

**Some interactions between NLMs
PHR and vocabulary standards –
and hopes for simple data capture
standard**

Kyoto Japan

May 8, 2009

Clement J. McDonald MD

Disclaimer

- These remarks are based on my opinion and experience and do not necessarily represent an official opinion or position of the National Library of Medicine or NIH

Back ground

- A story about
- Using vocabulary standards in a NLM Public PHR development
- The effect of that development on the standards
- And on an idea for a new standard for data capture
- Will talk about all the three parts

To start

- When we started the development of NLM PHR , we decided to vocabulary –code standards and HL7 data types (vs. 2.x for now)
- This made sense because NLM supports a number of vocabulary standards
- We also wanted to organize the data as much like HL7 as we could- to ease importing and exporting.

Starting vocabulary “standards”

- RxNorm – for medications
- LOINC for observations
- Gopher terms –SNOMED for medical conditions –

As we progressed

- We got greedy
- We needed more (and slightly different)

Greed

- For all of them we wanted
 - URL links to consumer information about the concept.
 - So we could offer info buttons that the user could click on to learn about the disease, or drug or what whatever tics
 - We now have some of that
 - We wanted frequency of use statistics
 - We got some-- An enormous help to the menu look up via auto complete (explain)

Enhancement extensions

➤ LOINC

- Panel structure useful for defining input form
- Needed more E.g. if we ask for entry of a blood hemogram
 - Need to show units and normal ranges- (at least as starting set
 - But most of these fields were not populated
 - They will be in next release

Harnessing Rx.Norm work for PHR (and ordering)

What is RxNorm

- A standardized nomenclature for clinical drugs created by NLM
- Clinical drug
 - The name includes ingredients, strengths and form e.g.
 - *Acetaminophen 500 MG Oral Tablet*
 - *Acetaminophen 500 MG Oral Tablet [Tylenol]*

RxNorm

- Provides Standardized names and codes for clinical drugs
- Permanent identifiers (RXCUI)
- Includes links to . brand and generic names, and to commercial knowledge bases
- Includes drug to ingredient links
Acetaminophen 500 MG Oral Tablet linked to Acetaminophen and Oral Tablet)
- Designated vocabulary standard for clinical drugs in the U.S.

Not ideal for drug ordering prescription entering

- When you look up by partial name match- lists are too long and too wide
- The names can be very long Difference between choices difficult to spot
- When you type in Amoxicillin you get

Amoxicillin 50 MG/ML Oral Suspension
Amoxicillin 125 MG Chewable Tablet
Amoxicillin 10 MG/ML Oral Suspension
Amoxicillin trihydrate 600 MG Disintegrating Tablet
Amoxicillin 250 MG / Clavulanate 125 MG Oral Tablet
Amoxicillin 25 MG/ML / Clavulanate 6.25 MG/ML Oral Suspension
Amoxicillin 875 MG / Clavulanate 125 MG Oral Tablet
Amoxicillin 200 MG / Clavulanate 28.5 MG Chewable Tablet
Amoxicillin 50 MG/ML / Clavulanate 25 MG/ML Oral Suspension
Amoxicillin 250 MG Oral Tablet
Amoxicillin 875 MG Oral Tablet
Amoxicillin 40 MG/ML Oral Suspension
Amoxicillin 125 MG/ML Oral Suspension
Amoxicillin 250 MG/ML Oral Suspension
Amoxicillin 200 MG Oral Tablet
Amoxicillin 50 MG/ML / Clavulanate 10 MG/ML Injectable Solution
Amoxicillin 500 MG / Clavulanate 125 MG Oral Tablet
Amoxicillin 250 MG / Clavulanate 62.5 MG Chewable Tablet
Amoxicillin 50 MG/ML / Clavulanate 12.5 MG/ML Oral Suspension
Amoxicillin 1000 MG / Clavulanate 62.5 MG Extended Release Tablet
Amoxicillin 775 MG Extended Release Tablet
Amoxicillin 60 MG/ML Oral Suspension
Amoxicillin 125 MG / Clavulanate 31.2 MG Chewable Tablet
12 HR Amoxicillin 1000 MG / Clavulanate 62.5 MG Extended Release Tablet
Amoxicillin 100 MG/ML Oral Suspension
Amoxicillin 250 MG Oral Capsule
Amoxicillin 5 MG/ML / Clavulanate 2.5 MG/ML Oral Solution
Amoxicillin 40 MG/ML / Clavulanate 5.7 MG/ML Oral Suspension
Amoxicillin 120 MG/ML / Clavulanate 8.58 MG/ML Oral Suspension
Amoxicillin 80 MG/ML Oral Suspension
Amoxicillin 500 MG Oral Capsule
Amoxicillin 400 MG Oral Tablet
Amoxicillin 20 MG/ML Oral Suspension
Amoxicillin 400 MG / Clavulanate 28.5 MG Chewable Tablet
Amoxicillin 200 MG/ML Injectable Solution
Amoxicillin 200 MG Chewable Tablet
Amoxicillin 400 MG Chewable Tablet
Amoxicillin 500 MG Oral Tablet
Amoxicillin 25 MG/ML Oral Suspension
Amoxicillin 80 MG/ML / Clavulanate 11.4 MG/ML Oral Suspension
Amoxicillin 25 MG/ML / Clavulanate 25 MG/ML Oral Suspension
Amoxicillin 800 MG / Clavulanate 125 MG Oral Tablet
Amoxicillin 50 MG Oral Tablet
Amoxicillin 400 MG/ML Injectable Solution
Amoxicillin 167 MG/ML Injectable Solution
Amoxicillin 250 MG Chewable Tablet
Amoxicillin 400 MG / Clavulanate 57 MG Chewable Tablet
Amoxicillin 200 MG/ML / Clavulanate 28 MG/ML Oral Suspension
Amoxicillin 100 MG Oral Tablet

