

Accessing Patient Data for Chronic Disease Management

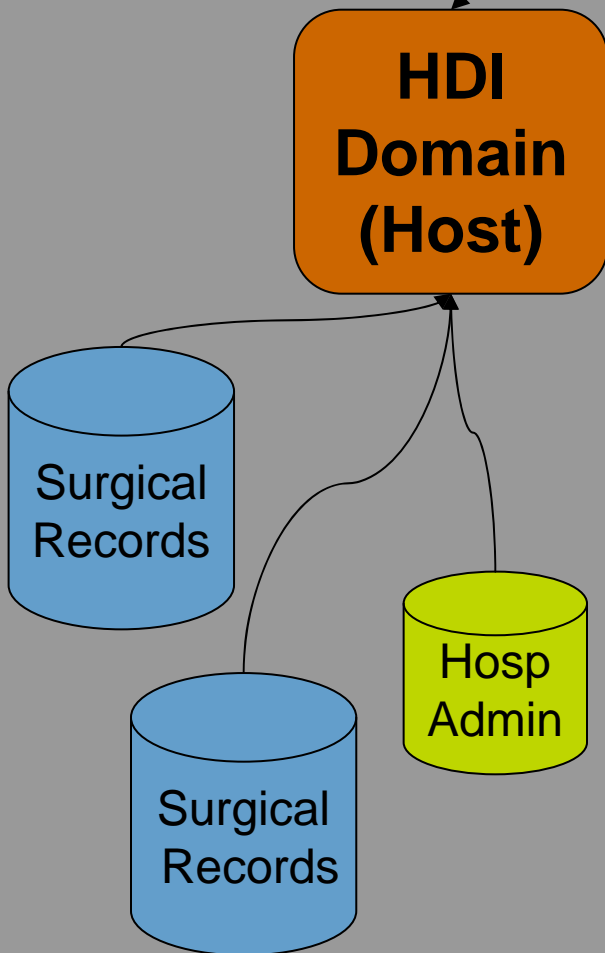
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The Australian E-Health Research Centre, CSIRO ICT Centre, Brisbane, Australia

Patients with complex diseases

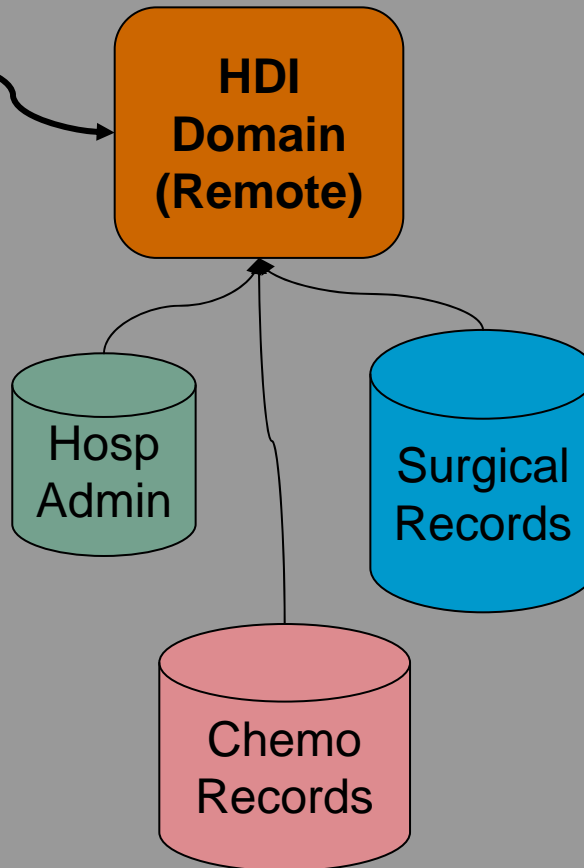
- **Data is collected in a way which is**
 - Distributed
 - Captured in lots of places
 - Complex
 - ... using lots of formats
 - ... using different technologies
- **But in an electronic world we – hope – it ends up on a computer**
 -somewhere

