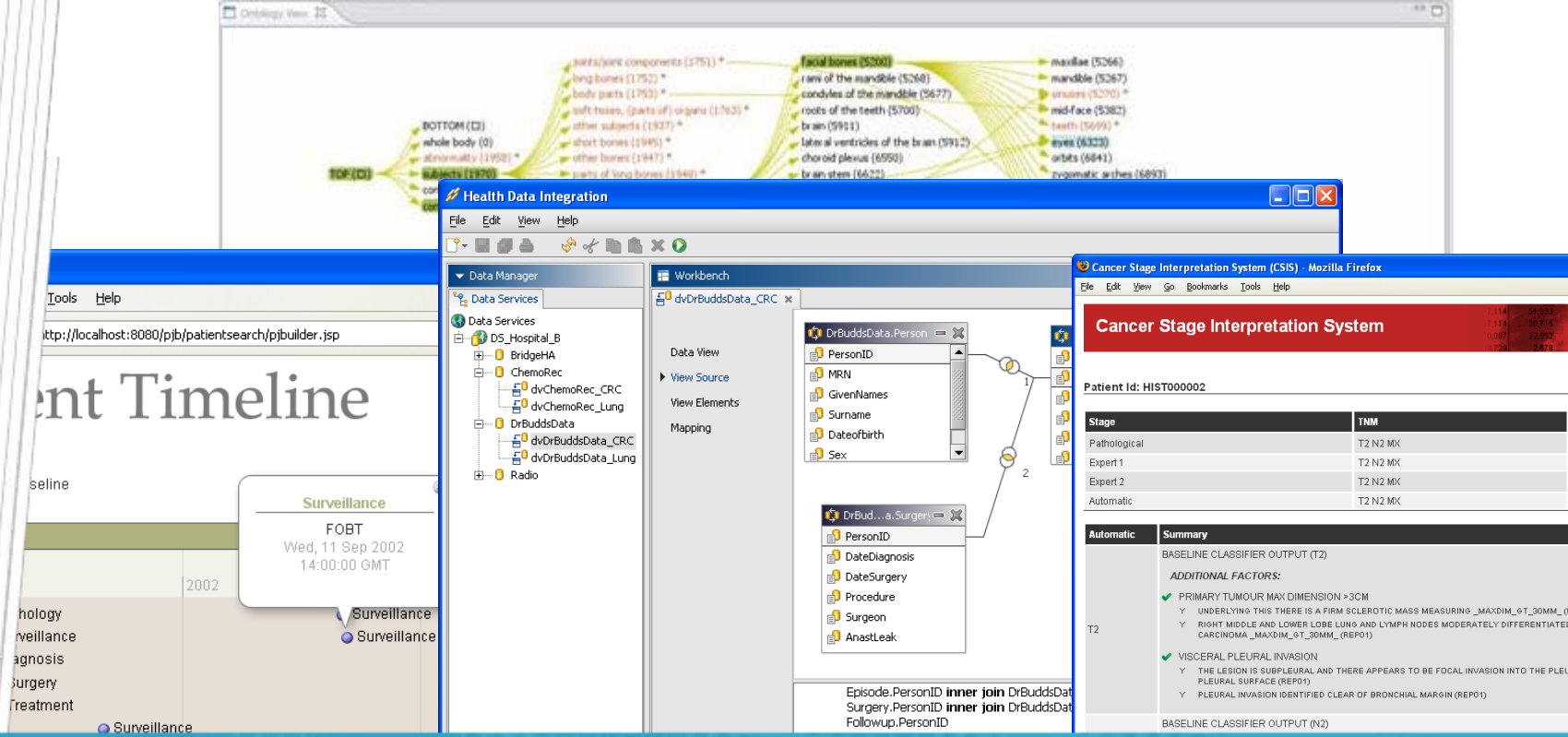

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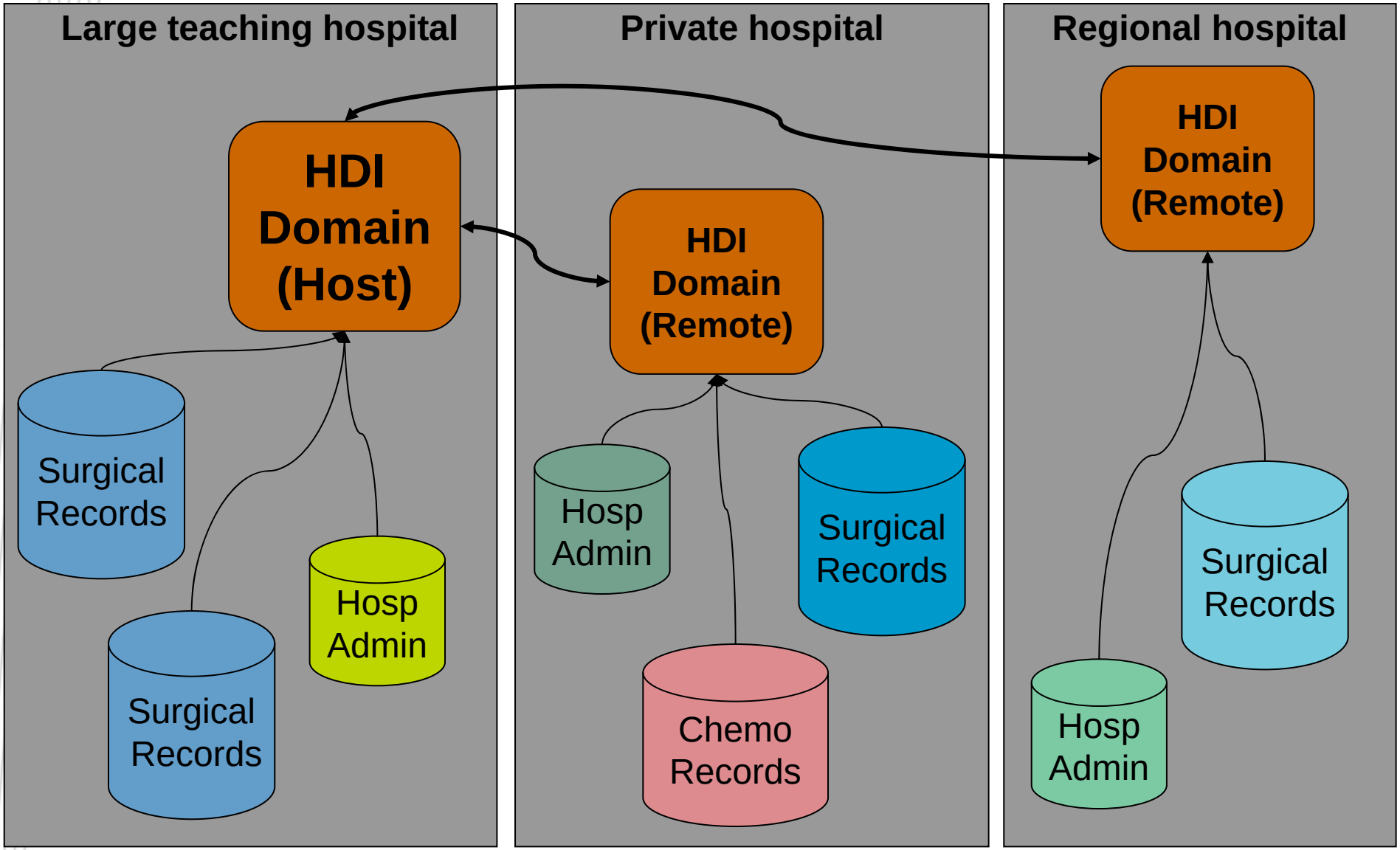
Accessing Patient Data for Chronic Disease Management

D. P. Hansen, M. J. Lawley, D. Vickers, J. Ryan-Brown, K. Harrap, M. O'Dwyer, K. Melki and S. McBride
The Australian E-Health Research Centre, CSIRO ICT Centre, Brisbane, Australia

Patients with complex diseases

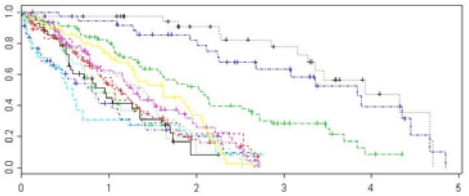
- **Data is collected in a way which is**
  - Distributed
    - Captured in lots of places
  - Complex
    - … using lost of formats
    - … using different technologies
- **But in an electronic world we – hope – it ends up on a computer**
  - ….somewhere