How to fix

- Both problems (big lists and long names) can be solved by information segmentation and reorganization:

Amoxicillin 500 MG / Clavulanate 125 MG Oral
Tablet

Amoxicillin/Clavulanate

500-125

Divide and conquer

➤ Type 'amoxicillin'

| |
|--|
| Amoxicillin (Injectable) |
| Amoxicillin (Oral-liquid) |
| Amoxicillin (Oral-pill) |
| Amoxicillin/Clavulanate (Oral-liquid) |
| Amoxicillin/Clavulanate (Oral-pill) |
| Amoxicillin/Clavulanate XR (Oral-pill) |

➤ Pick appropriate drug/route

| | |
|---------------|-------------|
| Chewable Tabs | 125-31.2 MG |
| Chewable Tabs | 200-28.5 MG |
| Chewable Tabs | 250-62.5 MG |
| Chewable Tabs | 400-57 MG |
| Tabs | 250-125 MG |
| Tabs | 500-125 MG |
| Tabs | 875-125 MG |

Rx.Terms

- Work of Kin Wah Fung
- Enhancement of Rx.Norm
- Yields Rx.Norm code when both drug name/route and strength form are defined

Differences

- Thinned (about ½ number of items
 - Removed drugs that can not be prescribed.
- Restructured as above
- Names shortened and more conventional
- Synonyms added
- Tall man lettering

Tall man lettering

- Recommended by FDA to avoid medication errors
- To use visually differentiating names for 16 pairs of look-alike drug names

| Established Name | Recommended Name |
|------------------|------------------|
| Acetohexamide | AcetaHEXAMIDE |
| Acetazolamide | AcetaZOLAMIDE |
| Bupropion | BuPROPion |
| Buspirone | BusPIRone |
| Chlorpromazine | ChlorproMAZINE |
| Chlorpropamide | ChlorproPAMIDE |
| Clomiphene | ClomiPHENE |
| Clomipramine | ClomiPRAMINE |
| Cyclosporine | CycloSPORINE |
| Cycloserine | CycloSERINE |
| Daurorubicin | DAUNOrubicin |
| Doxorubicin | DOXOrubicin |

Available for download and testing

- <http://wwwcf.nlm.nih.gov/umlslicense/rxtermApp/rxTerm.cfm>
- Free of charge, no license needed
- Contact information required (first download)
- Monthly updates
- Try it
- <http://rxterms.nlm.nih.gov:8080/>

Where used

- Medicare is using RxTerms in a pilot of their Post acute care form- a 200+ item web based data collection form – eventually to be used on all post acute care discharges
- NLM's PHR is using it
- [Show]

LOINC back ground

- Coded system for observations (reports) orders and packages of these things (panels)
- Lots of international use. Translations to German, French, Spanish, Portugese, Korean, Chinese, Spanish, Estonian.
- Required for federal use in US.
- No cost- Down load from LOINC via

