a multi-disciplinary team based environment to generate and translate new knowledge for better health. Dr. Garg currently serves as Ontario provincial lead for the ICES Kidney, Dialysis and Transplantation (KDT) Program, has a Medical Lead Role at the Ontario Renal Network to improve access to kidney transplantation, and is the director for ICES Western.



Frank Gavin

For over twenty years Frank Gavin has worked to advance patient- and family-centred care. In 1995 he joined the Family Advisory Committee to The Hospital for Sick Children, chairing it from 1997 to 2001. In 2002 Frank founded and then for six years chaired the Canadian Family Advisory Network, which links family councils at paediatric centres across Canada. From 2011 to 2017 he was a public member of The Canadian Drug Expert Committee at CADTH. He serves on the boards of The Canadian Association for Health Services and Policy Research, The Ontario SPOR Support Unit, and on CIHR's Institute of Human Development, Child and Youth Health. Since 2016 he has chaired the Citizen Engagement Council of CHILD-BRIGHT, the national CIHR research network focused on children with brain-based disabilities.

Frank received the inaugural Volunteer Humanitarian Award from The Hospital for Sick Children in 2002, the Contribution to Child Health Award from The Canadian Association of Paediatric Hospitals in 2008, and the Best Patient Reviewer Award from The BMJ in 2017.

For nearly 30 years he taught English at Centennial College.



Jennifer Gibson

Jennifer Gibson is Sun Life Financial Chair in Bioethics and Director of the University of Toronto Joint Centre for Bioethics, Associate Professor in the Dalla Lana School of Public Health, and Director of the World Health Organization Collaborating Centre for Bioethics at the University of Toronto. Jennifer has a PhD in Philosophy. Her program of research employs qualitative social science methods and normative analysis to study ethical issues in health institutions and systems. She is particularly interested in the role and interaction of values in decision-making at different levels in the health system.

Currently, she is leading a new program of research on 'Ethics and AI for Good Health'. Jennifer has served on government and policy advisory committees related to medical assistance in dying, public health emergency preparedness, public health surveillance, critical care triage, drug funding and supply, and healthcare resource allocation. She also works closely with the World Health Organization on global health ethics issues.



David Goodis

David Goodis is Assistant Commissioner (Policy & Corporate Services) with the Information and Privacy Commissioner of Ontario. David is a graduate of Western University's law school, and was called to the Ontario Bar in 1988. David has represented the IPC in hearings before the Divisional Court, the Ontario Court of Appeal, and the Supreme Court of Canada. David recently authored the 2019 Annotated Ontario Freedom of Information and Protection of Privacy Acts, and teaches administrative law at the University of Toronto's Faculty of Law and Osgoode Hall Law School.

Sheryl Groeneweg

Forthcoming



Micheal Hillmer

Michael Hillmer is Executive Director of Information Management, Data & Analytics and Acting Assistant Deputy Minister, Capacity Planning & Capital Division at the Ministry of Health and Long-Term Care. He is responsible for ensuring the data and analytic needs of the health system are met and oversees the province's health privacy legislation. In this role, Michael has overseen the creation of an advanced analytics branch focusing on simulation, machine learning, and artificial intelligence applications.

Michael's academic background includes graduate degrees from the University of Toronto and he is currently an adjunct Assistant Professor at the University of Toronto.



Huda Idrees

Huda is the Founder and CEO of Dot Health, a real-time personal health data platform. With a background in engineering from the University of Toronto and a prolific career at some of Toronto's best known startups including Wattpad, Wave, and Wealthsimple, her latest venture is transforming the way people access and control their own health information for good. Huda's work has been featured in The Globe and Mail, Toronto Star, Metro News, CNBC, and Metro Morning. She has been recognized amongst the Top 5 CEOs in Toronto Life, a Top 25 Women of Influence in 2017, and named Top 30 under 30 by the Bay Street Bull in 2018. Huda serves on the Business Innovation and Development committee at Sinai Health System and on the Canadian Federal Economic Strategy Table for Health and Biosciences.



