

# Importance of Data Sharing and Demystifying the Process



CHEER Webinar

**Tuesday, May 3, 2022**

9-10 PDT / 12-1 EDT

[Link to Register](#)

## Overview

By the end of this session, you will have a firm understanding of the importance of data sharing in pediatrics as well as some of the unique challenges faced by those doing research in this area. We will outline key considerations for Canadian researchers and present some newly produced tools aimed at addressing common barriers to data sharing.

## Session Topics

### **Importance of Data Sharing and Demystifying the Process**

*Holly Longstaff and Charles Burchill*

### **HDRN Privacy Legislation Tool**

*Donna Curtis Maillet*

### **HDRN Consent Tool**

*Donna Curtis Maillet*



**Holly Longstaff, PhD**

Director, Privacy and Access, PHSA Research and New Initiatives, Provincial Health Services Authority, British Columbia



**Charles Burchill**

Associated Director, Repository, Manitoba Centre for Health Policy, University of Manitoba



**Donna Curtis Maillet, PhD**

Privacy Officer, New Brunswick Institute for Research Data and Training & Research Associate, Faculty of Law, University of New Brunswick

# Speaker Bios

**Holly Longstaff, PhD**, Director, Privacy and Access, PHSA Research and New Initiatives, Provincial Health Services Authority

Holly is responsible for guiding the development, recommendation and implementation of innovative approaches to privacy policy and practice to build accountable information stewardship and privacy conscious practices that enable the execution of PHSA's expanded mandate and the conduct of health research. She advises on the privacy requirements relating to new and expanded provincial initiatives working closely with PHSA's Information, Access and Privacy, and Legal Services teams. She also provides leadership in developing and implementing governance mechanisms to enable nimble, multidisciplinary review of privacy and security requirements for new and expanded initiatives and research, including province-wide platforms and systems, digital and information technologies, and data access/sharing. Holly is a PhD level trained ethicist and research consultant. She has worked as a consultant for Health Canada, the Public Health Agency of Canada, and the CIHR Ethics Office and her work has been published in a variety of journals including CMAJ, Trends in Neurosciences and Cell Stem Cell.

**Charles Burchill**, Associated Director, Repository, Manitoba Centre for Health Policy, University of Manitoba.

Charles has been working at the Manitoba Centre for Health policy since the early 1990s taking on a variety of roles including IT support, database management, analytics, and privacy and access. The Manitoba Population Research Data Repository represents over 100 databases or programs and is supported on behalf of the Province of Manitoba for use by the local, national and international research community. Currently there are over 250 active projects using the Repository with more than half of these being lead by researchers outside of MCHP. MCHP researchers rely upon the Repository to describe and explain patterns of care and profiles of health and illness, but also enables exploration of social determinants that influence health, such as income, education, social supports, and justice involvement.

**Donna Curtis Maillet, PhD**, Privacy Officer, New Brunswick Institute for Research Data and Training & Research Associate, Faculty of Law, University of New Brunswick

Donna has been the Privacy Officer for the NB-IRDT since it originated in 2015 and is lead for the Health Data Research Network Canada Privacy Team. In addition to a background in library and information sciences, she holds an interdisciplinary PhD and has research work experience in science and technology studies and legal pluralism. Dr. Curtis Maillet has been a part-time lecturer in sociology and public policy at St Thomas University since 2014.