Example Scenario – Integrating data across hospitals

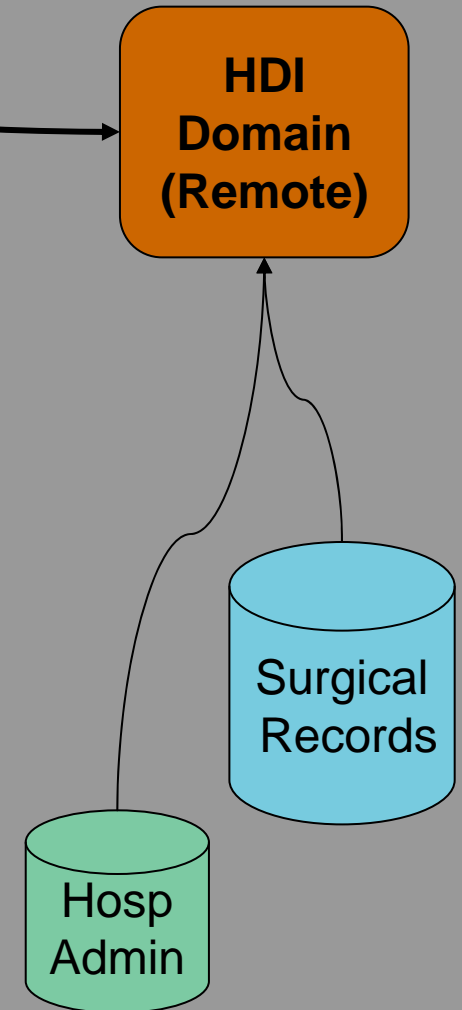
Large teaching hospital



Private hospital

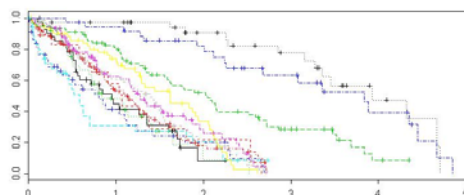


Regional hospital

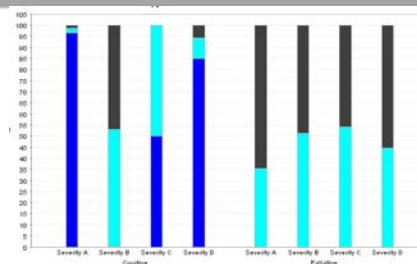


HDI Platform Technology

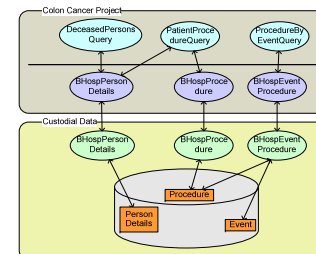
**De-identified
linked data for
analysis**



**Statistical Packages
e.g. R, SPSS**

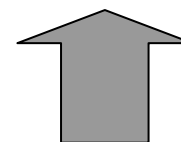


**Reporting Tools
e.g. Crystal Reports**



Custom Applications

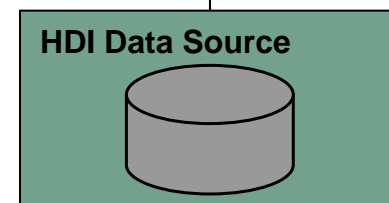
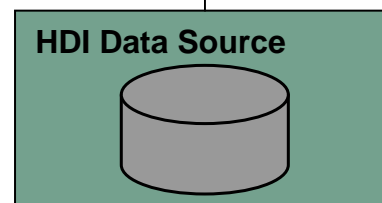
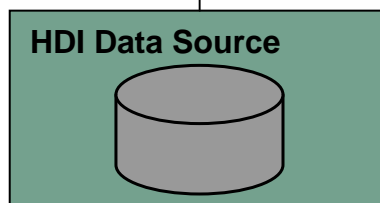
**De-identified virtual
linked data set**



