



QUEEN'S UNIVERSITY LIBRARY



# Research Data Management at Queen's

Sharon Murphy  
Head, Academic Services

Jeff Moon  
Data Librarian &  
Academic Director, Queen's Research Data Centre



<http://www.betakit.com/wp-content/uploads/2014/06/Open-data.jpg>

[http://www.library.gatech.edu/research-data/sites/library.gatech.edu/research-data/files/images/whatisdigitalpreservation\\_hvaderdigitalbevaring\\_digitalpreservation.png](http://www.library.gatech.edu/research-data/sites/library.gatech.edu/research-data/files/images/whatisdigitalpreservation_hvaderdigitalbevaring_digitalpreservation.png)

[https://www.asme.org/getmedia/700e0777-13ad-486d-ba10-0b1437597280/Embedding\\_Ethics\\_in\\_Engineering\\_Education-hero.jpg.aspx?width=460](https://www.asme.org/getmedia/700e0777-13ad-486d-ba10-0b1437597280/Embedding_Ethics_in_Engineering_Education-hero.jpg.aspx?width=460)



# Benefits of Research Data Management:



- **ensure long-term preservation of data for future researchers**
- **meet grant requirements and/or produce a more competitive grant application**
- **increase the impact and visibility of your research**
- **encourage discovery and use of existing data to explore new research questions**
- **make sure your data are accurate, complete, authentic, and reliable, and reusable**
- **ensure compliance with ethics and privacy policies**



# **Funding Agency Policies**

**2013 Granting Councils Consultation Document**

**NSERC, SSHRC, CIHR, CFI, and Genome Canada**

**Towards a Policy Framework for Advancing  
Digital Scholarship in Canada**



# Current CIHR Policy

## CIHR

“Grantees must deposit bioinformatics, atomic and molecular coordinate data into the appropriate public database immediately upon publication of research results (e.g., deposition of nucleic acid sequences into GenBank). Refer to the [Annex](#) of this policy for examples of research outputs and the corresponding publicly accessible repository or database.

Data retention, as already required by the majority of institutions, is mandated by CIHR. Grantees must retain original data sets arising from CIHR-funded research for a minimum of five years after the end of the grant. This applies to all data, whether published or not. The grantee's institution and Research Ethics Board may have additional policies and practices regarding the preservation, retention and protection of research data that must be respected.”



# Archiving Research Data

## CIHR

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# Queen's University Library

## Research Data Management Service

*We can help you with:*

- ***Planning for data management***  
data management plans & grant applications
- ***Preparing your data***  
coding, formatting, anonymizing, and more
- ***Documenting your data***  
describing your data so others can understand and use it
- ***Archiving your data***  
finding an appropriate repository or archive
- ***Making your data discoverable***  
promoting open access, indexing, assigning DOI's



# Queen's Library Data Services

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## **Epidemiology of Neuropathic Pain in Canada, 2012**

The purpose of this study is to estimate the prevalence of "pain of predominantly neuropathic origin" (POPNO) in Canada and its associated resource utilization. The primary objective is to estimate and compare the prevalence of POPNO using two screening tools that were recently used to document the prevalence of POPNO (S-LANSS) and pain with neuropathic characteristics (DN4) in the general population. The secondary objective is to quantify the association between POPNO and resource utilization and costs.

**Lead Researcher:** Elizabeth VanDenKerkhof, Department of Anesthesiology and Perioperative Medicine and School of Nursing, Queen's University

**Embargoed:** data and documentation will be available in January 2016

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## **Practice and Research in Nursing (PRN) Wound Studies, 1999-2009**

PRN Wound Studies consists of 6 studies examining the treatment and delivery of care for leg ulcers.

**Research Group:** [Practice and Research in Nursing Group](#)

**Access:** [QSpace](#) | [Dataverse](#)

**Restrictions:** Queen's University IP

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## **Understanding Chronic Pain Following Surgery in Women, 2006-2009**

The object of this study was to evaluate the incidence of, and risk factors for, chronic post-surgical pain in women undergoing gynecologic surgery.

