

Data Access/Data Integration for Precision Health



Precision Medicine Policy Network

**October 25-26, 2017
Hotel Alma, University of Calgary
Calgary, Alberta, Canada**

October 25-26, 2017
Hotel Alma, University of Calgary
Calgary, Alberta, Canada
Data Access/Data Integration

Table of Contents

Workshop description.....2

Workshop agenda.....3

Workshop participants.....4

Workshop Sponsors



Workshop description

Precision health represents a spectrum of transformative approaches from medicine to public health. Precision medicine aims to harness a wave of 'omics discoveries to deliver the right treatment to the right patient at the right time. Precision public health aims to apply those discoveries to better direct public health interventions. Precision health initiatives are reliant on efficient access to, as well as integration and analysis of big data.

Over the 1.5 day workshop, participants will consider enablers and barriers to the use of big data by Canadian health systems to support precision health in real-time. In particular, health systems must be able to evaluate precision health technologies and interventions to ensure they are cost-effective, not once, but throughout their post-adoption life-cycle, i.e. Life-Cycle Health Technology Assessment.

Using case examples from Canadian provinces, the goal of this workshop is to discuss best practices and pose solutions to the following questions:

1. Are data access issues, especially with respect to data integration across multiple databases within Provinces, the result of legislative, policy, or practice (e.g., risk-benefit calculus) barriers;
2. How can we improve the architecture of databases to inform Precision Health initiatives and Life-Cycle Health Technology Assessment;
3. Can current data infrastructures support Precision Health initiatives and Life-Cycle Health Technology Assessment; and
4. What are the impediments to inter-provincial data sharing?

Case context 1. Canadian Hepatitis C Network: With the availability of improved and effective, but costly therapies for HCV, a greater number of infected individuals are seeking treatment, and more patients are being diagnosed with HCV due to increased screening initiatives. Members of the Canadian Hepatitis C Network have been working to develop economic and epidemiological models to optimise screening, diagnosis and treatment strategies. Significant advances have been made in integrating the necessary data streams, especially in British Columbia, however, a pan-Canadian strategy would benefit from inter-provincial data sharing and improved data on vulnerable populations, including immigrant and indigenous health data.

Case context 2. Genomic Medicine: Cancer & Rare Diseases. In the context of cancer care, the advent of next generation, high-resolution and highly sensitive DNA sequencing enables early cancer detection and the molecular characterization of the cancer to direct the most effective treatment regimen. These new diagnostics methods will rely on integrated data platforms and will drive significant costs in precision oncology therapies. The value to the health system in terms of health outcomes for cancer patients following these test-directed treatments will therefore need to be evaluated in real time. Sustainable health systems must become adept at disinvestment from as well as investment in new technologies.

The workshop will be held under 'Chatham House Rules' to encourage a full and frank exchange of views amongst participants.

Workshop Outputs

With your permission, we will take notes from each session and summarize into a workshop proceedings manuscript, which will be submitted for journal publication. No statements will be attributed to individuals without their express consent.

October 25-26, 2017
 Hotel Alma, University of Calgary
 Calgary, Alberta, Canada
Data Access/Data Integration

Workshop location: Senate Room, 7th Floor

Oct 25, 2017

9:00-9:30	Breakfast		
9:30-9:45	Welcome, introduction, overview of objectives	Tania Bubela	
9:45-10:15	Context: Data Issues in Precision Health		
	<i>Speaker</i>	Larry Svenson	
	<i>Chair</i>	Tania Bubela	
10:15-11:00	Panel response and discussion	<i>Panel</i>	Tim Murphy Diane Alguire Michael Craig
11:00-11:20	Refreshment Break		
11:20-12:00	Case context 1: Canadian Hepatitis C Network		
	<i>Speaker</i>	Mel Krajden	
	<i>Chair</i>	Charles Victor	
12:00-13:30	Panel response and discussion	<i>Panel</i>	Beate Sander Naveed Janjua Dorcas (Cas) Taylor Hussain Usman
13:30-14:15	Lunch		
14:15-15:00	Case context 2: Genomic Medicine: Cancer & Rare Diseases		
	'Accessing CCO Data for Research Purposes'		
	<i>Speaker</i>	Nicole Mittmann	
	<i>Chair</i>	Deborah James	
15:00-16:30	Panel response and discussion	<i>Panel</i>	Katerina Podolak Francois Bernier Stacey Hume
18:15	Workshop Dinner		
	Saltlik (101, 8 Avenue Southwest, Calgary, AB T2P 1B4)		
	Reception at 18:15		
	Dinner at 18:45		