Tara Kiran

Tara Kiran is the Fidani Chair in Improvement and Innovation and Vice-Chair Quality and Innovation at the Department of Family and Community Medicine, University of Toronto. Much of her research has focused on evaluating the impact of Ontario's primary care reforms on quality of care. She has also developed a passion for quality improvement research including initiatives to improve cancer screening rates, measure and reduce care disparities, and support physicians to learn from data. She practices family medicine at the St. Michael's Hospital Academic Family Health Team where she led the quality improvement program from 2011 to 2018. She is an Associate Scientist in the Centre for Urban Health Solutions at St. Michael's Hospital and an Adjunct Scientist at ICES. She is also currently an Embedded Clinician Researcher with Health Quality Ontario where she leads a program of research to improve the experience of care for patients transitioning from hospital to home.



Lydia Lee

Lydia Lee, is a Partner at KPMG Canada and National Lead for Digital Health. She has over twenty years of experience in healthcare administration and consulting focused on health system design, large-scale business transformation and jurisdictional digital health leadership. She leads KPMG's Digital Health Practice focusing on digital health strategy, clinical systems and infrastructure renewal, health technology innovation and advanced analytics. Lydia has a collaborative management style that drives high performance and innovation in healthcare settings and complex multi-organizational initiatives and was awarded the distinction of IT Association of Canada (ITAC) Public Sector Canadian CIO of the Year (2015). Prior to her role at KPMG, Lydia was the Senior Vice President and Chief Information Officer at the University Health Network (UHN), Canada's largest academic health sciences centre and learning institution, where she led all aspects of enterprise information management (IM) strategy and information technology (IT) service delivery. Lydia also served as the Executive Sponsor and Project Lead for several major government funded e-health initiatives in Ontario including ConnectingGTA - regional longitudinal EHR for 7.5M citizens, GTA West Diagnostic Imaging Repository - RIS/PACs regional repository for 4 LHINs and Resource Matching and Referral - standardized e-referral system for all hospitals, rehab/complex care, home care and long-term care institutions in the Toronto Central LHIN. Lydia has a BA in Economics from Northwestern University and MBA in Management and Finance from the University of Texas at Austin.



Craig Lindsay

As a volunteer, and a member of the Kidney Foundation Board of Directors, Ontario Branch, I have the privilege of helping to raise awareness of the immense burden of living with kidney disease. Advocating for better supports for kidney patients, and for a broader strategy to address the growing crisis in chronic disease management is just part of the work I find meaningful at the Kidney Foundation.

I am active as a patient and family advisor with Scarborough Health Network, the Central-East Local Health Integration Network, Health Quality Ontario, and the Ontario Renal Network. I also serve as a patient surveyor with Accreditation Canada, helping organizations adopt best-practices in engaging meaningfully with their patients and family caregivers.

Prior to experiencing kidney failure I worked as a flight paramedic within the Ontario air ambulance system.



Muhammad Mamdani

Dr. Mamdani is the Director of the Li Ka Shing Centre for Healthcare Analytics Research and Training (CHART) of the Li Ka Shing Knowledge Institute of St. Michael's Hospital in Toronto. He is also Professor in the Leslie Dan Faculty of Pharmacy, the Department of Medicine of the Faculty of Medicine, and the Institute of Health Policy, Management and Evaluation of the Dalla Lana Faculty of Public Health. He is also adjunct Senior Scientist at the Institute for Clinical Evaluative Sciences (ICES). Dr. Mamdani also is a member of the Human Drug Advisory Panel of the Patented Medicine Prices Review Board (PMPRB) and is a co-Principal Investigator of the Ontario Drug Policy Research Network. In 2010, Dr. Mamdani was named among Canada's Top 40 under 40. Prior to joining the Li Ka Shing Knowledge Institute and St. Michael's Hospital, Dr. Mamdani was a Director of Outcomes Research at Pfizer Global Pharmaceuticals in New York.