Example Scenario – Integrating data across hospitals

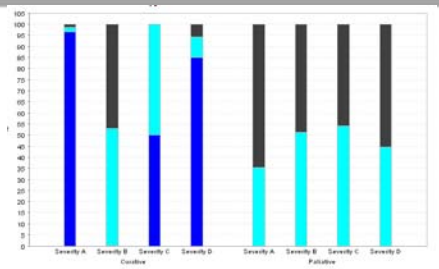


HDI Platform Technology

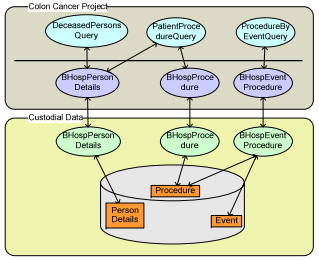
De-identified linked data for analysis



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

THE AUSTRALIAN E-HEALTH RESEARCH CENTRE
CSIRO
National Research FLAGSHIPS Preventative Health
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Queensland Government
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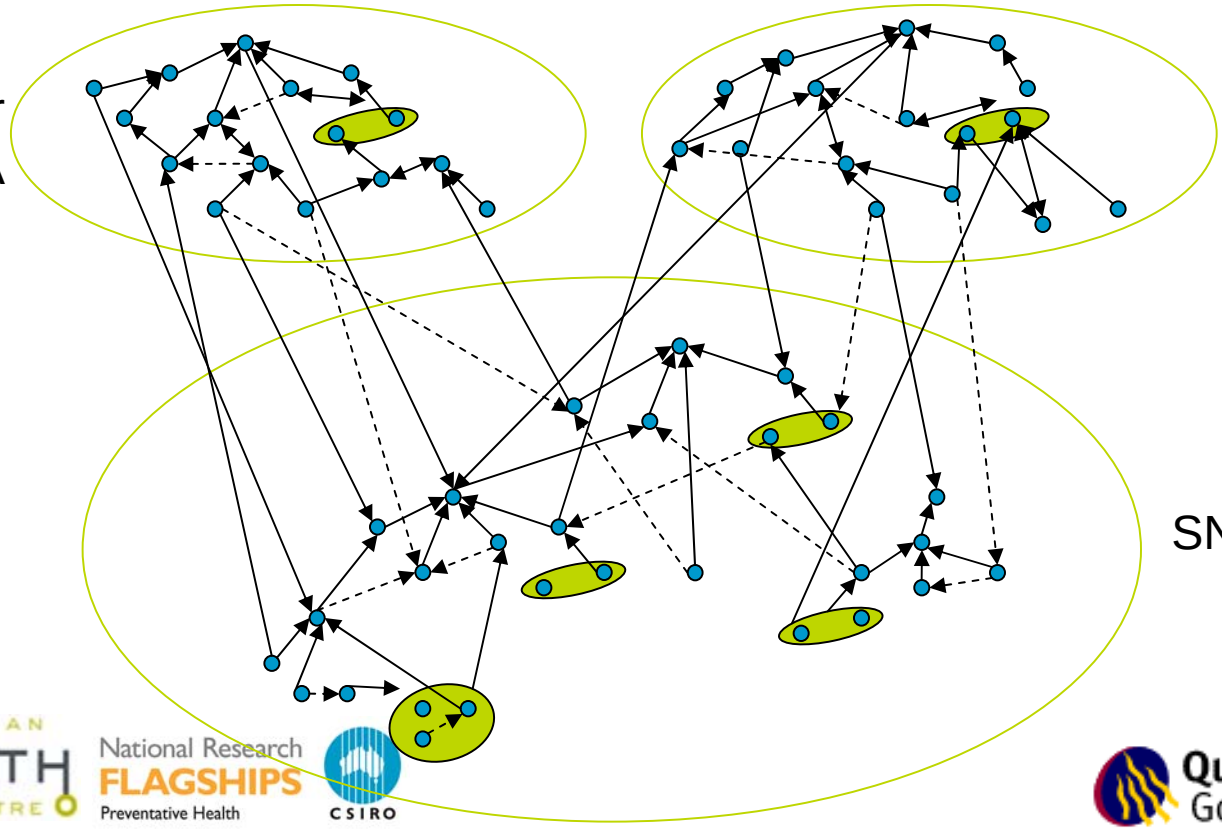
To integrate data

