HRDR Mission Statement

"The HRDR will create an environment which guarantees the confidentiality and security of personal health information and research data…by employing clearly operationalized, industry standard "data stewardship" protocols that govern access to data as well as its analysis, storage, preservation, and curation."

HRDR
Health Research Data Repository

What is the HRDR?

- Secure confidential virtual environment for supporting health research and multi-disciplinary collaboration

- Based in the Faculty of Nursing, U of A

- Houses health research data and metadata throughout their lifecycle

- Encourages data management based on best practices

- Promotes secondary use and re-purposing of research data

- Minimal cost recovery

HRDR
Health Research Data Repository

HRDR: Immediate Researcher Benefits

- Risk Reduction
- Competitive research advantage
- Secure remote access
- Regular suite of analytic software provided
- Data Management Guidance
- Educational Opportunities

HRDR
Health Research Data Repository

Why is there a need for the HRDR?

Ensures compliance with funding agency policies:

- **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

The minimum security required is justified by the most sensitive variables

- **CIHR** has begun to request data management plans with grant applications, requires retention of data files for min. 5 yrs, & depositing of appropriate data into public databases upon publication
- **SSHRC** requires research data to be made available for use by others within a "reasonable amount of time", typically 2 years

HRDR
Health Research Data Repository
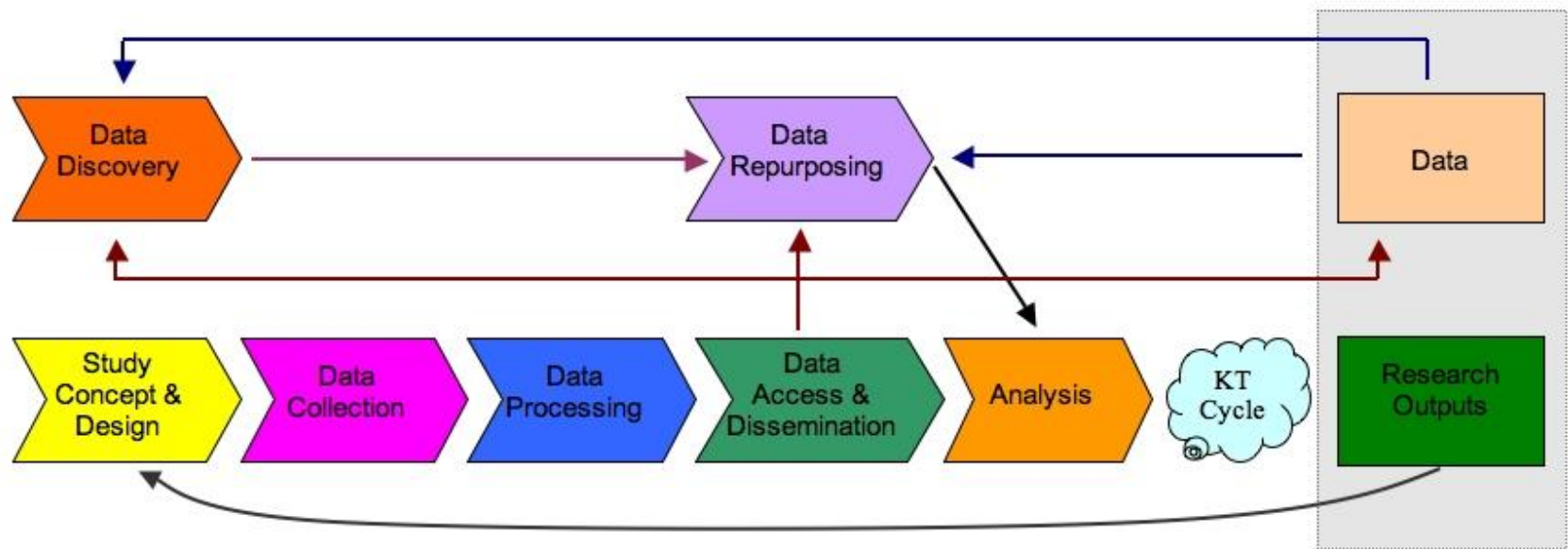
Why is there a need for the HRDR?

Data Management: cost of managing vs. not managing data

"Maintaining a reliable, managed environment for protecting the considerable investment involved in creating research data represents a comparatively small cost when placed against the prospect of the higher and perhaps prohibitive costs or re-creation later on or the complete and irretrievable loss of data"

CARL, Research Data: Unseen Opportunities (2009)

HRDR
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Why is there a need for the HRDR?

As data increasingly become more complex, there is a need for structured, secure environments to house them within and to provide support throughout their lifecycle

HRDR Research Project Enrollment

1. **Project request made to HRDR Manager**

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2. **Policies & Procedures reviewed; 'Terms of Use' signed**

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3. **Project Discovery meeting**

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4. **Approved users' access**

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5. **Folder structure developed**

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6. **Secure ingestion of Data/Metadata**

HRDR Current Status: March '13

- ✓ Operational phase commenced January 2013
- ✓ Working group established to support overall infrastructure and daily operational activities
- ✓ Working Policies & Procedures revised and finalized
- ✓ Analytic software: SPSS, STATA, SAS, Mplus, Lisrel, Nvivo, and MSOffice
- ✓ Current approved users include over thirty researchers spanning ten research projects
- ✓ Approved users include researchers at local, national, and international institutions
- ✓ Delivery of educational sessions in progress; first HRDR presentation offered January 2013

HRDR
Health Research Data Repository

HRDR Moving forward in 2013

- Continued User Participation
- Educational sessions & workshops
- User Engagement & Project presentations
- Citrix
- Audit at end of 2013

And Beyond….

- Access to archived data

Questions?

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