Oct 26, 2017

8:30-9:00	Breakfast		
9:00-10:30	Moderated discussion on challenges and solutions		
	<i>Moderator</i>	Alexander (Sandy) Dubyk	
			<i>Breakout chairs</i>
			Kim Simmonds Susan Anderson Naveed Janjua Elaine Hyshka
	Break out groups and reporting back		
10:30-10:50	Refreshment Break		
10:50-12:00	Moderated group discussion		
	<i>Moderator</i>	Alexander (Sandy) Dubyk	
12:00	Boxed Lunch available		

October 25-26, 2017
Hotel Alma, University of Calgary
Calgary, Alberta, Canada
Data Access/Data Integration

Workshop Participants (alphabetically by last name)



Diane Alguire

Diane Alguire is the Director of the Information and Privacy Office at the University of Alberta. She leads its Information and Privacy Office in providing advice and education related to the FOIP Act and the Health Information Act, and manages the University's access and privacy program. Prior to this role, Diane was Senior Legal Counsel to the University, and provided legal advice on a variety of privacy issues. She focuses on making compliance as simple and understandable as possible. She works with people to help them find a reasonable, legally compliant way to fulfil the University's mission to discover, disseminate, and apply new knowledge. In addition to her L.L.B., she is also a certified information privacy professional (CIPP/C).



Susan Anderson

Susan Anderson is the Managing Director Orion Health for the Canadian Business. Susan is an accomplished e-health strategist with more than 25 years' experience in healthcare informatics. Most recently, she was the Assistant Deputy Minister and CIO for the Health Information Technology and Systems Division at Alberta Health, where she played a pivotal role in transforming Alberta's healthcare system into one of the most digitally connected in North America. At the forefront of Alberta's Electronic Health Record implementation, she helped steer the expansion of EHR data sources, deployment to users, integration for physicians and pharmacists, and introduced public access to EHRs. Susan is a Director on the board of Canada's Health Informatics Association (COACH), and is the co-chair of ITAC Health Membership and Program Development Committee.



Francois Bernier

Francois Bernier is the Head of and Associate Professor in the Department of Medical Genetics, Cumming School of Medicine, at the University of Calgary. He is also the Section Chief, Clinical Genetics for Alberta Health Services. He has a specific interest in the clinical and molecular delineation of a novel autosomal recessive disorder (dilated cardiomyopathy, cerebellar ataxia and 3-methylglutaconic aciduria), which he has described in the Hutterite population. This work culminated in the identification of the responsible gene and further studies to characterize what appears to be a unique developmental and functional pathway are underway. Dr. Bernier also has an interest in the genetics of autism and is part of CIHR sponsored research group. He has recently completed a study on the long-term outcome of children who had choroid plexus cysts identified prenatally and a survey which explored the relationship between expectations and satisfaction in genetic counseling.



Tania Bubela

Dr. Bubela is an expert in health and intellectual property law and policy, combining her training in genetics (PhD Biology, University of Sydney) and law (Gold medalist, University of Alberta). She is the Dean of Faculty of Health Sciences at Simon Fraser University, leading the development of sector-leading policies, processes, practices and infrastructure to support excellence in interdisciplinary education, research, and engagement that will improve health, health equity, and well-being. Dr. Bubela's research interests include intellectual property law and policy, health law, genomics, technology transfer, commercialization of biomedical research and science communication. She currently co-leads two precision health: the Genome Canada PACEOMICS project and the Alberta Ocular Gene Therapy Team (CRIO-AI). She is also a theme lead for commercialization and intellectual property considerations within the Genome Canada Precision Medicine Policy Network (lead by Drs McCabe and Rousseau). She also leads a project on the enablers and barriers for personalized cancer biotherapies in Canada.



