



ACCESSING DATA for HEALTH RESEARCH

WEDNESDAY, OCTOBER 11, 2023

CONFERENCE PROGRAM



University
of Victoria

Institute on Aging
& Lifelong Health

TERRITORIAL ACKNOWLEDGEMENT

We acknowledge and respect the Lək'wəŋən peoples on whose traditional territory the University of Victoria stands, and the Songhees, Esquimalt and WSÁNEĆ peoples whose historical relationships with the land continue to this day.

CONFERENCE AGENDA

9:00 AM -
9:10 AM

Welcome & Territorial Acknowledgement

Sarah Nutter

9:10 AM -
10:05 AM

**Health Data Research Network Canada and the
Pan-Canadian Health Data Strategy**

Kim McGrail

Stretch Break

10:15 AM -
11:10 AM

Population Data BC

Joanne Kirton

Stretch Break

11:20 AM -
12:15 PM

Health Data Platform BC

Dinki Thakkar

Lunch Break

1:00 PM -
1:55 PM

Using CanPath to Support Innovative Health Research

Parveen Bhatti & Sheraz Cheema

Stretch Break

2:05 PM -
3:00 PM

**Canadian Longitudinal Study on Aging – What It Is and How to
Access It**

Theone Paterson

Stretch Break

3:10 PM -
4:25 PM

UVic Libraries: Supporting Researchers With Their Data Needs

Zahra Premji, Daniel Brendle-Moczuk & Herbert Schuetze

4:25 PM -
4:30 PM

Closing Remarks

Jae-Yung Kwon

Health Data Research Network Canada and the Pan-Canadian Health Data Strategy

9:10 AM - 10:05 AM

The term “health data” includes population health, public health, and health system data. Health Data Research Network Canada is a not-for-profit organization that recognizes the need for access to multi-jurisdictional data that will allow researchers to address health challenges that cross boundaries. The network brings together provincial, territorial, and federal organizations that hold and manage and/or support data use. The Pan-Canadian Health Data Strategy is being developed by the federal government in collaboration with the provinces and territories to improve the creation, exchange, and use of critical health data for the benefit of people in Canada. This session will describe Health Data Research Network Canada as well as the development of the Pan-Canadian Health Data Strategy, its current status, and plans for the future.

About the Speaker:



Kimberlyn McGrail is a Professor at UBC in the School of Population and Public Health and the Centre for Health Services and Policy Research. She is Scientific Director of Health Data Research Network Canada and Population Data BC, and was part of the Expert Advisory Group for the Pan-Canadian Health Data Strategy. She is currently a member of the Global Partnership on Artificial Intelligence. Her research interests include: ethical and technical aspects related to the development and operation of large linked data systems; aging and the use and cost of health care services; and quantitative policy evaluation.

Population Data BC

10:15 AM - 11:10 AM

Population Data BC (PopData) facilitates interdisciplinary research on the determinants of human health, well-being, and development by supporting access to an extensive collection of population health data. Data sets include longitudinal, person-specific, de-identified data on 5.3 million residents in BC. With PopData, data from one source can be linked to information on the same individual in another source. Linking data makes it possible for researchers to gain a more comprehensive understanding of a question than what can be obtained from a single data source. This session will provide an overview of Population Data BC, the types of data currently available, the types of questions it can be used to address, and information regarding data access.

About the Speaker:



Joanne Kirton is the Lead for Data Access Research and Development for Population Data BC at UBC. She manages the DAU (Data Access Unit) which provides academic researchers with access to a vast and comprehensive population health data collection.

Joanne has a foundation in Sociology and Anthropology and a clinical background in midwifery. Additionally, she has extensive experience as the primary data access point for Perinatal Service BC. With this combination of expertise, Joanne has efficiently streamlined data access for academics and researchers.

Health Data Platform BC

11:20 AM - 12:15 PM

Health Data Platform BC supports research and analysis in the health sector and academia by providing access to health data from multiple organizations on a single secure platform. The platform is being developed by the BC Ministry of Health, CIHR's Strategy for Patient Oriented Research, the BC SUPPORT Unit and the Province of BC. The goal is to improve access to health data for analysis in BC by providing timely, secure access to integrated multi-organizational health data; increasing process transparency and efficiency; and increasing appropriate use of health data. Access to the platform is project based. This session will describe the development of the Health Data Platform; current data holdings, and how the data can be accessed.