LOINC in Google's lab "message"

```
</Test> </Result> </Results <Text>Leukocytes</Text>
  <Code> <Value>26464-8 </Value>
  <CodingSystem>LOINC</CodingSystem> </Code>
  </Description>
<TestResult> <Value>6400</Value>
  <Units>cells/microlite</Units>
</TestResult> <NormalResult>Leukocytes: 4,000-10,000
  cells/microliter
</NormalResult>

</Test> <Test> <Description> < <Text>Hemoglobin</Text>
  Code> <Value>718-7</Value>
  <CodingSystem>LOINC</CodingSystem> </Code>
  </Description> <TestResult> <Value>15.6</Value>
  <Units>gm/dL</Units> </TestResult>
  <NormalResult>...</NormalResult>
```

LOINC's data package (Panel)

➤ LOINC has always had a representation for panels. E,g

- Serum Electrolytes contains “four” tests
 - Sodium
 - Potassium
 - Chloride
 - CO2
- LOINC could carry the relation ship between the panel ‘name” and the individual test name via a Relation ship table

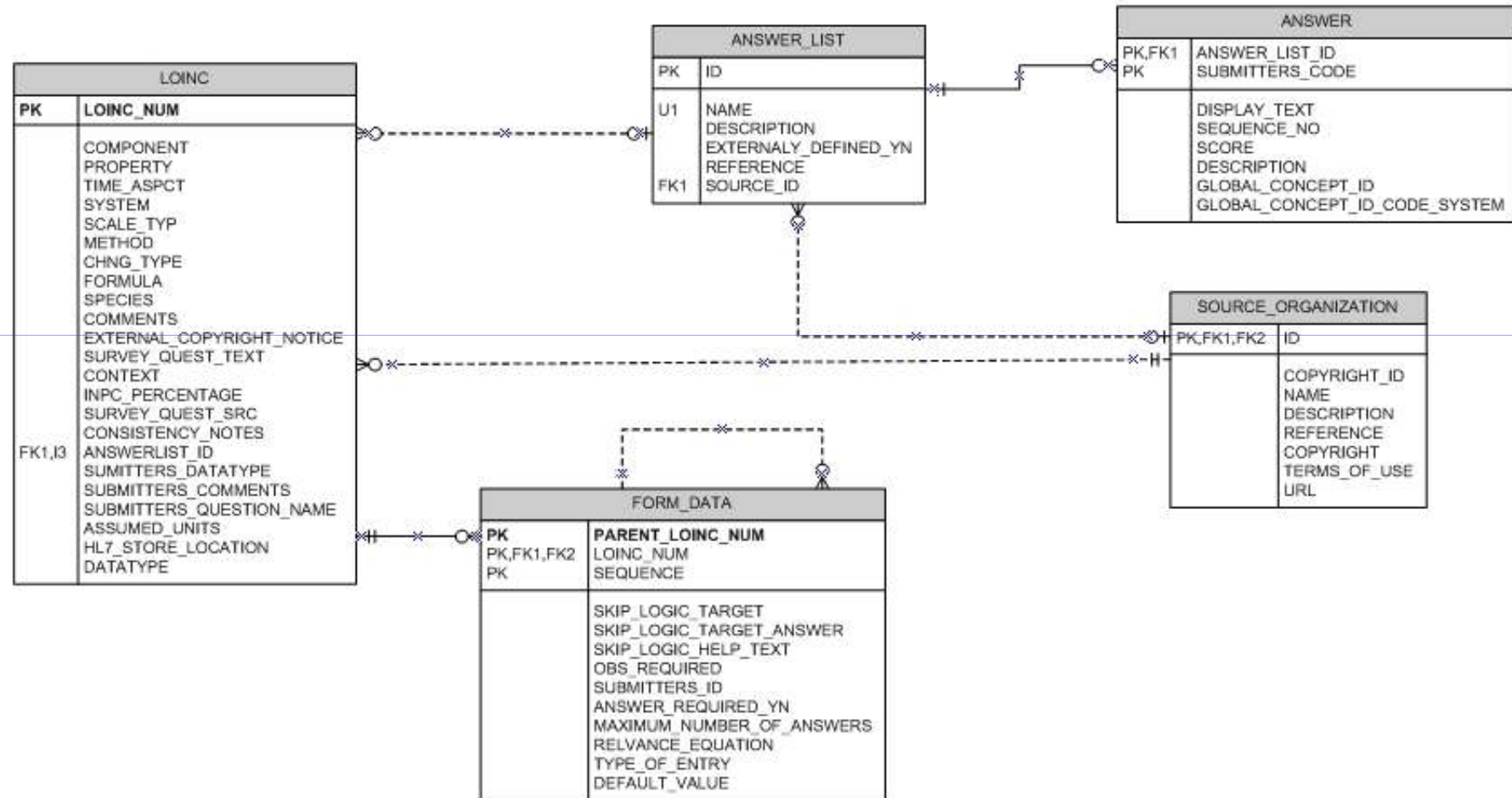
LOINC's package structure

- LOINC panels also needed more
- A new name--packages-
- Now many include “all” of the information that is needed to define a form for capturing the data in the panel
- Includes attributes that may over ride “usual “ value recorded with the LOINC code, cardinality
- Permits nested and repeating sub structures

Still more

- Data types to control input
- Special edit checks
- Units and normal ranges for numeric things
- Answer lists for nominal things
- User help per variable
- Etc

Approximate Data Model for LOINC data package



LOINC's Specific packages

- All lab panels can drive data entry
- Braden skin break down scale
- PHQ-9 depression
- US Surgeon General's family history
- Medicare's OASIS form
- HL7's Clinical genomics reporting structure
- Lots more
- Could we make a standard for this structure that describes a data package- Sub

A little on the PHR

- Written in Ruby on Rails and java script
- Uses loss of open source Java script
- Increasingly Dojo
- Application forms generated on the fly from description of the form which could nest indefinitely

A quick over view of PHR

- Aimed at care giver who manages care of children and dependent older relative
- Info buttons for every key terms
- HL7 data type for dates, (allows approximate dates, CE (CWE) data type for coded data
- Auto complete statistically based
- Rule based decision support
- Form is dynamic (fields appear depending on values of other fields

Approach

➤ Patient entered

- (no external data – yet)

➤ Target “market”

- Adult caring for frail parent or young child