Michael Craig

Michael Craig, BSc in Pharmacy, CPHIMS-CA, is a Vice President of National Solutions with Orion Health responsible for promoting Orion Health solutions and partner solutions into the Canadian Marketplace. Michael led Orion's Electronic Health Record (EHR) initiatives across Canada and Australia and has had direct involvement in solution architecture, clinical requirements gathering and clinical workflow mapping. Michael is currently part of Orion's initiatives to improve patient's access to clinical information and the incorporation of genomic data into the patient's electronic health record. Michael has held consulting positions with Pricewaterhouse Coopers, Accenture, Shared Medical Systems (SMS) and Electronic Data Systems (EDS).

October 25-26, 2017
Hotel Alma, University of Calgary
Calgary, Alberta, Canada
Data Access/Data Integration



Xinjie Cui

Xinjie is the Chief Analytics Officer at PolicyWise for Children & Families and is responsible for the overall data and information strategy. She has strong background in policy-relevant research using administrative data. Xinjie has 12 year work experience with the provincial health ministry; led and managed health surveillance projects to support for policy changes and program development. At PolicyWise, she leads multiple data initiatives such as the Child and Youth Data Lab (CYDL) that links data across six provincial ministries and the Secondary Analysis to Generate Evidence (SAGE)

Initiative that facilitates the linking and sharing of existing research data and service delivery data for secondary use. She has a Bachelor's degree in Medicine, a PhD in Psychology and holds adjunct appointments with both University of Alberta and University of Calgary.



Stafford Dean

Stafford Dean is the Chief Analytics Officer at Alberta Health Services. He has been using administrative and clinical data to support decision making for over 25 years in Alberta's health system. Stafford has also had data and analytic roles at the Alberta Ministry of Health, Calgary Health Region, and the Health Quality Council of Alberta. The analytics role enables decision making by providing timely, relevant data and reporting services.

Stafford's research interests include health system planning models and clinical analytics to support continuous quality improvement. Stafford has a PhD in Health Research, a master's degree in Economics and a bachelor's degree in Actuarial Science.



Alexander (Sandy) Dubyk

Alexander (Sandy) Dubyk (BSc(Pharm), ACPR, PharmD, MBA) is Director of Operations, Alberta Academic Health Network working with senior leadership (academia, clinical, administrative, and government) to develop an implementation strategy on precision health for Alberta. He co-authored the report, "Precision Health for Alberta - A Prospectus", in January 2017. In addition, he teaches two modules in the Master of Biomedical Technology, Cumming

School of Medicine--one on Regulatory Affairs, as well as Communication, Marketing and Sales, consults on strategy development and practices clinically as a pharmacist. Alexander has held various leadership and senior roles in strategy development, business operations, pharmaceutical industry, advanced education, business entrepreneurship, health outcomes research, primary and acute clinical care delivery.



Tanya Ewashko

Tanya has worked in the health system for about 30 years, the last 8 with Alberta Health Services. She began her health career as a physical therapist in Edmonton, followed by a Master of Public Health from Johns Hopkins School of Public Health in Baltimore. Her continued interest in population health, applied research and knowledge translation was strengthened upon completion of the SEARCH program. Tanya has contributed to Health Technology Assessment processes in the last decade and is now part of this innovative AHS team. She is also collaborating on the Precision Health Strategy and related initiatives in Alberta. Tanya is known for her creativity and social ways, and brings a "joie de vivre" wherever she works!



Peter Faris

Peter Faris, PhD (Biostatistics) is the Director of Research Facilitation in the Department of Analytics in Alberta Health Services (AHS), and is an Adjunct Professor in Community Health Sciences at the University of Calgary where he is co-instructor for a unique graduate course on the analysis of administrative data. He has 25 years of experience in providing statistical support to projects in several clinical areas including Cardiology, Psychology, Neurology, Nephrology, Cancer and Orthopedics. He has expertise in Biostatistics, Epidemiology, Privacy, and data sources within AHS.



