IMECCHI Global Health Metadata Catalogue: Defining the Scope of Codified Administrative Health Data

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Background

IMECCHI 2005: Banff AB, Canada

De Coster et al. Identifying priorities in methodological research using ICD-9-CM and ICD-10 administrative data: report from an international consortium. BMC Health Services Res (2006) vol. 6 pp. 77

- "Thirteen potential areas of research were identified.
- 1. 'Meta-data' documentation of international administrative data: Every field in each country's hospital administrative data system would be defined and described. While not as exciting as more applied projects, a compilation of this nature would be necessary for international comparative studies, and would also serve to highlight identified problems or issues with the data from specific countries."
Background

- Other groups have identified the need for improved international statistics & metadata:
  - CDC 2005: “Developing Metadata to Organize Public Health Datasets”
  - Health Metrics Network - 2005 (WHO)
  - Millenium Development Goals
  - The Institute of Electrical and Electronics Engineers (IEE): 2002 “Metadata Principles and Practicalities”
  - World Bank
  - OECD
  - Eurostat
  - IMF
Motivation

Given the increase in international comparative research:

- Need was identified for central repository of administrative data

- To enable comparative research by creating a single access point for an array of national level data

- Optimal use of existing data resources to positively affect the health of populations requires awareness of existing data and the features of those data
Data of interest

- Administrative accounts of codified individual level health care encounters
  - ICD-10, ICD-9, SNOMED
- Supporting documents that describe data elements
- Validity documents when available
- Diverse Administrative Sources
  - Vital statistics
  - Health insurance registries
  - Inpatient care, day surgery, physician services, homecare
  - National registries (cancer, transplant, reportable diseases)
  - Prescription databases
Objectives

- Creation of an online compendium of existing international health data resources
- An open access ‘meta-data directory’
- A tool for researchers and organizations interested in accessing codified resources
- Extend the scope to all officially listed countries in the world
Methods

- Web searching, telephone interviews, e-mails, written correspondence and document analysis to gather ‘metadata’ in three distinct layers:
  - **Layer 1** consists of contact information on national-level agencies or individuals who hold coded health data (i.e., Canada: Statistics Canada and CIHI)
  - **Layer 2** provides a nominal description of content for each individual dataset held by any given agency
  - **Layer 3** provides information about elements within the database, validity checks, and supporting documents that further describe the databases or datasets compiled. Also information on how to access the information
e-Tool

- We are compiling these ‘metadata’ on a web based tool
  - central database
  - open access

- Available through the IMECCHI website
  (www.imecchi.org)
### World Wide Agencies

<table>
<thead>
<tr>
<th>COUNTRY</th>
<th>AGENCY</th>
<th>WEBSITE</th>
<th>CONTACT</th>
<th>EMAIL</th>
<th>PHONE</th>
<th>NOTES</th>
</tr>
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<tbody>
<tr>
<td>Australia</td>
<td>Australian Institute of Health and Welfare (AIHW)</td>
<td><a href="http://www.aihw.gov.au">www.aihw.gov.au</a></td>
<td><a href="mailto:info@aihw.gov.au">info@aihw.gov.au</a></td>
<td></td>
<td>61 2 6244 1000</td>
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- The National Centre for Classification in Health (NCCIH) is a world leader in its field, with expertise in the development of disease classification systems.

### Database Collection

<table>
<thead>
<tr>
<th>DATABASE NAME</th>
<th>DOCUMENT LINK</th>
<th>DESCRIPTION OF CONTENT</th>
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### Database Information

<table>
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<tr>
<th>DOCUMENT DESCRIPTION</th>
<th>DOCUMENT LINK</th>
<th>COMMENTS</th>
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- National GRIM Books: All Causes Combined includes information on all causes of death for the period 1900-2010.
- National GRIM Books: All certain infectious and parasitic diseases includes mortality data for specific infectious and parasitic diseases.
- National GRIM Books: All neoplasms includes mortality data for all neoplasms.
- National GRIM Books: All diseases of the blood and blood-forming organs includes mortality data for diseases of the blood and blood-forming organs.
- National GRIM Books: All diseases of the circulatory system includes mortality data for diseases of the circulatory system.
Progress To Date:

- At least partially populated 43 countries
- Presented at one other international conference: SGIM Apr. 2010
- International Collaborators
- Completed OECD
- Began LD 20 and middle income countries
- Prepared package for funding application
Progress To Date:
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What We’ve Learned

- Great variability in data:
  - Availability and validity of data elements
  - Data Definitions
  - ICD 9 vs. ICD 10
  - Individual versions of ICD 10
  - Researchers within their countries know their data best
  - Information Paradox exists
Challenges

- Language
- Availability of Data
- Information Barriers
- Evergreening and Maintenance
- Funding
Funding

- Does not fit traditional research/development role
- Potential sources of funding may include:
  - Bill and Melinda Gates Foundation
  - CIDA
  - Lupina Foundation
- Current work supported by monies from
  - IMECCHI
  - University of Calgary, CIPPH
  - Alberta Health Services
Information Paradox

- i.e. lack of codified resources expected in many countries
- Currently GHMC data: OECD vs. LD 20
- Opportunities for knowledge sharing of best practices
- The GHMC as a roadmap for other countries for the development of health info systems
- The GHMC has potential to harmonize international approaches to health data management
Information Paradox

- It Exists
- Work done to collect data from LD-20
  - Angola
  - Afghanistan
  - Bangledesh
  - Burundi
  - Cambodia
  - Central African Republic
  - Equatorial Guinea
  - East Timor
  - Eritrea
  - Gambia
  - Haiti
  - Kiribati
Need for peer review participation

- Majority of the countries populated through the advice of researchers who knew the data
- Ensure accuracy, completeness and validity of database holdings
- Ability for remote and distributive updating
  - Assignment of read/write permissions
- Active, engaged community would help overcome:
  - Language barriers
  - Completeness, evergreening
Electronic Innovation

- IMECCHI as a site for:
  - Health services resource
  - Auto-updating software
  - Auto-translating tools
  - Cellular updating
  - Mobile apps
  - Knowledge translation
  - Forum
  - Social Media (FB etc.)
Conclusions

- A health metadata catalogue vis a vis the IMECCHI collaborative, is a work in progress
- Web accessible, open access model
- Peer participation and investment is required
- Initiative comes about as Health IT is actively expanding to a global scope