Accessing Patient Data for Chronic Disease Management

The Australian E-Health Research Centre, CSIRO ICT Centre, Brisbane, Australia
Patients with complex diseases

- **Data is collected in a way which is**
  - Distributed
    - Captured in lots of places
  - Complex
    - … using lost of formats
    - … using different technologies

- **But in an electronic world we – hope – it ends up on a computer**
  - ....somewhere
Example Scenario – Integrating data across hospitals

Large teaching hospital

HDI Domain (Host)

Private hospital

HDI Domain (Remote)

Regional hospital

HDI Domain (Remote)

Surgical Records

Hosp Admin

Hosp Admin

Surgical Records

Surgical Records

Chemo Records

Surgical Records

Surgical Records
HDI Platform Technology

De-identified linked data for analysis

Statistical Packages
e.g. R, SPSS

Reporting Tools
e.g. Crystal Reports

Custom Applications

De-identified virtual linked data set

HDI links and integrates data

HDI Domain

Custodial controlled data

HDI Data Source

HDI Data Source

HDI Data Source
To integrate data

- **Structural integration**
  - HDI does this really well
    - Including tackling privacy and security concerns

- **Semantic integration**
  - What does this piece of information mean?

- **Many users of HDI wanted patient level access to data**
  - Initially HDI was developed for population or cohort analysis
What to do about adding meaning?

• Hypothesis: Can we use SNOMED CT as a base ontology and add “new bits of knowledge” to fully describe data which is collected using other terminologies?
SNOMED CT Support Extensions

• SCT documentation gives 2 reasons for supporting extensions:
  • maintain unique identification across organizations for data transmission and sharing but share a common structure for ease in application development
  • to define a structure so that it is easy to submit, include, use, and migrate terminology developed as part of an extension into the core content.

• Requirement for additional concepts, descriptions, relationships or subsets to support a particular need
  • National or local requirements
  • Organisational requirements
  • Disease focussed requirements

• Current extensions
  • USA Drug Extension
  • Australian Medicines Terminology
Ad Hoc Extensions?

- Back to our hypothesis.
- Can we create ad-hoc extensions relatively painlessly to cover our existing data using
  - Local terminologies
  - Our current electronic health records
  - Medical text
  - Extensions based on use:
    - This term has a high proportion of use, should there be specialities defined?
    - This term is not used at all, should it be maintained?

- Building Ad Hoc extensions requires support for
  - Reverse mapping technology
  - Pre vs Post coordination
Snapper: for creating extensions
Issues for ad-hoc extensions

- When should an extension be published or made official?
- What to do when multiple extensions are contradictory?
- QA/peer review
- Will it be supported by the SNOMED CT workbench?
  - Extension development by domain experts will require tools and services which support distributed development
- Maintenance
- Primitive vs Fully-defined concepts
  - It is likely there will be more fully-defined concepts in extensions
Now that we have SNOMED Extensions

• We can query across the data using information from the hierarchy

• “find me all colonoscopy events in the patient records”
Now we can query across multiple electronic medical record systems for patient information.

<table>
<thead>
<tr>
<th>PatientID</th>
<th>DateDiag</th>
<th>DateSurg</th>
<th>Procedure</th>
<th>Surgeon</th>
<th>Polyps</th>
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<tbody>
<tr>
<td>31X4</td>
<td>21 Jun 1998</td>
<td>21 Jun 1998</td>
<td>Open colonoscopy</td>
<td>Bill</td>
<td>0</td>
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<td>...</td>
<td>...</td>
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<td>19 Jul 2002</td>
<td>Sigmoidoscopy</td>
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<td>3 Sep 2006</td>
<td>Colonoscopy</td>
<td>Chris</td>
<td>6</td>
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<tr>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
</tbody>
</table>

There are lots of open issues!

- "meaning" split across multiple fields (even across tables)
  - potential for conflict
  - rules for resolution
  - similar problems and solution to supporting expressions
Visualising summary patient data

Patient Timeline

[Diagram showing patient timeline with events labeled as Surveillance, Pathology, Diagnosis, Surgery, and Treatment.

Surveillance event details: FOSR, Wed, 11 Sep 2002, 14:00:00 GMT]
Patient Timeline Configuration Tool

- Connects to multiple data sources
  - HDI data views
  - Relational databases
  - Electronic Health Records
- Extracts summary information
  - Extraction of data from a data field
  - Uses SNOMED CT hierarchy to expand query
  - Search for codes directly
- Integrated with Ontology Viewer to allow selection of appropriate terms
A Colorectal Cancer Example

• **A exemplar system for CRC**
  - Use HDI to link data about patients in multiple electronic medical records
  - Use our mapping tool to create SNOMED CT extensions to cover the data
  - Extracted summary data from the electronic medical records for each patient
    - Stored as codes from the extended SNOMED CT
  - Created “events” which described the patient journey
    - Surveillance – covering both FOBT and colonoscopy
    - Diagnosis
    - Surgery
Providing integrated data to users
David Hansen
The Australian e-Health Research Centre

Thank you