Guillermo (Will) Fiebelkorn

Guillermo (Will) Fiebelkorn, MA, is the privacy and records specialist in the Faculty of Medicine at the University of Calgary. He provides advice and support regarding privacy compliance and information management best practices. Before this he was the manager for the Records and Information department at Cangene Corporation, bio-pharmaceutical company with headquarters in Winnipeg. Will earned a Master's Degree in Archival Studies at the University of Manitoba and a Bachelor of Arts degree in History of Fine Arts at the National University of La Plata, Argentina, his country of birth.

October 25-26, 2017
Hotel Alma, University of Calgary
Calgary, Alberta, Canada
Data Access/Data Integration



Cynthia Ho

Cynthia Ho, PhD, has been with the Ontario Ministry of Health and Long-Term Care since 2010 working on various policy development and business improvement projects. Cynthia is currently a Senior Program Consultant in the Laboratories and Genetics Branch of the ministry where she leads a number of genetics initiatives including the development and implementation of a provincial Genetic Services Framework and related strategy and policy work, transition of the Genetic Testing Advisory Committee (GTAC) to Health Quality Ontario (HQO), and establishment of the Consultation and Advisory Group for Genetics in Ontario (CAGO) for genetic sector input and advice to the branch on strategy and operations of the provincial genetics services system. Cynthia has an Honours BSc from the Department of Genetics, University of Western Ontario, a PhD from the Department of Medical Biophysics, University of Toronto, and completed postdoctoral studies at the Lunenfeld-Tanenbaum Research Institute at Mount Sinai Hospital in Toronto.



Steve Hughes

Steve Hughes recently joined the University of Alberta as the Health Information Privacy Advisor in the Faculty of Medicine & Dentistry. In this role, Steve currently provides advice and assistance with a number of different issues, including privacy and security reviews, privacy impact assessments, research initiatives involving health information, privacy breach investigations, drafting of privacy policies and interpreting the provisions of the Health Information Act and Freedom of Information and Protection of Privacy Act. Before joining the University of Alberta, Steve practiced as a civil litigation lawyer with Miller Thomson LLP, where he specialized in privacy law and advised clients on various topics including privacy policies, access requests, employee privacy rights and trans-border information flow.



Stacey Hume

Dr. Hume has been with the Edmonton Molecular Diagnostic Lab in Alberta Health Services since 2005 - initially as the assistant director and since 2008 as the lab head. She is also an Associate Professor within the department of Medical Genetics at the University of Alberta. Dr. Hume's professional interests include serving with her college (Canadian College of Medical Geneticists), mitochondrial diagnostics, and improving lab quality. As the laboratory has moved into the realm of Next Generation Sequencing as well as implementing a new lab information system, she is familiar with the challenges, delivering personalized medicine in a public healthcare system.



Stacy Hung

Hello! I am a bioinformatician at the British Columbia Cancer Agency in Dr. Christian Steidl's laboratory where I get to work with scientists, clinicians, and other bioinformaticians to understand the genetic basis of common lymphomas through high-throughput next-generation sequencing datasets. My current work focuses on the development and application of a capture-based targeted sequencing pipeline to identify actionable gene mutations in lymphoma patients, with the ultimate goal of generating personalized clinical reports to improve treatment outcomes. I am originally from Ontario where I completed my B.Sc. in Biology and Bioinformatics at UW, and my Ph.D. in molecular genetics at U of T. My thesis involved the identification of novel drug targets in the malaria parasite. I thoroughly enjoy road cycling, tea, and making a positive difference in the world!



Elaine Hyshka

Elaine Hyshka, BA, MA, PhD is an Assistant Professor of Health Policy and Management at the University of Alberta's School of Public Health, and Scientific Director of the Inner City Health and Wellness Program at the Royal Alexandra Hospital. Dr. Hyshka's program of applied health services and policy research focuses on advancing a public health approach to substance use in Canada, and her work is conducted in partnership with health and social service providers, advocacy organizations and governments at the local, provincial, and national level. Dr. Hyshka's strong commitment to mitigating the societal costs of substance use has been recognized by several awards, including an Early Career Transition salary award from Alberta's Policywise for Children and Families. In June, Dr. Hyshka was appointed Co-Chair of the provincial Minister of Health's Opioid Emergency Response Commission.