**HDI links and
integrates data**



**Custodial
controlled data**



To integrate data

- **Structural integration**

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

- **Semantic integration**

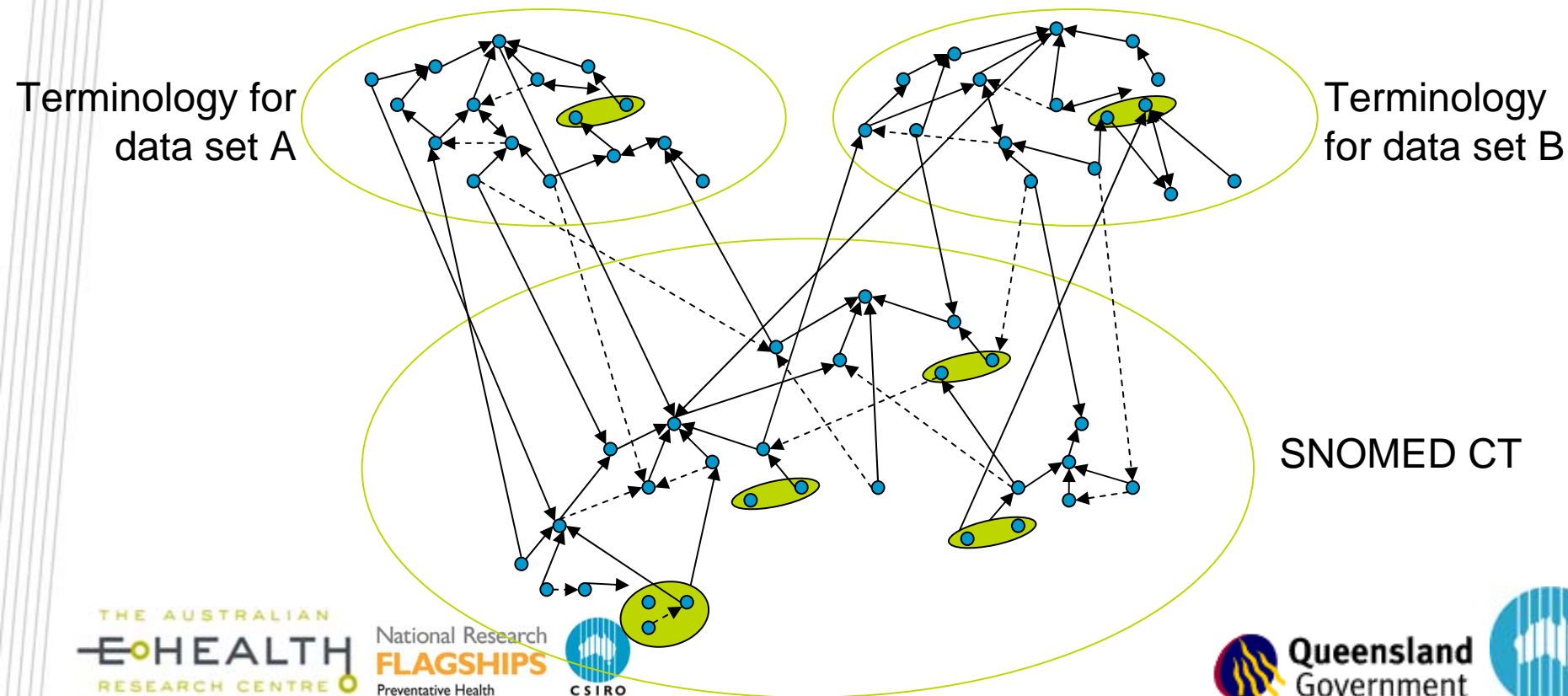
- What does this piece of information mean?