About the Speaker:



Dinki Thakkar is a Program Director working on Health Data Platform BC with the Ministry of Health. She completed her master's in electrical engineering from New York University and has over 12 years of experience building products and services in different industries within the US and Canada. Dinki has experience leading and strategizing product builds backed by multiple data contributors. She joined the Ministry and Health Data Platform in 2023 and is primarily focused on user experience, scalability, and platform enhancements.

Using CanPath to Support Innovative Health Research

1:00 PM - 1:55 PM

The Canadian Partnership for Tomorrow's Health (CanPath) combines seven cohort studies from across Canada. Collectively, these include over 330,000 participants who have provided health information and biological samples to help researchers learn more about how environment, lifestyle, and biology contribute to cancer and other chronic conditions. Researchers can link CanPath's harmonized and de-identified health and biological information to provincial and national administrative data repositories to support pan-Canadian research. The cohort is designed to facilitate collaboration with other large-scale international research initiatives such as the UK Biobank. This session will describe CanPath and the BC Generations Project (BCGP), one of the cohort studies that contributes to CanPath, including the types of questions the data can be used to address, and how the data can be accessed.

About the Speakers:



Parveen Bhatti is a Distinguished Scientist at the BC Cancer Research Institute and Scientific Director of the BC Generations Project. He is an epidemiologist whose multidisciplinary research program focuses on using biomarkers in the context of population-based studies to identify and better understand the impacts of occupational, environmental, and behavioural factors on cancer risk.



Sheraz Cheema is the Data Manager at CanPath's National Coordinating Centre. He manages CanPath's research data, supports data requests from national and international researchers, generates datasets for approved projects, maintains data auditing programs for quality assurance purposes, and provides advice on data requirements.

Canadian Longitudinal Study on Aging – What It Is and How to Access It

2:05 PM - 3:00 PM

The Canadian Longitudinal Study on Aging (CLSA) is a national study that is following approximately 50,000 Canadians over a 20-year period. Biological, medical, psychological, social, lifestyle and economic data are being collected in three-year phases from participants who were between 45 and 85 years of age when the study began in 2012. As of September 2023, the fourth phase is well underway. CLSA data are being collected by researchers located at 11 universities across Canada, including the University of Victoria. This session will describe the design of the CLSA as well as several related substudies, the types of data that are currently available, the data access process, and the range of supporting tools and knowledge translation materials that are available.

About the Speaker:



Theone Paterson is an Assistant Professor in the Department of Psychology at the University of Victoria, a registered psychologist, and Chair of the Clinical Neuropsychology Section of the Canadian Psychological Association. She is also a Local Site Principal Investigator for the UVic site of the CLSA. Her research interests include improving understanding of the interplay between neurocognition and psychosocial functioning in aging and chronic illness groups. Aims of this work are to translate basic research to clinical settings through design and implementation of screening measures with utility in diverse groups, and to develop psychological and cognitive programs aimed at improving real-world health outcomes.

UVic Libraries: Supporting Researchers With Their Data Needs

3:10 PM - 4:25 PM

Libraries provide extensive collections and offer opportunities for researchers wishing to access data from various databases and sources to consult with librarians and other data partners. This session will describe:

- a) health-related datasets held in UVic's Dataverse Collection;
- b) how the library can facilitate access to data held by Statistics Canada, BC Stats, the Canadian Institute for Health Information and similar organizations; and
- c) how the library can assist researchers to identify and access databases held in other countries (such as the UK Biobank and the Baltimore Longitudinal Study of Aging).

About the Speakers:



Zahra Premji is the Health Research Librarian at the University of Victoria. She is the librarian for the Kinesiology, Neuroscience, Public Health, and Social Dimensions of Health programs and also supports multidisciplinary health research. She has expertise and experience conducting evidence synthesis reviews on a wide range of topics and is interested in data management as it relates to evidence synthesis.



Daniel Brendle-Moczuk is the Geospatial and Data Librarian at UVic. He is also the representative for the Statistics Canada Data Liberation Initiative and the Inter-University Consortium for Political and Social Research. He supports all disciplines and faculties with their data needs. He works with researchers in geospatial analysis to create visual presentations of data, particularly maps that convey both what and where.



Herbert Schuetze is the Director of the Statistics Canada Research Data Centre at UVic and an Associate Professor in the Department of Economics. His research has focused on issues related to self-employment, including male-female differences in self-employment dynamics, the role of labour market policies, immigrant self-employment, and self-employment among older workers. He has consulted for several government organizations on self-employment issues.

Thank you for attending the *Accessing Data for Health Research* Conference.



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