Deborah James

Deborah James, BSc (Pharm), PhD, is Executive Director of Innovation for the Faculty of Medicine & Dentistry, University of Alberta. With more than 15 years of academic-executive and consulting experience, she provides leadership and strategy to the Faculty's innovation and partnership portfolio. Her particular interests are in precision diagnostics, point of care testing, digital health, and how new disruptive technologies are substantially changing healthcare delivery. Among other responsibilities, she leads the Faculty's Precision Health initiative that is founded on access to and analysis of robust health data, and bringing new health innovations to market and/or adoption. Dr. James received her degree in clinical pharmacy from the Faculty of Pharmacy and Pharmaceutical Sciences, University of Alberta and completed her PhD studying the neuro-immunological basis of airways disease. She has taught courses in therapeutics, toxicology, pharmacology, immunology and disease mechanisms.

October 25-26, 2017
Hotel Alma, University of Calgary
Calgary, Alberta, Canada
Data Access/Data Integration



Naveed Janjua

Dr. Naveed Zafar Janjua is a Senior Scientist at the BC Centre for Disease Control and Clinical Associate Professor at School of Population and Public Health, University of British Columbia. Dr. Janjua is a Medical Doctor with a Master of Science degree in Epidemiology & Biostatistics and Doctorate in Public Health. His work involves surveillance, research and policy advice and programming related to hepatitis B and C in British Columbia (BC). His research interests include hepatitis B and C epidemiology, syndemics of substance use, mental illness and blood-borne and sexually transmitted infections, intervention effectiveness, disparities in treatment access and disease outcomes, HCV care access and strategies to enhance access to care. Most of his work is based on the BC Hepatitis Testers Cohort, a longitudinal cohort of about 1.7 million individuals tested for HCV or HIV or diagnosed with HBV or TB in BC linked with their medical visits, hospitalization, cancer, prescription drugs and mortality.



Mel Krajden

Mel Krajden MD, FRCPC is the Director of BC's Public Health Laboratory and the Medical Head, Hepatitis at the British Columbia Centre for Disease Control. He is also a Professor of Pathology and Laboratory Medicine at the University of British Columbia. Dr. Krajden's clinical research involves integration of hepatitis prevention and care. His laboratory research involves the application of molecular and genomic techniques to: diagnose viruses; assess correlates between infection and clinical disease; monitor antiviral efficacy and track microbial infections. He has extensive clinical trials expertise and is a Co-investigator/Mentor on the CIHR funded National Research Training Program (CanHepC). He spearheads the BC-Hepatitis C Tester's Cohort (BC-HTC) which contains 25 years of de-identified health information on 1.7 million British Columbians. This world-class dataset is used to determine net costs of services and health outcomes. The goal is to drive value-based practices from the bench to population level – translating discovery into practice across a range of health-related questions.



Markus Lahtinen

As Director, Health System Analytics, Markus oversees the HQCA's measurement and analytical functions, as well as many of the monitoring and reporting functions such as population-level surveys and health system performance reporting. This involves survey and administrative data analytics, and survey development, methodology, and reporting. Markus plays a key role in the HQCA's use of objective information to drive actionable improvement that enhances quality healthcare. Markus joined the HQCA following a career with Statistics Canada's Research Data Centre at the University of Calgary where he was responsible for managing and coordinating daily operations, and conducting population research. Markus holds a PhD in sociology, with a specialization in health research from the University of Calgary, and has training in both quantitative and qualitative methods. He is also a Certified ROI Professional, and an Adjunct Professor at the School of Public Health, University of Alberta.

Sarah McDermott

Sarah McDermott is the Manager of the Notifiable Disease and Field Surveillance Section in the Public Health Agency of Canada. The Section manages the Canadian Notifiable Disease Surveillance System which receives annual data submitted voluntarily by provinces and territories on approximately 60 nationally notifiable diseases. Prior to managing this Section, Sarah worked for over ten years in the Health Promotion and Chronic Disease Prevention Branch of the Agency.