- They all come into clinic with hand written lists of medicine - we can

help that

PHR more

- We noticed that every thing of interest can be described as a 2 dimensional table
- Got to point where we generate forms for collecting data packages on the fly (Think we could extend to other tables -- but today's focus is on data package -- and possibly of an HL7 standard for the package structure (and maybe reference implementation of data capture tool)

Medical conditions is a table

Race or Ethnicity: ?

Medical Conditions ? Research Studies

| Medical Condition ? | Status ? | When started ? | Description/Comment ? |
|----------------------------|----------|---|---------------------------------------|
| | | 1990 | Mostly the knees. Don't want surgery. |
| Asthma | Active | 1955 | Gotten better over the years. |
| Deep Vein Thrombosis | Inactive | 2006 | Following surgery with long bed rest. |
| Headache | | | |
| Chronic Obstructive Pulmor | Active | <input type="text" value="2009 May 8"/> | didn't know I had id |
| Heart | | <input type="text" value="YYYY/mm/dd"/> | |
| | | <input type="text" value="YYYY/mm/dd"/> | |

Bioprosthetic Heart Valve
 Congenital Heart Disease
 Congestive Heart Failure
 Coronary Artery Disease
 Heart Attack
 Mechanical Heart Valve
 Rheumatic Heart Disease

See more items (Ctl Ret)

7 of 36 total; 355 bytes in 239 ms

| Strength ? | Instructions ? | Why Stopped ? | Expire Date ? |
|-------------|-------------------------|---------------|---------------|
| 250 MG Caps | Take 1 BID for acne | | |
| 50 MG Tabs | Take for stress, fright | | |

Drugs as table

NLM Personal Health Record - Mozilla Firefox

File Edit View History Bookmarks Tools Help

https://swdef.nlm.nih.gov/app/phr/eab8a37aa5/edit

Drugs Active Inactive

| Drug Name ? | Status ? | Strength ? | Instructions ? | Why Stopped ? | Expire Date ? |
|----------------------------|---------------|--------------------------------------|---|---------------|---------------|
| Tetracycline (Oral-pill) | Active | 250 MG Caps | Take 1 BID for acne | | |
| Propranolol (Oral-pill) | Active | 20 MG Tabs | Take for stage fright. | | |
| Beclomethasone (Inhalant) | Active | 0.042 MG/ACTUAT Metered Dose Inhaler | Twice a day when having asthma attacks. | | |
| TUMS E-X (Oral-pill) | Active | 750 MG Chewable Tabs | Twice a day for heartburn. | | |
| LASIX (Oral-pill) | Inactive | 20 MG Tabs | Take in AM for swelling. | | |
| INDERAL (Oral-pill) | Active | 20 mg Tabs | | | YYYY/MM/dd |
| AMP | | | | | YYYY/MM/dd |