Dr. Mamdani obtained a Doctor of Pharmacy degree (PharmD) from the University of Michigan (Ann Arbor) in 1995 and subsequently completed a fellowship in pharmacoconomics and outcomes research at the Detroit Medical Center in 1997. During his fellowship, Dr. Mamdani obtained a Master of Arts degree in Economics from Wayne State University in Detroit, Michigan. He then completed a Master of Public Health degree from Harvard University in 1998 with a concentration in quantitative methods, focusing on biostatistics and epidemiological principles.



Kaelan Moat

For nearly a decade, Kaelan has been involved in the development, implementation and evaluation of innovative mechanisms that aim to support the use of research evidence in policymaking, with a particular interest in how political factors influence the likelihood that research is used in the decision-making process. His work at the McMaster Health Forum finds him working with policymakers, stakeholders and researchers provincially, nationally, and internationally to address pressing health- and social-system challenges with the best evidence, and systematically-elicited citizens' values and stakeholder insights. He played a key role in supporting the development of Health Systems Evidence, world's most comprehensive free access point for synthesized evidence about strengthening health systems (www.healthsystemsevidence.org), and has recently helped to lead the development of Social Systems Evidence (www.socialsystemsevidence.org), the world's most comprehensive, free access point for evidence about strengthening 16 government sectors and program areas, and achieving 14 of the 17 Sustainable Development Goals. He has also delivered many capacity-building workshops to policymakers and stakeholders in Canada and around the world to support them in their efforts to find and use research. He holds a B.H.Sc. from Western University, an M.Sc. from the London School of Economics (U.K.), and a PhD from McMaster University. Kaelan currently lives with his wife and two daughters in Toronto, Ontario.



Ted McDonald

Dr. Ted McDonald is a Professor of Economics at the University of New Brunswick in Fredericton. He holds a Ph.D. and a Master of Commerce in Economics from the University of Melbourne. Dr. McDonald was designated a UNB Research Scholar for 2012-2014 and has been PI or co-PI on over \$9 million of research funding since 2009. He is the founding Director of the NB Institute for Research, Data and Training, the New Brunswick lead for the Maritime SPOR SUPPORT Unit, and Chair of the Canadian Research Data Centre Network Academic Council. His main areas of research include the health status and health services use of immigrants, rural residents, minority groups and other subpopulations, as well as an ongoing program of research on the socioeconomic and demographic determinants of cancer. He has also researched extensively on immigrant labour market issues. He has published his work in a broad range of academic journals including *Social Science and Medicine*, *Canadian Journal of Economics*, *Canadian Public Policy*, and *BMC Public Health*. Dr. McDonald also co-authored with Dr. Chris Worswick a chapter on high skilled immigration in the *Handbook on the Economics of International Migration* published by Elsevier.



Emily Nicholas

Emily's patient journey has taken her through ER's, OR's, MRI's and many acronyms in between. Her broad range of experiences led to a keen interest in how patients can become partners in their own care and in health system improvement. Emily has been helping bring the patient voice to Canadian health care for over ten years. She previously sat on the board of Patients Canada and is one of the founding members of The Patient Advisors Network (PAN). She has consulted on patient and family engagement with hospitals, government agencies, research institutes and other organizations across Canada. She currently has advisory roles with The Canadian Medical Association Journal (CMAJ) Collection for Patient Oriented Research panel, Health Quality Ontario's Health System Performance committee, and the policy research centre Converge3. Emily works as Director of Health Engagement and Communication with Reframe Health Labs where she specializes in bringing the patient perspective to RHL's evidence-based approach to health and wellness communication.