Nicole Mittmann

Dr. Nicole Mittmann is the Chief Research Officer at CCO. She is an Assistant Professor at the University of Toronto in the Department of Pharmacology and Toxicology and an Associate Scientist at Sunnybrook Health Sciences Centre. At CCO, she is building the first strategy and framework for research at the organization. Dr. Mittmann has conducted and collaborated on notable research in the areas of meta-analysis, economic evaluations, outcomes research and drug/patient safety. Research methodologies include the examination of large databases, economic methodologies and decision analysis. Funded by the Ontario Cancer Research Institute/Cancer Care Ontario, recent work is determining the burden of cancer from a Canadian health system perspective and developing economic guidelines for oncology products. Other areas of research include understanding and measuring health preferences for patients across the disease continuum. Dr. Mittmann is also the co-chair of the Committee on Economic Analysis (CEA) at the Canadian Cancer Trials Group.



Tim Murphy

Tim Murphy has more than 20 years of senior executive leadership experience in the health care sector. Prior to joining Alberta Innovates Health Solutions as the Vice President, Provincial Platforms and SPOR, Tim established an independent consulting practice and worked with clients such as the CHILD Foundation, the Institute for Health System Transformation and Sustainability, and the Movember Foundation. Prior to establishing his consulting role, Tim was the inaugural Senior Vice President at the Michael Smith Foundation for Health Research (MSFHR), a provincial research organization based in Vancouver. He joined the Foundation after working for more than 10 years in senior management positions with two comprehensive Academic Oncology Centres - the Princess Margaret Hospital and British Columbia Cancer Agency. Tim holds a Bachelor of Science Degree, Life Sciences from Queen's University; a Masters of Health Administration from the University of Toronto; a Masters of Business Administration from Queen's University; and a Certified Management Accountant (CMA) designation.

October 25-26, 2017
Hotel Alma, University of Calgary
Calgary, Alberta, Canada
Data Access/Data Integration



Raymond Ng

Raymond Ng is the Director of the Data Science Institute at UBC, a Professor of Computer Science, and the Canada Research Chair in Data Science and Analytics. His main research area for the past two decades is on data mining, with a specific focus on health informatics and text mining. He has published over 200 peer-reviewed publications on data clustering, outlier detection, OLAP processing, health informatics and text mining. For the past decade, he has co-led several large-scale genomic projects funded by Genome Canada, Genome BC and industrial collaborators. Since the

inception of the PROOF Centre of Excellence, which focuses on biomarker development for end-stage organ failures, he has held the position of the Chief Informatics Officer of the Centre. From 2009 to 2014, Dr. Ng was the associate director of the NSERC-funded strategic network on business intelligence.



Louise Pelletier

Dr. Louise Pelletier is the senior medical adviser with the Centre for Surveillance and Applied Research of the Health Promotion and Chronic Disease Prevention Branch, Public Health Agency of Canada. She has also worked at the regional level, and internationally as a medical epidemiologist with WHO for nearly 2 years. She has extensive experience in chronic and infectious disease surveillance, and in disease prevention and control. In collaboration with the Provinces and Territories, she has been involved in the development of one of the most robust surveillance system on chronic diseases in Canada. This national collaborative surveillance model, the Canadian Chronic Disease Surveillance System (CCDSS), is

based on the linkage of administrative databases and all the challenges encountered in combining data such as technical and procedural. She obtained her Medical Degree at Université Laval, a Master of Public Health at Johns Hopkins University, and her Public Health and Preventive Medicine specialty with the University of Ottawa.



Mark Phillips

Mark Phillips works in comparative privacy and data protection law, particularly where it intersects with health data sharing. His academic background is in law and computer science, and he is a practicing member of the Quebec Bar Association. He works at the Centre of Genomics and Policy at McGill University as an Academic Associate, and is the co-chair of the Data Protection Task Team of the Global Alliance for Genomics and Health's Research and Ethics Work Stream. He plays a leading role in the ethico-legal module of the Cancer Genome Collaboratory, a novel international genomic cloud data-sharing initiative. His comparative legal research focuses on topics including cloud computing, the

identifiability of personal data, bioinformatics, and open data.