- **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?**

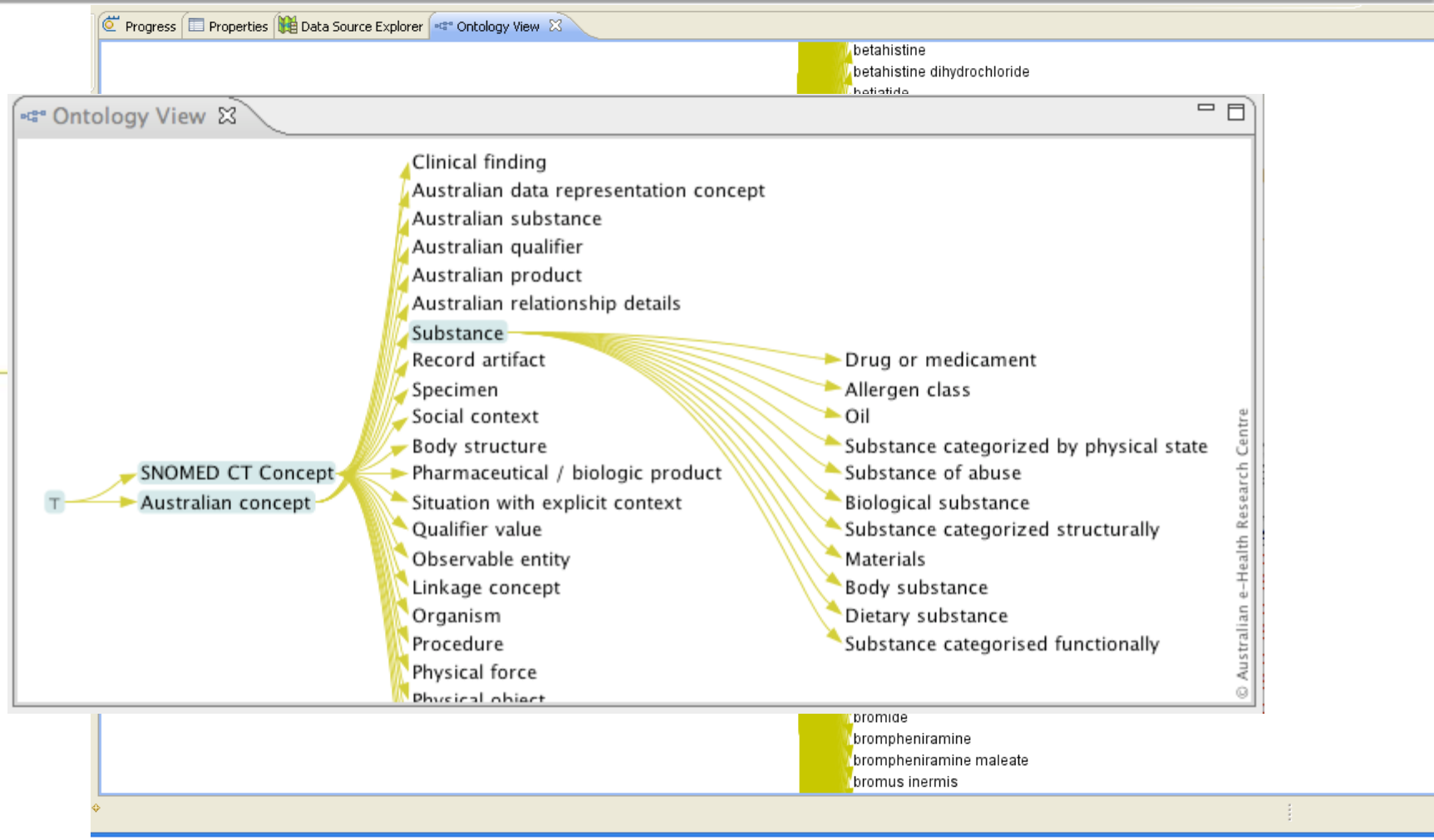


SNOMED CT Support Extensions

- **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

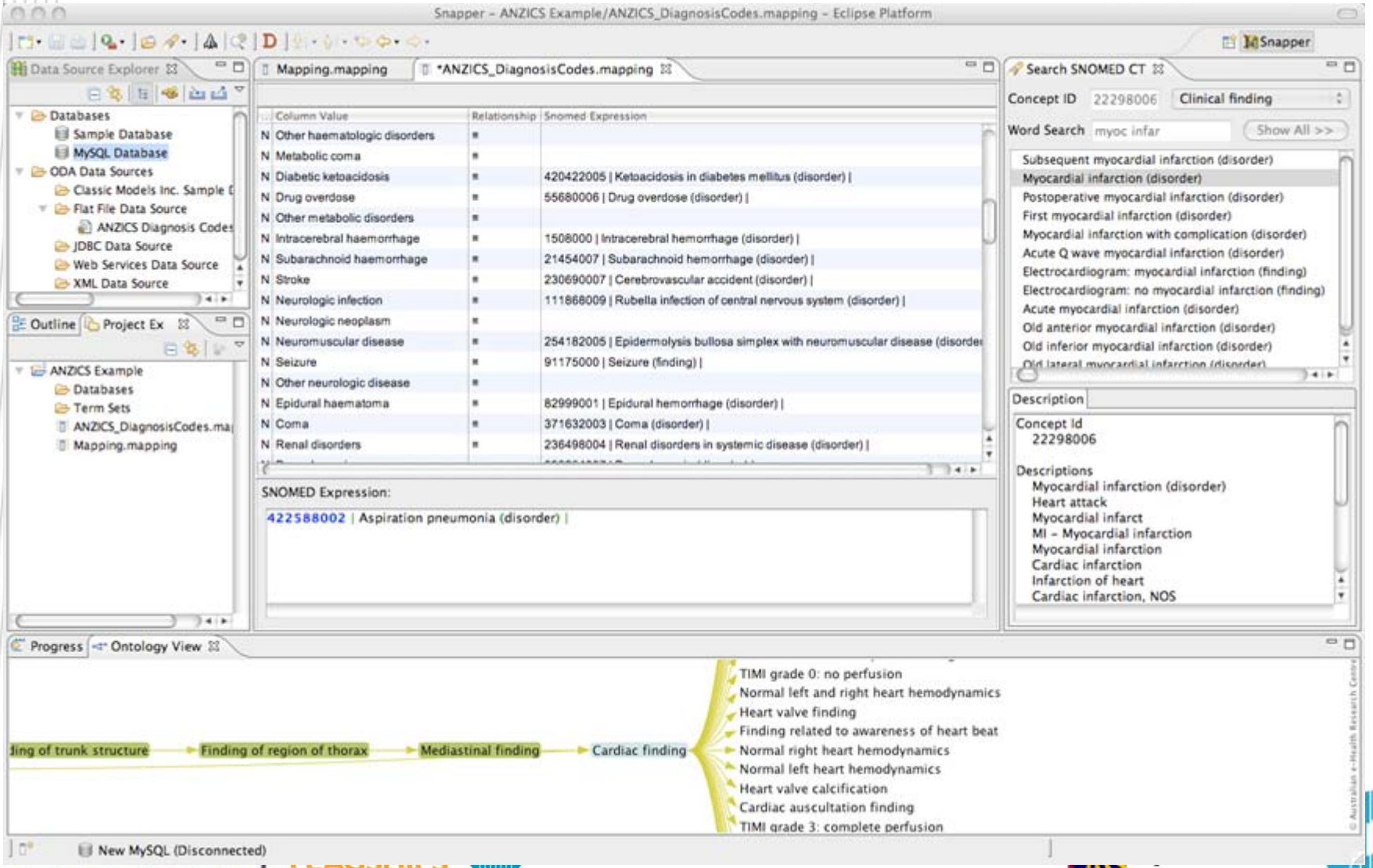

Progress
Properties
Data Source Explorer
Ontology View
betahistine
betahistine dihydrochloride
Ontology View
Clinical finding
Australian data representation concept
Australian substance
Australian qualifier
Australian product
Australian relationship details
Substance
Record artifact
Specimen
Social context
Body structure
Pharmaceutical / biologic product
Situation with explicit context
Qualifier value
Observable entity
Linkage concept
Organism
Procedure
Physical force
Physical object
SNOMED CT Concept
Australian concept
Drug or medicament
Allergen class
Oil
Substance categorized by physical state
Substance of abuse
Biological substance
Substance categorized structurally
Materials
Body substance
Dietary substance
Substance categorised functionally
© Australian e-Health Research Centre
bromide
brompheniramine
brompheniramine maleate
bromus inermis