- **Many users of HDI wanted patient level access to data**

- Initially HDI was developed for population or cohort analysis

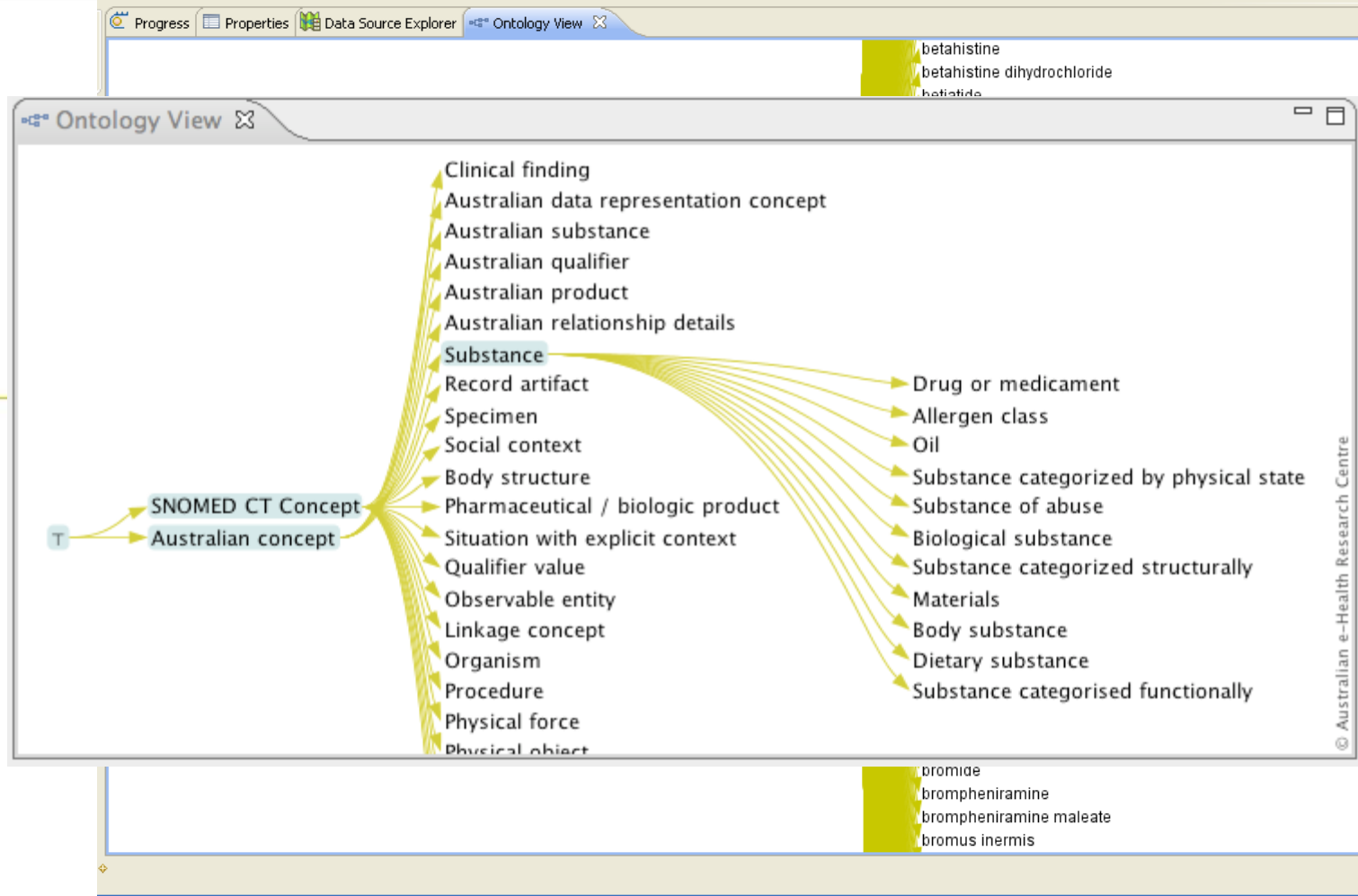
What to do about adding meaning?

- **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

The screenshot displays the Snapper application interface, which is used for creating extensions. The main window is titled "Snapper - ANZICS Example/ANZICS_DiagnosisCodes.mapping - Eclipse Platform".