Alison Paprica

As Vice President, Health Strategy and Partnerships, Alison Paprica is the Vector Institute's corporate lead for health strategy, overseeing health research collaborations, health data partnerships and health AI application projects. Prior to joining Vector in November 2017, Alison's roles included: Director, Strategic Partnerships at the Institute for Clinical Evaluative Sciences (ICES), Director of the Planning, Research & Analysis Branch at the Ontario Ministry of Health & Long-Term Care and Manager of Performance Measurement & Results at the Ontario Ministry of Research & Innovation. From 1993-2001 she worked in international pharmaceutical R&D at Eli Lilly, Astra Pharma and Genpharm Inc. Alison holds an Honours Combined BSc in Biochemistry and Chemistry (McMaster), a PhD in organic chemistry (Western University) and is Assistant Professor (status) at IHPME. She is among the first 5% of people to obtain Project Management Professional (PMP) certification internationally, and developed and delivers courses and workshops at the University of Toronto focused on leadership and management of research.



Carole Piovesan

Carole is a lawyer at McCarthy Tétrault and co-leads the national Cybersecurity, Privacy and Data Management group. She is also the co-author of the firm's White Paper on AI, and editor of the CyberLex blog. She frequently writes and speaks about issues regarding AI and law. Carole regularly consults with clients on adopting a holistic framework to AI integration that includes legal, ethical, commercial and technical considerations. In addition, she has advised the Canadian government on policy issues related to AI and was recently invited by the Canadian Minister of Innovation, the Honourable Navdeep Bains, to serve as one of six Innovation Leaders, tasked with facilitating national consultations with enterprise, academics, civil society, and others, to inform Canada's position on data and digital transformation.



John Roberts

John Roberts is the Chief Privacy Officer and Archivist of Ontario at the Ministry of Government and Consumer Services since September 2015. In this role he has been active in addressing privacy and recordkeeping issues in data and digital initiatives throughout the Ontario public sector, and promoting access to the Archives of Ontario's collections.

He has over thirty years of experience in operational, policy and senior leadership roles delivering government information management and digital government initiatives, primarily working in the New Zealand government.

His extensive knowledge of information management and privacy protection has contributed to his numerous achievements in policy, strategy, legislation, and modernisation of public sector information management.

His enthusiasm for archives and recordkeeping, and his passion for improving public service through customer-centred information management, began during a student internship position at Archives New Zealand while completing an MA in medieval German at Victoria University of Wellington.

John has also held leadership roles in a number of professional associations, has been active in international initiatives, and has frequently published and presented internationally. He holds an MA from Victoria University of Wellington, and a Masters in Information Management and Systems from Monash University in Australia.

Frank Rudzicz

Forthcoming



Michael Schull

Michael Schull is CEO and Senior Scientist at ICES, Professor in the Department of Medicine at the University of Toronto, and a Senior Scientist at the Sunnybrook Research Institute. His research focuses on health service utilization, quality of care, health system integration and patient outcomes, and the evaluation of health policy. Under his leadership, ICES has expanded the types of data available for researchers, created a virtual platform where researchers outside ICES can access and analyze linked datasets, launched a health artificial intelligence data and analysis platform, and engaged the public in the work of ICES to ensure it remains aligned with public values. Dr. Schull leads the participation of ICES in a pan-Canadian initiative to build a national health and social data platform. He practices as an Emergency Medicine specialist at Sunnybrook Health Sciences Centre in Toronto.



Pam Snively

Pamela Snively is TELUS' Chief Data & Trust Officer. She leads the team responsible for privacy and, more broadly, data governance. Pamela is charged with enabling and supporting TELUS' commitment to earning and maintaining customer trust through demonstrably accountable and ethical data practices.

Pamela participates in a number of national and international think-tanks and governance bodies related to privacy and data governance, including serving as a Board member for the Information Accountability Foundation, on the Privacy Advisory Committee for the Sidewalk Labs Waterfront Toronto project, and on the Privacy and Data Advisory Committee for the Canadian Marketing Association.



