Development of the Health Research Data Repository and the TREC Longitudinal Monitoring System

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What is the HRDR?

- Secure virtual environment for housing and managing health research data and metadata throughout their lifecycle
- Based in the Faculty of Nursing, University of Alberta
- Supports and promotes health research and multi-disciplinary collaboration
- Provides secure remote access to data and a regular suite of analytic software
- Clearly operationalized policies and procedures, with user orientation process
- Operates on a ‘minimal cost recovery’ basis
- Promotes and provides educational opportunities regarding data management based on best practices
- Promotes secondary use and re-purposing of research data
HRDR Current Status: May ‘13

✓ Manager of HRDR position funded and filled, November 2012
✓ Operational phase commenced January 2013
✓ Working group established to support overall infrastructure (Admin, Tech, & Physical) and daily operational activities
✓ Working Policies & Procedures revised and finalized
✓ Regular suite of analytic software: SPSS, STATA, SAS, Mplus, Nvivo, and MSOffice
✓ Approved users include researchers at local, national, and international institutions
✓ Delivery of educational sessions in progress; first HRDR presentation offered January 2013
✓ Current approved users include over fifty researchers spanning sixteen research projects
HRDR Forward steps 2013/2014

- Continued enrollment within FoN
- HRDR as part of regular orientation to new faculty
- Cost recovery (i.e. ‘regular’ usage costing scenarios)
- Expansion beyond FoN (i.e., Public Health, Campus Alberta)
- Educational opportunities, including focused workshops
- External audit (4th quarter 2013)

- Beyond security and storage (i.e., curation, DDI,...)
- KUSP/TREC LMS Data Infrastructure Project
Translating Research in Elder Care (TREC) Project

- PI Dr. Carole Estabrooks (T1 Canada Research Chair in KT)
- 5 year (2007-2012), $4.7 million CAD, CIHR funded
- Research program assessing the influence of organizational context on the use of knowledge (especially research) and, in turn, the influence of knowledge use on long-term care residents’ outcomes
- Practical objective is to contribute to improving the quality of care and quality of life/end of life for residents living in residential LTC settings and quality of work life for care providers
- Setting is 36 residential LTC facilities across three Canadian prairie provinces—focus is at the care unit level (clinical microsystem)
- 30+ investigators, as well as policy and decision makers, trainees, staff
- Two main projects (quantitative & qualitative), and three interrelated pilot projects
Project 1: Building context
‘An organizational Longitudinal Monitoring System’

LMS Data Sources:

1. TREC care provider surveys (N= 4000)
   - Two waves of data collection
   - HCAs (75%) & regulated staff
   - ~200 variables
   - Alberta Context Tool (ACT) embedded; derived context scales
   - Administered using CAPI (HCAs) and online (regulated staff)

2. Facility Profile Survey (N=36)
   - Collected in second wave only
   - 183 variables
   - Administered in paper format by research managers

3. Care Unit Profile Survey (N=103)
   - Collected in second wave only
   - 107 variables
   - Administered in paper format by research managers

4. RAI-MDS 2.0 (N = >100,000)
   - ~500 variables
   - Collected continuously through project (Oct 2007 – Dec 2012)
   - Full Admission, Annual, and Quarterly assessments
   - Administered by care providers; data acquired from data stewards (n = 6)
Hypotheses

Context → KT → Resident Outcomes → Provider Outcomes → Context

1. Context
2. KT
3. Provider Outcomes
4. Resident Outcomes
5. Context
Technical Implementation

- Metadata Technology / Nooro
- Metadata driven infrastructure
  - Automate ingestion / processing / publications
  - DDI compliant
- Researchers tools
  - Discovery / Documentation
  - Produce research subsets (data personalization)
  - Support collaborative researcher
- Business Intelligence
  - Reporting
  - Data mining
Components / Infrastructure

Portal

Knowledge Users

UofA

Metadata
Aggregates DWH
Files

HRDR

Files
Metadata
Micro DWH
Aggregates DWH

VRE

Researchers

TREC

RAI

HRDR = Health Research Data Repository
DWH = Data Warehouse

VRE = Virtual Research Environment
Questions?

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