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

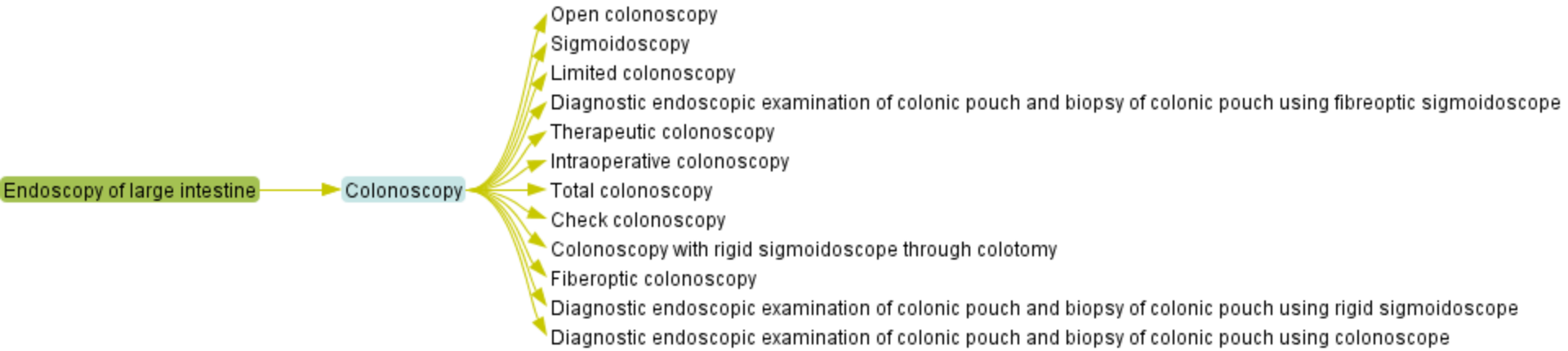


Issues for ad-hoc extensions

- **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"