Mapping Editor: The central pane shows a table with columns: Column Value, Relationship, and Snomed Expression. It lists various medical conditions and their corresponding SNOMED CT codes.

| Column Value | Relationship | Snomed Expression |
|--------------------------------|--------------|---|
| N Other haematologic disorders | | |
| N Metabolic coma | | |
| N Diabetic ketoacidosis | | 420422005 Ketoacidosis in diabetes mellitus (disorder) |
| N Drug overdose | | 55680006 Drug overdose (disorder) |
| N Other metabolic disorders | | |
| N Intracerebral haemorrhage | | 1508000 Intracerebral hemorrhage (disorder) |
| N Subarachnoid haemorrhage | | 21454007 Subarachnoid hemorrhage (disorder) |
| N Stroke | | 230690007 Cerebrovascular accident (disorder) |
| N Neurologic infection | | 111868009 Rubella infection of central nervous system (disorder) |
| N Neurologic neoplasm | | |
| N Neuromuscular disease | | 254182005 Epidermolysis bullosa simplex with neuromuscular disease (disorder) |
| N Seizure | | 91175000 Seizure (finding) |
| N Other neurologic disease | | |
| N Epidural haematoma | | 82999001 Epidural hemorrhage (disorder) |
| N Coma | | 371632003 Coma (disorder) |
| N Renal disorders | | 236498004 Renal disorders in systemic disease (disorder) |

Search SNOMED CT: The right pane shows a search window with the following details:

- Concept ID: 22298006
- Clinical finding
- Word Search: myoc infar
- Search Results:
 - Subsequent myocardial infarction (disorder)
 - Myocardial infarction (disorder)
 - Postoperative myocardial infarction (disorder)
 - First myocardial infarction (disorder)
 - Myocardial infarction with complication (disorder)
 - Acute Q wave myocardial infarction (disorder)
 - Electrocardiogram: myocardial infarction (finding)
 - Electrocardiogram: no myocardial infarction (finding)
 - Acute myocardial infarction (disorder)
 - Old anterior myocardial infarction (disorder)
 - Old inferior myocardial infarction (disorder)
 - Old lateral myocardial infarction (disorder)
- Description:
 - Concept Id: 22298006
 - Descriptions:
 - Myocardial infarction (disorder)
 - Heart attack
 - Myocardial infarct
 - MI - Myocardial infarction
 - Myocardial infarction
 - Cardiac infarction
 - Infarction of heart
 - Cardiac infarction, NOS

Ontology View: The bottom pane shows a hierarchical ontology structure:

```

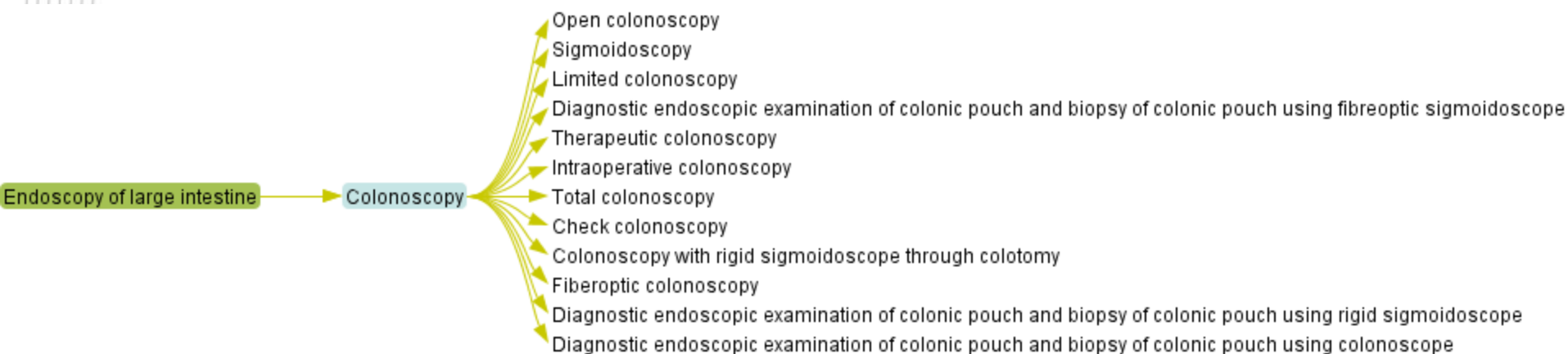
graph LR
    A[Finding of trunk structure] --> B[Finding of region of thorax]
    B --> C[Mediastinal finding]
    C --> D[Cardiac finding]
    D --> E[TIMI grade 0: no perfusion]
    D --> F[Normal left and right heart hemodynamics]
    D --> G[Heart valve finding]
    D --> H[Finding related to awareness of heart beat]
    D --> I[Normal right heart hemodynamics]
    D --> J[Normal left heart hemodynamics]
    D --> K[Heart valve calcification]
    D --> L[Cardiac auscultation finding]
    D --> M[TIMI grade 3: complete perfusion]
    
```

