Manitoba Centre for Health Policy

What Are We Doing Here: Large Databases and the Human Touch

Les Roos
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“...the majority of revolutions are tool-driven”
“Just a little of that human touch”
MCHP Houses the Anonymized Population Health Research Data Repository

Population-Based Health Registry

- CancerCare
- Income Assistance
- Social Housing
- Education
- Justice
- Healthy Child MB
- Immunization
- Medical Services
- Lab
- Nursing Home
- Clinical
- Provider
- Vital Statistics
- Emergency Department
- Health Links
- Home Care
- Pharmaceuticals
- Hospital
- Family Services
- Census Data at Area Level

- K to Grade 12
- Post-Secondary (UofM)
- Families First
- Healthy Baby
- EDI
- ICU
- FASD
- Pediatric Diabetes
- Post-Secondary (UofM)
- K to Grade 12
- Pediatrics
- Diabetes
- FASD
- ICU
- Health Links
- Home Care
- Pharmaceuticals
- Hospital
- Family Services
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Repository

Large N
Interventions can be studied
Time
Space
Individuals and Families
Collaborative Model

1) Permits use

2) Facilitates expansion—Data Sets come in one by one

3) Time consuming
Challenges of Linked Data

Each Site has different problems – Access, Quality, Relationships

Around the world, researchers complain
A Population Registry should be a core aspect of repository

Quality and number of elements are critical

Used across studies

Provide flexible denominators
Data Management is critical

Documentation (such as Concept Dictionary) increasingly necessary.

Start ‘small’ - collect papers, appendices, and notes on Web-site.
Manitoba Data Challenges

Stats Canada Linkage (Resolved!)
Cancer Care Linkage (20+ years – Resolved!)
Marital Status (a Core Measure)
Non Standard Measures (Small Area, Not Individual) <a general problem>
Human Touch

Communications to Constituencies
Persistence (Preferably Smiling)
Patience
Paperwork
Lessons 1:

Save the rants for your partner/spouse
Lessons 2:

1) Try hard to abide by rules.
2) Save ‘Sorry, I was clueless’ defense for emergencies