Terry Sullivan

Terrence Sullivan is a behavioral scientist, Professor and Senior Fellow at the Institute for Health Policy, Management & Evaluation, Dalla Lana School of Public Health, University of Toronto and adjunct professor in the Department of Oncology at McGill University. His research interests span Cancer Control, Quality and Performance Strategies, and Disability Policy. (<https://scholar.google.ca/citations?user=BJDRqZkAAAAJ&hl=en>)

Current board/governance roles include immediate past chair of the board of the Canadian Agency for Drugs and Technologies in Health (2011-2018), current chair of the quality and safety committee of the Hospital for Sick Children board, chair of governance and nominations committee of Exactis Innovation (a business-led federal NCE focused on precision oncology) and chair of audit and finance committee on the Board of Vector Institute for Artificial Intelligence. He chairs the International Advisor Committee for the Rossy Cancer Network affiliated with McGill University, and the advisory group for the EXTRA program at CFHI and he is a member of the steering council for the Diabetes Action Canada SPOR.

From 2001 to March 2011 he occupied leadership positions at Cancer Care Ontario (CCO), the final seven years as President and CEO during which the organization transformed its business model to a cancer control organization with a strong focus on commissioning services, performance measurement, reporting and quality improvement. While at CCO at the request of government, he also played formative roles in the creation, design and governance of Public Health Ontario and Health Quality Ontario. Founding president of the Institute for Work & Health (1993-2001), he previously played senior roles in the Ontario Ministries of Health, Cabinet Office and as Assistant Deputy Minister, Constitutional Affairs and Federal-Provincial Relations during the Charlottetown negotiations. He served two successive First Ministers of Ontario as Executive Director of the Premier's Council on Health Strategy (1989-1992).

Professionally incorporated, he provides a range of advisory services to governments, health care and cancer organizations in Canada and internationally. These have included the Canadian Conference of Deputy Ministers of Health; World Bank (Brazil); WHO Europe and Western Pacific Region; Canadian Institutes for Health Research (IHSPR & IPPH), Canadian Institute for Health Information, Canadian Partnership Against Cancer, Canadian Foundation for Healthcare Improvement, Canada Health Infoway; Juravinski Cancer Center, Health Quality Ontario, Hamilton Health Sciences, St. Joseph's Health System; Saskatchewan Ministry of Health; Canadian Nurses Association; Cancer Care Manitoba, B.C. Cancer Agency, Princess Margaret Hospital, McGill University affiliated cancer hospitals, CorHealth Ontario.



Eric Sutherland

Eric Sutherland brings numerous years of experience in data management, governance and strategy, in both the public and private sectors, to CIHI's focus on internal and pan-Canadian health data governance. He is actively involved in developing our internal data governance approach and implementation plan.

Most recently, Mr. Sutherland was with the Ontario Ministry of Health and Long-Term Care, where he provided strategic leadership in developing a health system information management strategy. This included enabling trusted information through data standards, quality and stewardship; improving privacy-enabled access through education, processes and legislation; and creating insights that drive action to enable positive health outcomes by leveraging leading analytical methodologies. Mr. Sutherland is also a lecturer at the University of Toronto's School of Continuing Studies in the area of managing big data and predictive analytics. Other experience includes business, technology and information leadership positions at TD Bank across finance, risk and treasury over 20 years and has recently joined the CorHealth Board of Directors.



Charles Victor

Mr. Charles Victor, MSc, PStat, is the Senior Director, Strategic Partnerships and External Services at ICES, Canada's largest health services research institute. In this role he is responsible for developing and maintaining partnerships with data providers, governmental and non-governmental agencies, academic institutions and researchers, and industry partners. Over the past three years Mr. Victor has been responsible for the development and oversight of ICES' Data and Analytic Services, a unit aimed at providing high quality research ready health services data and analytic reports to clinical researchers, health system stakeholders, and industry partners globally. Prior to his current role, Mr. Victor was responsible for the internal Mr. Victor has over 15 years of experience as an epidemiologist and professional biostatistician providing methodological and statistical support to over 1000 research studies. His expertise spans several methodological and data resource domains including health administrative data, research study design and analysis, complex regression modelling techniques, and adult education in statistics. As an assistant professor at the Institute of Health Policy Management and Evaluation, University of Toronto, he is responsible for the development and delivery of the advanced biostatistics curriculum provided to clinical epidemiologists.