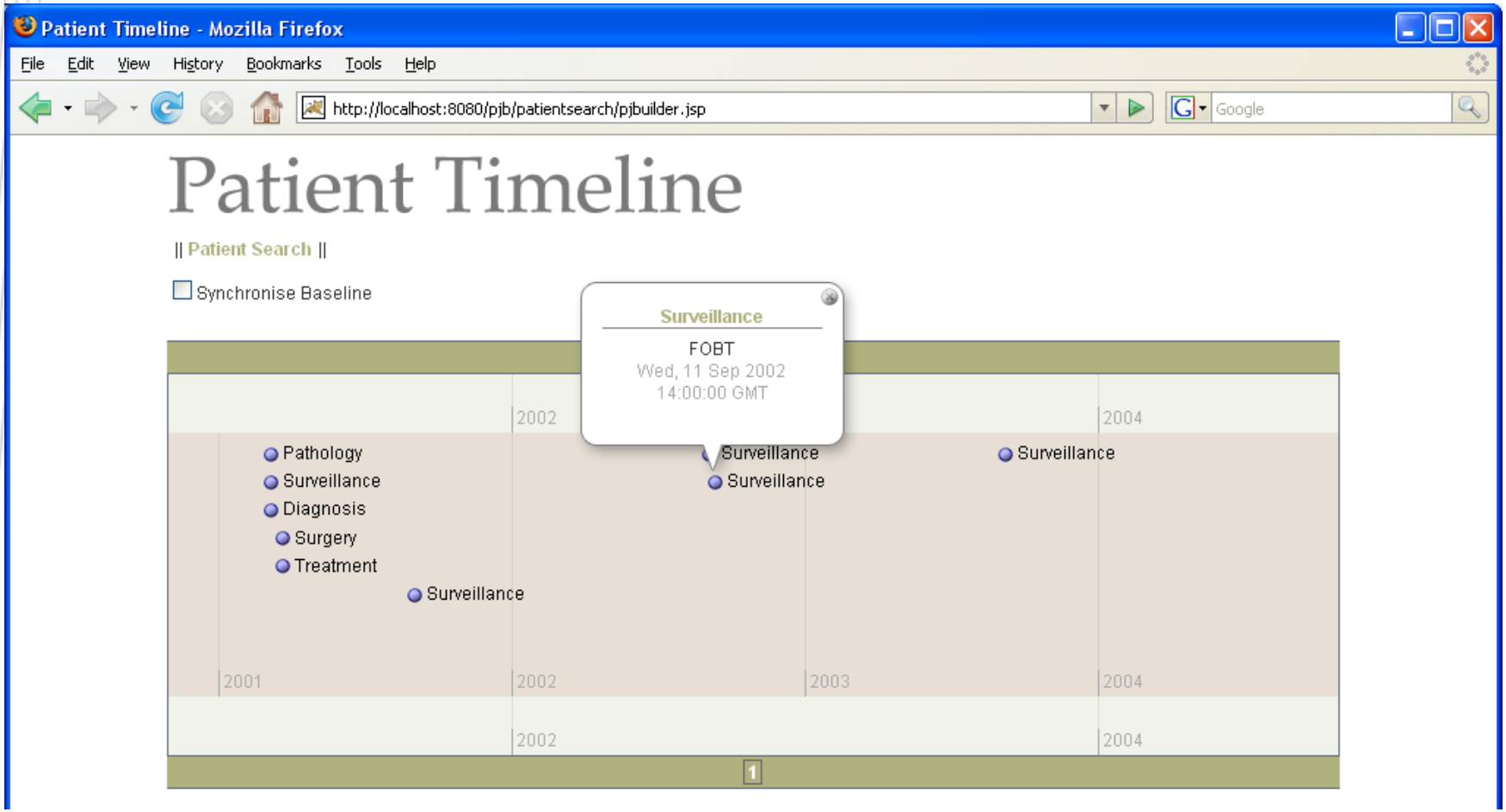
Information Model and Terminology

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

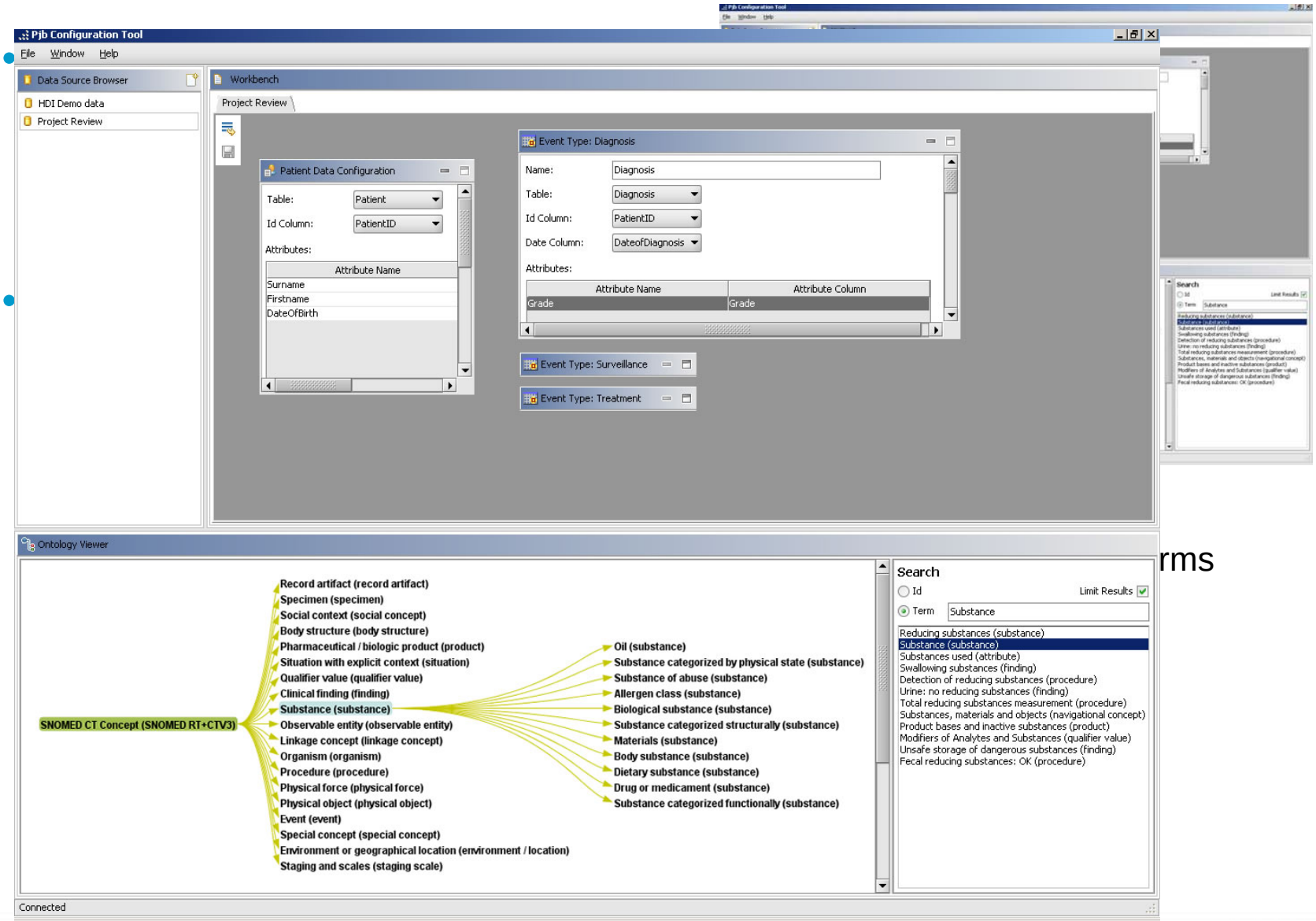
PatientID	DateDiag	DateSurg	Procedure	Surgeon	Polyps
31X4	21 Jun 1998	21 Jun 1998	Open colonoscopy	Bill	0
....	...	...	...	...	...
31X4	19 Jul 2002	19 Jul 2002	Sigmoidoscopy	John	1
31X4	1 Aug 2006	3 Sep 2006	Colonoscopy	Chris	6
...	...	...	...	...	...