**Lead Researcher:** Elizabeth VanDenKerkhof, Department of Anesthesiology and Perioperative Medicine and School of Nursing, Queen's University

**In progress**





# Queen's Library Data Services

## **The Globalization of Personal Data (GPD) Project International Survey on Privacy and Surveillance**

The Globalization of Personal Data (GPD) was an international, multi-disciplinary and collaborative research initiative drawing mainly on the social sciences but also including information, computing, technology studies, and law, that explored the implications of processing personal and population data in electronic format from 2004 to 2008. The GPD project was conducted in nine countries: Canada, U.S.A., France, Spain, Hungary, Mexico, Brazil, China, and Japan. Three data files were produced: a Seven-Country file (Canada, U.S.A., France, Spain, Hungary, Mexico, and Brazil), a China file, and a Japan file.

**Research Group:** Surveillance Studies Centre, Department of Sociology, Queen's University

**Access:** [QSpace](#) | [Dataverse](#) | [<odesi>](#)

[QSpace](#) | [Dataverse](#) | [<odesi>](#)

**Queen's  
Institutional  
Repository**

**Scholars Portal  
Data Archiving Tool**

**Scholars Portal Data  
Discovery/Exploration  
Portal**



## Beyond Queen's – Discipline-specific Data Repositories

<a href="#">Biospecimens/Biorepositories: Rare Disease Hub (RD-HUB)</a>	The Biospecimens/Biorepositories Database: Rare Disease-HUB (RD-HUB) contains a searchable database of biospecimens and is designed to assist interested parties and investigators search, locate, and identify desired biospecimens needed for the research and to facilitate collaboration and sharing of material and data among investigators across the globe. RD-HUB links to the <a href="#">Global Rare Diseases Patient Registry and Data Repository (GRDR)</a> via the GRDR Global Unique Identifier (GUID).
<a href="#">The Cancer Imaging Archive (TCIA)</a>	The Cancer Imaging Archive (TCIA) is a large archive of medical images of cancer accessible for public download. All images are stored in DICOM file format. The images are organized as "Collections", typically patients related by a common disease (e.g. lung cancer), image modality (MRI, CT, etc) or research focus.
<a href="#">PeptideAtlas</a>	PeptideAtlas is a multi-organism, publicly accessible compendium of peptides identified in a large set of tandem mass spectrometry proteomics experiments. Mass spectrometer output files are collected for human, mouse, yeast, and several other organisms, and searched using the latest search engines and protein sequences.

**Full list at NIH**



# Beyond Queen's – Discipline-specific Data Repositories

Research data	Public database or archive
Nucleic acid sequences	<a href="#">GenBank</a>
Gene expression data	<a href="#">Gene Expression Omnibus</a>
Structure data	<a href="#">Research Collaboratory for Structural Bioinformatics (RCSB) Protein Data Bank</a>
Single nucleotide polymorphisms (SNPs)	<a href="#">The Single Nucleotide Polymorphisms Database</a>
Molecular interaction data	<a href="#">International Molecular Exchange Consortium (IMEx) partners</a>
DNA and clinical data related to the human major histocompatibility complex (MHC).	<a href="#">dbMHC</a>
Data underlying scientific and medical publications	<a href="#">Dryad Repository</a>
Proteomics data <sup>3</sup>	<ul style="list-style-type: none"><li>• <a href="#">PRoteomics IDentifications database (PRIDE)</a> [European Bioinformatics Institute (EBI)]</li><li>• <a href="#">PeptideAtlas</a> [Institute for Systems Biology (ISB)]</li><li>• <a href="#">Global Proteomics Machine (GPM)</a></li></ul>

Full list at CIHR



# PORTAGE



## QUEEN'S UNIVERSITY LIBRARY



**Jeff Moon –**

Data and Government Information Librarian  
Academic Director, Queen's Research Data Centre  
[moonj@queensu.ca](mailto:moonj@queensu.ca)  
Ext. 77992

**Sharon Murphy –**

Head, Academic Services  
[murphys@queensu.ca](mailto:murphys@queensu.ca)  
Ext. 32836