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”



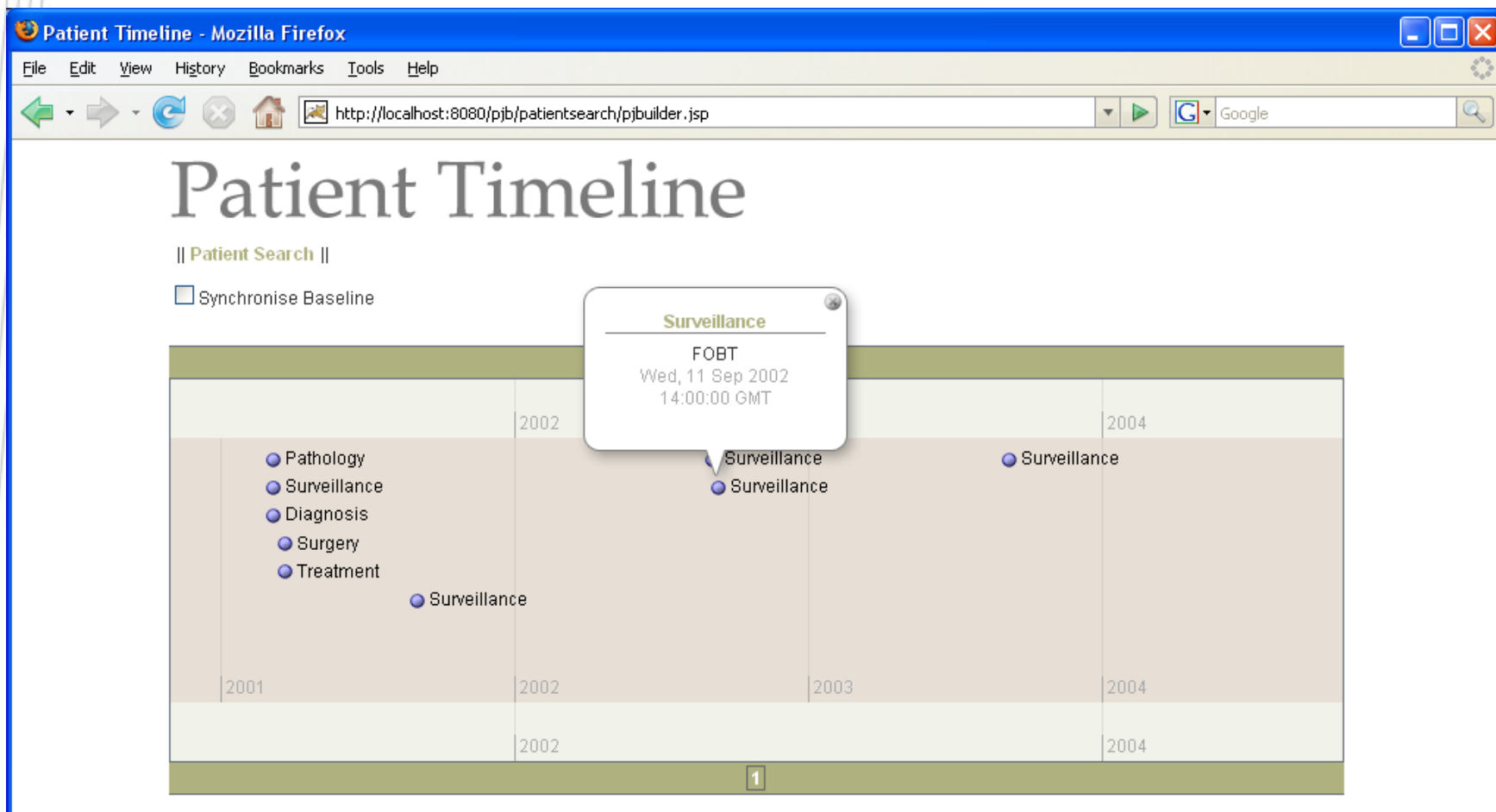
Information Model and Terminology

- Now we can query across multiple electronic medical record systems for patient information

