

# Health Data Summit

**March 28, 2011, Toronto**

OCUL is creating a Geospatial Portal with a Health Informatics component. One aspect of the portal project is to integrate and improve access to health data within the academic community using OCUL's digital access platforms.

The principal goal of the Health Data Summit is to identify and discuss creative solutions to remove existing barriers and improve accessibility to health data for research. It will also address the capabilities of Scholars Portal with respect to the anonymization and storage of health data for access by researchers. The Summit's objectives are to address the following:

- Use of existing health data, in conjunction with Statistics Canada data;
- Expand access to restricted health data to the academic community;
- Bridge researchers from Science to Social Sciences and other disciplines;
- Expand connections from academia to epidemiologists and other health data users;
- Discuss existing structures at OCUL to protect and secure health data and metadata mark-up of the data;
- Discuss issues surrounding anonymization of health data.

The potential outcomes of providing researchers with greater access to health data are significant and include the identification of emerging health threats, management of outbreaks to minimize the impact of disease, and effective treatment of patients by evidence-based decision making.

**When:** Monday, March 28, 2011

**Where:** Charbonnel Lounge, Elmsley Hall, St. Michael's College, University of Toronto, 81 St. Mary Street, Toronto. [View map](#)

**Time:** 9:00 am – 4:00 pm, Lunch will be Provided

**Registration:** Closed.

**Parking information:** Parking is available for a daily fee at [St. Michael's College](#). If this lot becomes full there are several nearby [Green P](#) lots.

[View Flyer](#)

## Program

8:30 Coffee & Muffins  
9:00 Introduction (Margaret Haines)  
9:10 Keynote (Dr. Kieran Moore)  
10:00 OCUL Scholars Portal Infrastructure (Scholars Portal Operations Team)  
10:30 Break  
10:45 Legal Expert Panel (Dr. Margaret Ann Wilkinson, Karen Weisbaum)  
11:15 Break Out Session - Legal Issues  
12:15 Lunch  
1:15 Research Panel (Dr. Iris Gutmanis, Dr. Piotr Wilk)  
1:45 Break Out Session - Research  
2:30 Break  
2:45 Solutions Discussion  
3:45 Closing Remarks and Next Steps (Jenny Marvin)

Facilitator - Meghan Kirwin

## Speaker Bios

**Dr. Kieran Moore**, MD CCFP FFCP EM DTM&H. Associate Professor in the Department of Family Medicine and Emergency Medicine, Queen's University. Director of Queen's Public Health Informatics. [www.qphi.ca](http://www.qphi.ca)

QPHI is a multidisciplinary group of medical, scientific, academic and information technology professionals working on various syndromic surveillance projects in Kingston, Ontario Canada. We work alongside health practitioners to develop, implement, and manage public health informatics systems strategically and effectively. QPHI helps end-users (from local to international) collect, analyze, manage, and translate data into information to support disease surveillance, management, and response. QPHI efforts include developing new technology solutions, educating stakeholders, informing policy, and conducting research on the appropriate use of real time public health information systems.

[Keynote Presentation Slides](#)

**Dr. Margaret Ann Wilkinson**, LLB, BA, MLS, PhD. Faculty of Law, University of Western Ontario. Director of the Area of Concentration in Intellectual Property, Information and Technology Law at Western.

Dr. Margaret Ann Wilkinson has taught "Intellectual Property, Licensing and the Regulatory Environment of Health" for a number of years in the Ivey Health Sector Program of the MBA at The University of Western Ontario (UWO). A version of the course has now been taught in the Faculty of Law as well. Professor and Director of the Area of Concentration in Intellectual Property, Information and Technology Law and Professor in the Faculty of Law at UWO, Dr. Wilkinson also holds supervisory status in the Faculty of Information and Media Studies. She has held visiting positions at Dalhousie and Newcastle Universities. Dr. Wilkinson is also a founding faculty member in the new interdisciplinary Masters of Health Information being developed at UWO. She has written and spoken widely in the areas of intellectual property, personal data protection, professionalism and ethics. Recently she is author, with her colleague Mark Perry, of "The Creation of University Intellectual Property: Confidential Information, Data Protection and Research Ethics," (2010: Special Issue, Guest Editor-Ysolde Gendreau) 26 *Canadian Intellectual Property Review* 93-122.



**Karen Weisbaum**, LLB, MA, BEd. Department of Family Medicine and Faculty of Health Sciences, Queen's University.

Karen Weisbaum is a trained ethicist and lawyer with a background in education. She teaches topics in bioethics, law and policy in the Department of Family Medicine and the Faculty of Health Sciences at Queen's University and has been a member of the Health Sciences and Affiliated Teaching Hospitals Research Ethics Board since 2004. Ms. Weisbaum is currently a co-investigator with a multi-disciplinary team examining ethical and legal issues related to privacy in pre-eclampsia research in one study and for another study about public understandings of science. Since 2003, Ms Weisbaum has provided research and consulting services to a number of organizations across Canada.

[Legal Panel Presentation Slides](#)

**Dr. Iris Gutmanis**, PhD. Director, Research and Evaluation, Specialized Geriatric Services, St. Joseph's Health Care London, Parkwood Hospital.

Dr. Iris Gutmanis is the Director, Research and Evaluation, Specialized Geriatric Service, St. Joseph's Health Care, London, Parkwood Hospital. She is also an Assistant Professor in the Department of Epidemiology and Biostatistics, Schulich School of Medicine and Dentistry at The University of Western Ontario and an Associate Scientist in the Aging, Rehabilitation & Geriatric Care Program, Lawson Health Research Institute. Current areas of research include geriatrics with a focus on measurement issues in this population, community capacity building and knowledge exchange.



**Dr. Piotr Wilk**, PhD. Assistant Professor, Department of Paediatrics and Department of Epidemiology & Biostatistics, University of Western Ontario. Scientist, Children's Health Research Institute, London, Ontario.



Dr. Piotr Wilk's program of research focuses on the impact of child-, family- and community-level risk and protective factors on the health and well-being of young children. Dr. Wilk's current research program is funded by the Canadian Institutes of Health Research and the Public Health Agency of Canada and it aims at developing a culturally-appropriate healthy weights intervention for First Nations and Métis children.

[Research Panel Presentation Slides](#)

### **Scholars Portal Operations Team**

The presentation on the OCUL Scholars Portal Infrastructure will be given by the following members of the Scholars Portal Operations Team:

- Leanne Hindmarch, Data and Geospatial Librarian
- Steve Marks, Digital Preservation Policy Librarian
- Amaz Taufique, Senior Systems Manager

[Scholars Portal Presentation Slides](#)

**Facilitator: Meghan Kirwin**, MBA. Founder, The Kirwin Group.

Meghan founded The Kirwin Group over seven years ago based on her drive to implement positive change in organizations. She has extensive experience working with leaders as a trainer, facilitator, project leader, and coach. Her depth of experience provides a valuable and innovative approach to many organizational issues. Meghan completed her Masters of Business Administration program specializing in the areas of Management and Organizational Behaviour at Wilfrid Laurier University.

