An Overview of the University of Alberta Health Research Data Repository

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A bit of my background....

- Educational background in social sciences (Psych & Criminology)
- ~13 years experimental research experience in social and health sciences:
  - ASD-CARC (Queen’s University; $5 million, 5 year, CIHR);
  - Roots of Youth Violence (U of T; $1 million, 1 year, TDSB))
  - Translating Research Elder Care (U of A; $4.7 million, 5 year, CIHR)
- Co-lead role in developing the U of A Health Research Data Repository (HRDR); 2009-2012
- Oversee management of the HRDR – operational phase began Jan 2013
Health Research Challenges: A Bird’s Eye View

- Lack of specific training & skills
- Lack of/unclear, data policies & standards
- Limited resources (immediate → institutional)
- Business model = Research = Limited and soft funding
- Incentives for managing data are not always recognized or immediate
“The HRDR is a secure virtual research environment (VRE) which guarantees the confidentiality and security of personal health information and research data...by employing clearly operationalized, industry standard “data stewardship” protocols that help to govern access to data as well as its analysis, storage, preservation, and curation.”
HRDR: Two broad strokes

1. **Risk reduction:**
   - Data security
   - Participant confidentiality
   - Data access
   - Data loss prevention

2. **Data Management:**
   - Data management plans
   - Primary data collection support
   - Data acquisitions
   - Data quality assurance
   - Data retention/archival/curation
Ok, so what is the HRDR??

- Comprehensive research data platform developed to support health based research
- The HRDR is not just one thing, but rather it is a collection of physical, technical, process, and educational related services
What is the HRDR?

- Secure virtual research environment (VRE) – remote access 24/7
- Located in Faculty of Nursing, U of A
- Operates off of the Citrix Receiver platform
- Developed to support health related research
- Regular suite of analytic software provided
- Lots of different types of projects & data: Quantitative, qualitative, personal health information...
- Standard and custom desktops & applications available
Why is there a need for the HRDR?

The minimum security required is justified by the most sensitive variables

The TRI-Council policy statement on ethical conduct for research involving humans states that data must be stored with all precautions appropriate to the sensitivity of the data.
Why is there a need for the HRDR?

As health research increasingly become more complex, there is a need for structured, secure environments to house them and to provide management support throughout their lifecycle.

“But what can the HRDR do for my research?”

- **Competitive advantage** during grant applications
- **Secure environment for housing data**—advantage for data acquisition requests, PIAs, funding applications, etc.
- **Securely access data** and related files from anywhere
- **Data management guidance/support throughout their lifecycle**
- **Provide analytic software**
- **Secure central transcribing service**
- **Enhances potential collaboration**
- **Increase visibility and impact** of research—potential for repurposing, open access, data citations, etc.
HRDR Current Status

Projects: >60 research projects
Approved active users: ~150
18 FoN Tenure Track Faculty members with active projects....and more coming!
HRDR Regular Suite of Software
Accessing the HRDR

Download Citrix Receiver

Access apps and desktops on any device

Citrix Receiver is the easy-to-install client software that provides access to your XenDesktop and XenApp installations. With this free download you can access applications, desktops and data easily and securely from any device, including smartphones, tablets, PCs and Macs.

Download Receiver 4.2.100 for Windows

Enter username/password

Citrix Receiver

User name: jdoiron
Password: ********
Log On
Choose a desktop....

Or an application.....
Bird’s eye view: HRDR project set-up

1. Grant funding application support:
   Initial resources assessment; Cost recovery estimate; HRDR budget line; Letter of support provided

2. Ethics application support
   Data handling, storage, access retention, etc.; Alignment of consent forms/contractual agreements

3. Detailed project assessment
   Detailed resource assessment: timelines, software, users, data types/magnitude; Note details re data – long/short term; finalized cost recovery assessment

4. Project space set up in HRDR
   Folder structure; Access rights determined; Quality assurance support (i.e., protocols, file naming conventions, etc.); Ingestion of existing files; HRDR Transfers folder in/out of project space;

5. Users orientation/training
   Orientation/Training session; Policies s& Procedures; Terms of Use; User accounts created; Instructions for access provided (accessing HRDR; How to securely upload files); Ongoing user support
## HRDR Cost Recovery Model

<table>
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<tr>
<th>Component</th>
<th>Services provided</th>
<th>Cost</th>
<th>Billing frequency</th>
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| **Project set-up**       | - Full project assessment  
- Assistance writing the HRDR into grant funding application and budget  
- Assistance with writing of  
- Root project space set-up  
- Folder structure development and implementation  
- Assignment of user access rights  
- Initial ingestion of project files  
- Initial user orientations                                                                                                                     | $250     | One time          |
| **Base services**        | - Project access for all approved internal NURS users  
- Orientations for all users  
- Access and use of all regular software  
- Overall development and maintenance of VRE infrastructure to ensure optimal functionality                                                         | $500     | Annual            |
| **External Users Access**| - Orientations to HRDR  
- Access to HRDR and approved project(s)  
- Ongoing technical support, as needed                                                                                                           | $150/user| Annual            |
| **Non-regular Software licensing** | - When applicable, software licensing costs for any non-regular software                                                                                                                                             | Determined by licensing cost and number required | Annual |
| **Project specific**     | *Indicators are:  
- Number of users  
- Number of transactions  
- Usage  
- Amount of data                                                                                                                                     | Tier 1 = $0  
Tier 2 = $500  
Tier 3 = $1000 | Annual  |
HRDR True Stories!

- PhD candidate currently collecting qualitative interviews in Ghana and securely uploading to the HRDR
- Custom multi-day SAS/RAI data workshops for 10+ users
- Scoping review project with a dozen international reviewers accessing
- CIHI data acquired and used for PhD dissertation – free via graduate student program
- Secure central transcribing service – over 200 interviews/focus groups securely transcribed
- TREC LMS Data Platform Project: CFI funded ($1 million CAD; DDI friendly metadata platform to support TREC 1.0, 2.0, & beyond
HRDR Forward steps in ‘15/’16

* Continued enrollment within the FoN
* HRDR as part of regular orientation to new faculty
* Scaling beyond FoN
* Cost recovery /sustainability
* Educational opportunities, including focused workshops
* HRDR audit
* Beyond security and storage (i.e., data mgmt platforms, metadata capturing (DDI), curation, linkages w/ other repositories/platforms, etc...........
Questions?

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