Katerina Podolak

Katerina Podolak is the Group Manager for Data Acquisition and Disclosure at Cancer Care Ontario, working with data partners to bring data into CCO, and health system partners who want access to CCO data. Katerina has extensive experience with information management in the hospital setting, as well as Ontario's Ministry of Health and Long-term Care, where she imbedded the use of timely data into program design and implementation cycles, as well as health system strategy.

Theresa Radwell

Theresa Radwell is the Vice President Program Investment at the Alberta Cancer Foundation and is responsible for the strategic development, leadership and management of the investments made by the Alberta Cancer Foundation in research, prevention, screening and enhanced care. Theresa joined the Foundation in January 2011 from her role as Associate Director in the Southern Alberta Cancer Research Institute (now Arnie Charbonneau Cancer Institute) overseeing the business and operational functions of cancer research in southern Alberta. Prior to working in cancer research environment, Theresa has accumulated over twenty years of experience in senior roles within the financial services sector in the United Kingdom, primarily in the areas of strategic marketing, customer and stakeholder relationship management and overseeing distribution channels of major organizations in this sector.



Negar Razavilar

I am a Health Economist and Data Analyst at the IHE. I received my PhD in Economics from the U of A under the supervision of Dr. Christopher McCabe in 2016. Before joining the IHE in August 2017, I had been working within Dr. McCabe's research team at the Department of Emergency Medicine Research at the U of A since May 2014. My areas of specialization/interest are Health Economics, Applied Microeconomics, and Applied Econometrics. My PhD dissertation includes three essays on the economic causes and consequences of health behaviours. I have also been

working on a number of projects on the economic evaluation of drugs/health technologies.

October 25-26, 2017
Hotel Alma, University of Calgary
Calgary, Alberta, Canada
Data Access/Data Integration



Beate Sander

Dr. Beate Sander's areas of expertise include health economics, decision analysis and simulation, infectious disease epidemiology, and population health decision-making. Her roles include Scientist & Director, Population Health Economics Research, University Health Network; Director, Health Modeling & Health Economics, THETA collaborative; Associate Professor & Faculty Lead HTA program, University of Toronto; and Adjunct Scientist for both Public Health Ontario and ICES. Beate currently leads large multidisciplinary international teams evaluating Zika and West Nile virus mitigation strategies using data-driven simulation models, and estimating the burden of infectious diseases using linked population-based data. She has spearheaded the linkage of laboratory and reportable disease data with administrative data, enabling novel approaches to study the burden of infectious diseases.



Marg Semel

Marg is an experienced health professional with over 30 years' experience in Alberta's Health Care System. She holds a MHA from University of Alberta and completed Alberta Health Service's Executive Education program in 12/13. Marg began her career at the Alberta Legislature supporting MLA's, transitioned to Alberta Hospitals and Medical Care (now Alberta Health) and then to Calgary as a Manager, Regional Manager, Director and Executive Director Patient Care in Nursing Administration, Surgery, Anaesthesia, Medicine, Women's Health and most recently with CancerControl Alberta as Executive Director, Cancer Measurement Outcomes Research and Evaluation. Marg is experienced in operational and strategic planning, leading change, facilitating inter-professional collaboration and team building. She is married with 2 adult children.



Kim Simmonds

Dr. Kimberley Simmonds, PhD, Director, Health Evidence & Policy, Alberta Ministry of Health. Dr. Simmonds has a PhD in hospital epidemiology with expertise in research methodology, infectious disease epidemiology and surveillance. Her current role has responsibilities including: leading provincial health technology assessments, collaborating with key stakeholders at the local, provincial, and national levels to ensure evidence is available to guide policy and to progress the liberation of health data in Alberta. Kim is an adjunct professor at the University of Calgary and University of Alberta.



Khokan Sikdar

Dr. Khokan C. Sikdar is a Biostatistician and Applied Health Research Scientist. He received a Ph.D. in Biostatistics/Community Health from Memorial University of Newfoundland. Khokan is currently in the role of an interim Director of Surveillance and Reporting, CancerControl Alberta, Alberta Health Services, and an Adjunct Assistant Professor with the Community xgHealth Science, Cumming School of Medicine, University of Calgary. With more than 10 years of experience in research and management roles, Khokan has gained considerable expertise in biostatistics, epidemiology, public health, privacy and ethics, as well as the development and utilization of administrative health data, population-based cancer registry, cardiac registry, survey, surveillance, and clinical trial data for research. Over the years, Khokan has been involved in a number of projects in a variety of health research areas, including studies that focus on breast and colorectal cancer, cardiovascular diseases, diabetes, hypertension, psoriasis and adverse drug reactions.



