

# The Health Research Data Repository

*“Supporting health research, Promoting sound data management”*

## What is the Health Research Data Repository?

Based within the Faculty of Nursing at the University of Alberta, the HRDR is a secure and confidential virtual research environment (VRE) created to support health related research projects, to support collaboration across research disciplines, to house health research data and meta-data throughout their life-cycle, and to promote the secondary use and re-purposing of health research data. The HRDR also has a mandate to promote and offer educational opportunities regarding research data management best practices. The mission of the Health Research Data Repository (HRDR) is to stimulate both qualitative and quantitative health related research while building a collaborative culture of respect relating to data management and confidentiality.

## The Importance of sound Data Management

The [Tri-Agency Statement of Principles on Digital Data Management](#) states:

### Data Management Planning

*“Data management planning is necessary at all stages of the research project lifecycle, from design and inception to completion.*

*Data management plans are key elements of the data management process. They describe how data are collected, formatted, preserved and shared, as well as how existing datasets will be used and what new data will be created. They also assist researchers in determining the costs, benefits and challenges of managing data. They should be developed using standardized tools, where available.” (Section 3. Expectations. Data Management Planning)<sup>1</sup>*

The [TCPS 2 - Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans](#) states:

*“In addition to the security measures researchers implement to protect data, safeguards put in place at the institutional or organizational level also provide important protection. These data security safeguards should include adequate physical, administrative and technical measures, and should address the full lifecycle of information. This includes institutional or organizational safeguards for information while it is currently in use by researchers, and for any long-term retention of information” (Article 5.4 Explanatory Text)<sup>2</sup>*

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<sup>1</sup> Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement of Principles on Digital Data Management*, modified December 2016.

<sup>2</sup> Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, December 2014.

## How can the Health Research Data Repository help *my* research project?

### The HRDR provides:

- **A secure and confidential environment** for housing and managing sensitive research data, allowing research teams to safely and securely work with data across the lifecycle of their projects while meeting security requirements imposed by grant funding agencies, institutions, and data stewards
- **Secure remote access** allowing research teams to securely access their data at any time and from anywhere. Research collaboration is promoted through these remote access components as they allow geographically distant researchers, and those with specialized knowledge and/or skillsets to collaborate securely and safely
- **Access to a regular suite of analytic software**, including SPSS, SAS, Nvivo, MPlus, Stata, Atlas.ti, MSOffice, (including Excel and Access), 'R' & R Studio, Notepad++.and StatTransfer, and Windows Media Player. Additional software packages are assessed and implemented on a case by case basis
- **Data management guidance** for research teams on topics that include, but are not limited to, folder and file structures, naming conventions, file versioning, data quality assurance and processing, and data/metadata capture and retention
- **Educational opportunities** in the form of presentations and workshops to its users relating to key topics in the area of research data management best practices in an effort to help build a sustainable culture of respect relating to sound research data management

### Health Research Data Repository: Current Status (January 2017)

- ✓ Operational phase commenced January 2013
- ✓ Working group established to support overall infrastructure and daily operational activities
- ✓ Cost recovery model finalized – able to support projects of all sizes
- ✓ Software currently available within the HRDR include: **SPSS, SAS, Nvivo, MPlus, Stata, Atlas.ti, 'R' & R Studio, Microsoft Office, Notepad++, and StatTransfer**
- ✓ To date, approved users accessing the HRDR have included **~250 users spanning in excess of 75 research projects**
- ✓ Approved users accessing and supporting research projects housed within the HRDR include **researchers at local, national, and international institutions** (US, UK, Germany, Spain, Australia, Sweden, and Denmark)
- ✓ **Presentations given at both local, national, and international conferences** (*IASSISTs 2013* (Cologne, Germany), *2014* (Toronto, Canada), & *2015* (Minneapolis, MN); *Open Repositories 2013* (PEI, Canada); *NADDI 2015* (Madison, WI); U of A Research Data Management weeks 2013-2016; Margaret Scott Wright Research Day 2013-2015)
- ✓ Ongoing educational sessions relating to research data management best practices

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