Horizontal indicates required information

Amphetamine/Dextroamphetamine (Oral-pill)
 Amphetamine/Dextroamphetamine XR (Oral-pill)
 AMPHOCIN (Injectable)
 AMPHOJEL (Oral-liquid)
 AMPHOJEL (Oral-pill)
 Ampicillin (Oral-liquid)
 Ampicillin (Oral-pill)
[See more items \(Ctrl Ret\)](#)
 7 of 20 total; 297 bytes in 638 ms

| Name ? | Reaction ? | Date ? |
|---------|------------|------------|
| Aspirin | Diarrhea | 1999 |
| NUTS | Itchiness | |
| | | YYYY/mm/dd |



Major Surgery and Implants

And more



- Allergies
- Surgeries
- All observations
- Are tables.

Observations are tables



▼ Blood Pressure Panel

| When done ? | Where done ? | Summary ? | Due Date ? | More |
|--|----------------------|----------------------|--|----------------------|
|  <input type="text"/> | <input type="text"/> | <input type="text"/> |  <input type="text"/> | More |
| Name ? | Value ? | Previous ? | Units ? | Range ? |
| BP Systolic | <input type="text"/> | <input type="text"/> | mm Hg | <input type="text"/> |
| BP Diastolic | <input type="text"/> | <input type="text"/> | mm Hg | <input type="text"/> |

▼ Height & Weight Panel

| When done ? | Where done ? | Summary ? | Due Date ? | More |
|--|----------------------|----------------------|--|----------------------|
|  <input type="text"/> | <input type="text"/> | <input type="text"/> |  <input type="text"/> | More |
| Name ? | Value ? | Previous ? | Units ? | Range ? |
| Height(Length) | <input type="text"/> | <input type="text"/> | Inches | <input type="text"/> |
| Weight | <input type="text"/> | <input type="text"/> | Pounds | <input type="text"/> |

▼ Lipid (Cholesterol) panel in Serum or Plasma

| When done ? | Where done ? | Summary ? | Due Date ? | More |
|--|----------------------|----------------------|--|----------------------|
|  <input type="text"/> | <input type="text"/> | <input type="text"/> |  <input type="text"/> | More |
| Name ? | Value ? | Previous ? | Units ? | Range ? |
| Cholesterol Total | <input type="text"/> | <input type="text"/> | mg/dL | <input type="text"/> |
| HDLc (Good Cholesterol) | <input type="text"/> | <input type="text"/> | mg/dL | <input type="text"/> |
| LDLc (Bad Cholesterol) | <input type="text"/> | <input type="text"/> | mg/dL | <input type="text"/> |

★ indicates required information



And we can generate them on the fly

▼ Pedometer Device Panel

| When done ? | Where done ? | Summary ? | Due Date ? | More |
|----------------------|----------------------|----------------------|----------------------|-------|
| <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/> | Fewer |

| Name ? | Value ? | Previous ? | Units ? | Range ? |
|------------------------------|----------------------|----------------------|----------|----------------------|
| Pedometer Step Count | <input type="text"/> | <input type="text"/> | #/day | <input type="text"/> |
| Pedometer Walking Distance | <input type="text"/> | <input type="text"/> | feet/day | <input type="text"/> |
| Pedometer Calories | <input type="text"/> | <input type="text"/> | kcal/day | <input type="text"/> |
| Pedometer Average Heart Rate | <input type="text"/> | <input type="text"/> | /MIN | <input type="text"/> |
| Pedometer Maximum Heart Rate | <input type="text"/> | <input type="text"/> | /MIN | <input type="text"/> |

New Panel:

* indicates required information

Where we are

- More than 500 packages that we have expanded to generate good data input form
- Could de-couple from LOINC –so users could generate their own forms for whatever
- Aim for simple. Not Xforms Redux
- SHOW SOME

That is the point

- LOINC's standard description of a data package is simple
- Three main tables- a few ancillary tables
- Can generate them on the fly via Ajax calls and java script
- Want to see about getting to a standard formulation for simple data capture forms
- We do have an implementation- -

Had great plans

- Shipped hand outs showing the details
- The never got out of Washington
- Send PDFs to Kyoto FedEx Kinkos.
- Not done yet
- But will be available for discussion at HL7 about standard data definition for automated simple data entry
- Start with observations- Might be able to extend to all clinical tables

THE END