Larry Svenson

Larry Svenson is the Provincial Health Analytics Officer and Executive Director for Analytics and Performance Reporting at Alberta Health. He is responsible for working with internal and external stakeholders to strengthen the analytic capacity of Alberta's health sector, and the promotion of evidence-based decision-making. Dr. Svenson is an Associate Professor with the Division of Preventive Medicine at the University of Alberta, and holds Adjunct Professor appointments with the University of Alberta School of Public Health and University of Calgary Cumming School of Medicine. He holds a PhD from Manchester Metropolitan University and is a Fellow in the Royal Society for Public Health. He has over 25 years of experience working in public health playing a leadership role in strengthening public health surveillance systems provincially and nationally. Larry is a member of the Public Health Agency of Canada expert surveillance advisory committees for cardiovascular disease, arthritis, chronic respiratory disease, neurological conditions, and diabetes. He recently chaired the National Surveillance Infrastructure Task Group of the Public Health Network Council of Canada, that developed a public health surveillance blueprint for Canada.



Cas Taylor

Cas Taylor is an epidemiologist at the Public Health Agency of Canada. Using her experience in infectious disease surveillance, she is currently the Federal Lead for the development of the Technical Annexes to the Multi-Lateral Information Sharing Agreement, a federal/provincial/territorial agreement on the sharing of data in support of the surveillance, case management, and response for communicable disease and public health events in Canada.

October 25-26, 2017
Hotel Alma, University of Calgary
Calgary, Alberta, Canada
Data Access/Data Integration



Adrian Thorogood

Adrian (B.A.&Sc., B.C.L./LL.B.) is a lawyer and Academic Associate at the Centre of Genomics and Policy (CGP) at McGill University in Montreal, Canada. He manages the Regulatory and Ethics Work Stream of the Global Alliance for Genomics and Health (GA4GH). This international public-private consortium frames policy and establishes technical standards to accelerate the sharing of genomic and health related data and improvements in human health. Adrian manages the development of policies addressing consent, privacy and security, data access, and research oversight that enable responsible data sharing between countries, institutions, and sectors. Adrian's legal research focuses on how law and policy need to adapt in an era of Big Data, precision medicine, and international collaboration. Adrian is a guest lecturer in the McGill Department of Human Genetics, and runs regular workshops for researchers and the public on the privacy, confidentiality, and "ownership" of genomic and health data.



Hussain R. Usman

Dr. Hussain R. Usman is currently working for Alberta Health Services (AHS) as Executive Director, Public Health Surveillance and Infrastructure. He comes with a diverse and unique set of experience and background consisting of degree in medicine (M.B.B.S.), M.Sc. in Epidemiology, Dr.P.H. in Public Health, and Fellowship in Public Health Informatics from the Centers for Disease Control and Prevention (CDC), Atlanta. With over 15 years of public health experience and significant accomplishment, Dr. Usman has authored many high impact peer reviewed articles and is a well-versed speaker on the topic of public health surveillance, research, big data, and data visualization.



Charles Victor

Mr. Charles Victor, MSc, PStat, is the Senior Director, Research and Data at the Institute for Clinical Evaluative Sciences (ICES). In his role he oversees all research and data operations including data acquisition, cleaning and maintenance, analysis and reporting resulting in the production of over 300 high impact peer-reviewed publications per year for the Institute and its scientists. Over the past two years Mr. Victor has played in integral role in the development of ICES Data and Analytic Services, a unit aimed at providing high quality research ready health services data and analytic reports to clinical researchers and health system stakeholders across Canada. He has over 15 years of experience as an epidemiologist and professional biostatistician, with expertise spanning 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 a senior lecturer 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 for clinical epidemiologists at the University of Toronto.