| PatientID | DateDiag | DateSurg | Procedure | Surgeon | Polyps |
|-----------|-------------|-------------|------------------|---------|--------|
| 31X4 | 21 Jun 1998 | 21 Jun 1998 | Open colonoscopy | Bill | 0 |
| ... | ... | ... | ... | ... | ... |
| 31X4 | 19 Jul 2002 | 19 Jul 2002 | Sigmoidoscopy | John | 1 |
| 31X4 | 1 Aug 2006 | 3 Sep 2006 | Colonoscopy | Chris | 6 |
| ... | ... | ... | ... | ... | ... |

- 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 Configuration Tool

The screenshot displays the 'Pjb Configuration Tool' interface, which is used for configuring patient timelines. The main workspace is divided into several panels:

- Data Source Browser:** Lists available data sources, including 'HDI Demo data' and 'Project Review'.
- Workbench:** The central area for configuration, currently showing 'Project Review'.
- Patient Data Configuration:** A window for configuring patient data. It includes:
 - Table:** Patient
 - Id Column:** PatientID
 - Attributes:** A list of attributes including Surname, Firstname, and DateOfBirth.
- Event Type: Diagnosis:** A window for configuring the 'Diagnosis' event type. It includes:
 - Name:** Diagnosis
 - Table:** Diagnosis
 - Id Column:** PatientID
 - Date Column:** DateofDiagnosis
 - Attributes:** A table with columns 'Attribute Name' and 'Attribute Column', containing 'Grade' and 'Grade'.
- Event Type: Surveillance:** A window for configuring the 'Surveillance' event type.
- Event Type: Treatment:** A window for configuring the 'Treatment' event type.
- Ontology Viewer:** A window at the bottom showing a hierarchical ontology structure. The 'SNOMED CT Concept (SNOMED RT+CTVS)' is highlighted, and its sub-concepts are listed, including 'Substance (substance)' and 'Observable entity (observable entity)'. A search bar is also present in the top right of this window.

On the right side of the image, the text 'rms' is visible.

A Colorectal Cancer Example

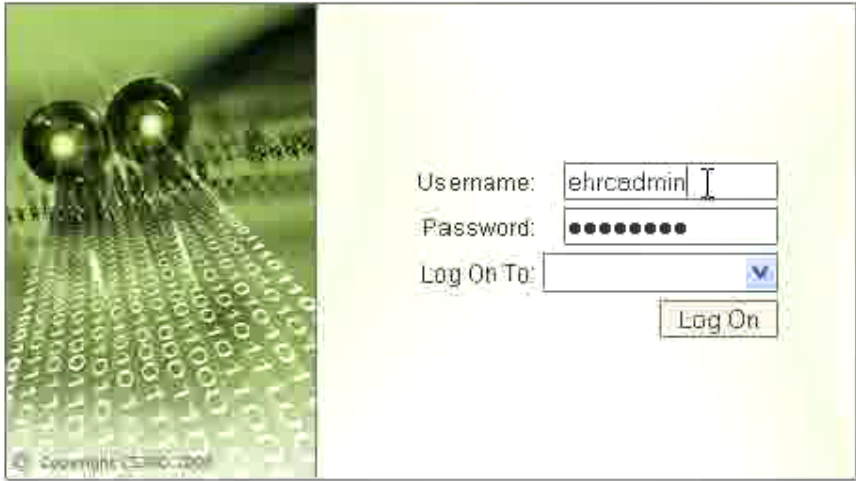
- **A exemplar system for CRC**

- 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


File Edit View History Bookmarks Tools Help

http://ehrc-han302-ict:8080/pjb/index.jsp



Username: ehrcadmin

Password:

Log On To: 

Log On

Done

David Hansen

The Australian e-Health Research Centre

Thank you

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