The Problem

• Even if all the guides in the User Guide are followed, there are concrete issues
  ➢ Using PROs requires many steps and many types of expertise
  ➢ Yet the knowledge for those steps is relatively unchanging
  ➢ Can that knowledge be maintained centrally and computationally?
    • “Computational”: A computer can execute steps without the need for human intervention
Using PROs requires many steps and many types of expertise
Currently

- Standardized PROs are available in **text** format
- IT developers create computer-based **forms**
- IT developers write **programs** to convert collected data into formats to be stored
- Statistical analysts write **programs** to convert the data into analytic variables
- Analysts confer with PIs to figure out the **rules** for analyzing the data
- PIs read some analytic guide to figure out the rules for themselves
PaTH Experience

- Over 20 PROs
- Collected in REDCap, Epic, Cerner
  - REDCap project surveys
    - Confusion over item vs epoch of administration
    - Need to revise item IDs
  - Epic Questions
  - Need to match REDCap items to Epic Question IDs
  - Bring them into i2b2
    - PRO:1000_f2_q12:3
But Wait, There’s More

- Extract from i2b2
- Assign to variables
- Label variables
- Label values
- Analyze
- In SAS, Stata, R
Diagrammatically

PROMIS29

Advance Directives

GERDQ

REDCap

Epic

i2b2

Stata

SAS

R

Johns Hopkins School of Medicine
Division of Health Sciences Informatics
Knowledge

PROMIS29: Items/Content

Variables/Values

Analytic Rules

PROMIS29

REDCap

Epic

i2b2

Stata

SAS

R
The knowledge for those steps is relatively unchanging
Knowledge

PROMIS29: Items/Content

Variables/Values

Analytic Rules

PROMIS29

REDCap

i2b2

Epic

Stata

SAS

R

Johns Hopkins School of Medicine
Division of Health Sciences Informatics
Can that knowledge be represented and maintained centrally and computationally?
Knowledge

Items/Content

- REDCap
- Epic

Variables/Values

- Relational Database
- i2b2
- Stata
- SAS
- R
XML Example of Format Conversion

- XML Document
- XML Schema
- XSLT
- Web Page
- Web Page
Knowledge

Knowledge Items/Content

- REDCap
- Epic

Knowledge Variables/Values

- Relational Database
- Stata
- SAS
- R
<table>
<thead>
<tr>
<th>Name</th>
<th>Flags</th>
<th>Card.</th>
<th>Type</th>
<th>Description &amp; Constraints</th>
</tr>
</thead>
<tbody>
<tr>
<td>Questionnaire</td>
<td>I</td>
<td></td>
<td>DomainResource</td>
<td>A structured set of questions&lt;br&gt; + The link ids for groups and questions must be unique within the questionnaire. Elements defined in Ancestors: id, meta, implicitRules, language, text Logical URI to reference this questionnaire (globally unique)</td>
</tr>
<tr>
<td>url</td>
<td>Σ</td>
<td>0..1</td>
<td>url</td>
<td>Additional identifier for the questionnaire</td>
</tr>
<tr>
<td>identifier</td>
<td>Σ</td>
<td>0..*</td>
<td>Identifier</td>
<td>Business version of the questionnaire</td>
</tr>
<tr>
<td>version</td>
<td>Σ</td>
<td>0..1</td>
<td>string</td>
<td>Name for this questionnaire (computer friendly)</td>
</tr>
<tr>
<td>name</td>
<td>Σ</td>
<td>0..1</td>
<td>string</td>
<td>Name for this questionnaire (human friendly)</td>
</tr>
<tr>
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<td>Σ</td>
<td>0..1</td>
<td>string</td>
<td>Draft</td>
</tr>
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<td>status</td>
<td>Σ</td>
<td>1..1</td>
<td>code</td>
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<td>experimental</td>
<td>Σ</td>
<td>0..1</td>
<td>boolean</td>
<td>Date this was last changed</td>
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<tr>
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<td>0..1</td>
<td>dateTime</td>
<td>Name of the publisher (organization or individual)</td>
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<td>string</td>
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<td>0..1</td>
<td>string</td>
<td>Why this questionnaire is defined</td>
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<td>0..1</td>
<td>markdown</td>
<td>When the questionnaire was approved by publisher</td>
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<td>date</td>
<td>When the questionnaire was last reviewed</td>
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<td>date</td>
<td>When the questionnaire is expected to be used</td>
</tr>
<tr>
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<td>0..1</td>
<td>Period</td>
<td>Context the content is intended to support</td>
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<td>useContext</td>
<td>Σ</td>
<td>0..*</td>
<td>UsageContext</td>
<td>Intended jurisdiction for questionnaire (if applicable)</td>
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<td>Jurisdiction ValueSet (Extensible)</td>
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<td>ContactDetail</td>
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<td>code</td>
<td>Resource that can be subject of QuestionnaireResponse</td>
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<tr>
<td>item</td>
<td>I</td>
<td>0..*</td>
<td>BackboneElement</td>
<td>Questions and sections within the Questionnaire</td>
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</tbody>
</table>
Knowledge

FHIR Questionnaire Resource structure

Conversion scripts

- REDCap
- Epic
- Relational Database

Items/Content

Variables/Values

- Stata
- SAS
- R
Converting *rules* to Stata/SAS/R programming *code* is more complicated

- On the FHIR side: There are formats for representing the rules
- On the Analytic side: Unclear that simple format conversion will work
Conclusion

• Creating a PRO “schema” in FHIR
  ➢ Format conversion for data collection, analysis: Development
  ➢ Application of rules: Research
Results: PRO on FHIR

- PRO definition can live in a single location
  - Does not need to be centralizd
- Write once, use many forms in different data collection systems
- Speeds up deployment
- Eases dissemination
- Increases sharabililty/integration of research results
- Increases commonalities in analyses
- Normalizes semantics of research results