- **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



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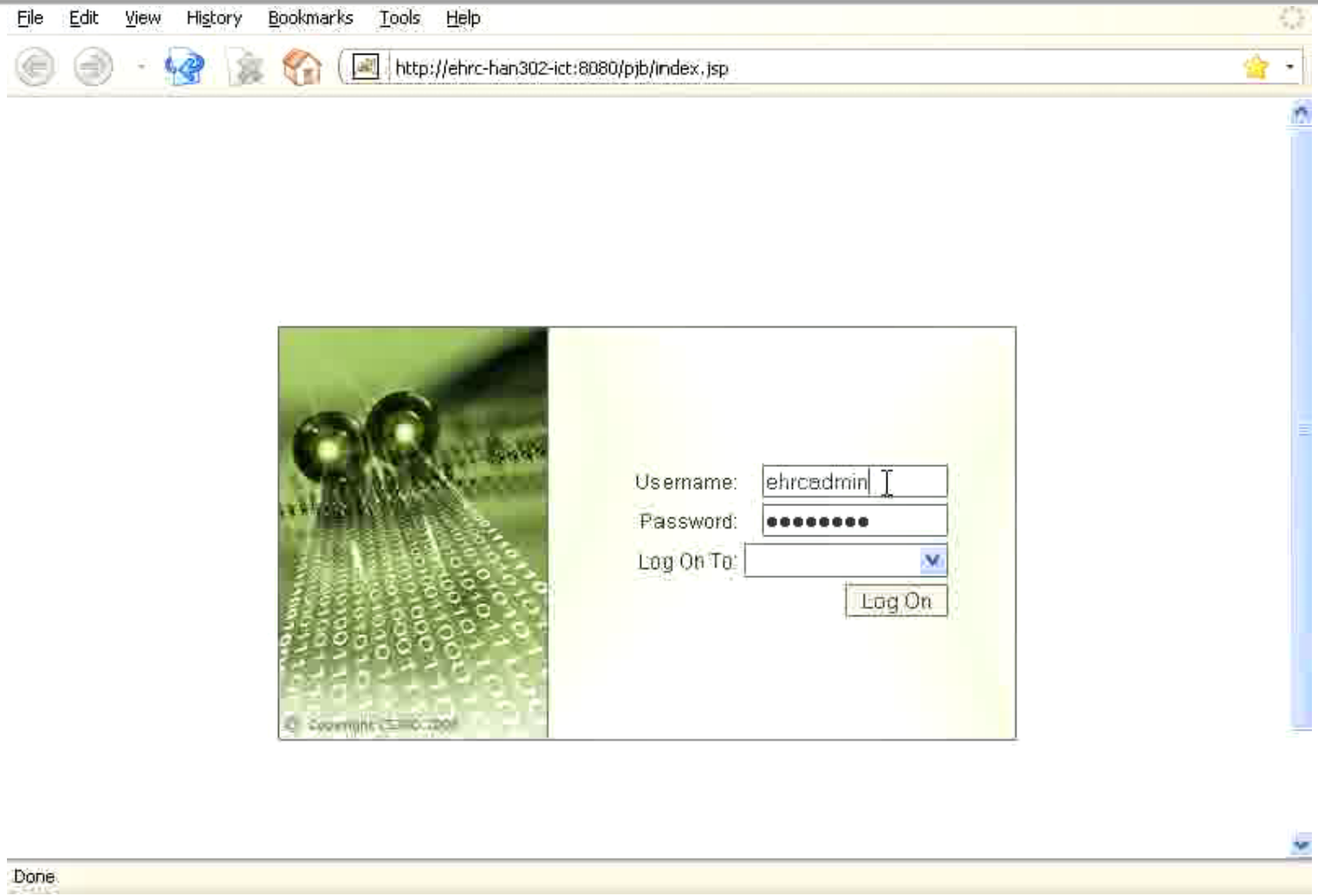
A Colorectal Cancer Example

- **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



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Thank you

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