Facilitating Reuse of Mental Health Questionnaires via Knowledge Graphs

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“Inconsistent use of terms and classification systems makes it challenging to integrate findings... and build bodies of knowledge even in domains that are consistently studied.” “The gap between what is known and the capacity to act on that knowledge has never been larger, and it continues to grow.”
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- National Cancer Institute
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- National Library of Medicine
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Mental Health Screening Questionnaires

● One of the most common instruments for screening patients for mental health disorders
● Composed of items whose answers can be scored to determine the probabilities associated with a disorder or diagnosis
● Items are organized in scales
  ○ Questionnaires can have a single scale (PHQ-9, DAG-7) or multiple scales (RCADS)
● Items are designed to assess specific symptoms
### PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

**Over the last 2 weeks, how often have you been bothered by any of the following problems?**  
(Use "✓" to indicate your answer)

<table>
<thead>
<tr>
<th>Problem</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Little interest or pleasure in doing things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Feeling down, depressed, or hopeless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Trouble falling or staying asleep, or sleeping too much</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Feeling tired or having little energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Poor appetite or overeating</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Trouble concentrating on things, such as reading the newspaper or watching television</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Moving or speaking so slowly that other people could have noticed?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. Thoughts that you would be better off dead or of hurting yourself in some way</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

**For office coding**  
0 + 0 + 0  

= **Total Score:**

---

### GAD-7

**Over the last 2 weeks, how often have you been bothered by the following problems?**  
(Use "✓" to indicate your answer)

<table>
<thead>
<tr>
<th>Problem</th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feeling nervous, anxious or on edge</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Not being able to stop or control worrying</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Worrying too much about different things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Trouble relaxing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Being so restless that it is hard to sit still</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Becoming easily annoyed or irritable</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Feeling afraid as if something awful might happen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

(For office coding: Total Score T = ___ + ___ + ___)
Revised Children’s Anxiety and Depression Scale (RCADS) Questionnaire

- 47-item youth self-report questionnaire
- With subscales (separation anxiety disorder, social phobia, generalized anxiety disorder, panic disorder, obsessive compulsive disorder, and major depressive disorder)
- And composite scales (total anxiety scale, total internalizing scale)
- Items are rated on a 4-point Likert-scale (from "Never" to "Always")
- A parent version is available (RCADS-P)
- Brief versions are available as well, with 25 items (RCADS-25)
- Translated to 19 languages
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Please put a circle around the word that shows how often each of these things happens to you. There are no right or wrong answers.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I worry about things</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I feel sad or empty</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>When I have a problem, I get a funny feeling in my stomach</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>I worry when I think I have done poorly at something</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I would feel afraid of being on my own at home</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>Nothing is much fun anymore</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>I feel scared when I have to take a test</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>I feel worried when I think someone is angry with me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I worry about being away from my parents</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Challenges with reuse of mental health questionnaires

- Current measurement architecture is essentially based in textual documents representing questionnaires
  - Limited knowledge about their creation, relationships to other questionnaires, relationships between item and symptoms, etc.

- Reuse with adaptation of these documents are prone to errors
  - Ad-hoc creation of derived questionnaires (e.g. shortening of items, combination of items from different questionnaires) may lead to inaccurate diagnosis

- Increased interest in widespread adoption of common measures in mental health
  - To support measurements across contexts, settings, and nations
Semantics of RCADS questionnaire items

6. Nothing is much fun anymore

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
</table>

assesses

Anhedonia (Symptom)

has part

Major Depressive Disorder Scale

In RCADS-47

Depression Scale

In RCADS-25
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Psychometrics ontology development

[Diagram showing the relationships between Scale, CompositeScale, SyndromeScale, Syndrome, Condition, vstoi Detector, vstoi Item, Symptom, Symptom Experience, hasSubscale, hasPart, detects, hasVariable, hasAttribute, hasExperience, experiences, hasEntity, isA, sio:Attribute, sio:Object (TargetEntity), sio:Human (TargetHuman)]
Semantic Instrument Repository (SIR)

- An infrastructure that manages knowledge graphs about data acquisition instruments
- SIR implements the notion of Semantic Instrument that includes a canonical RDF description of instruments and their building blocks
- SIR is being developed to provide the mapping from canonical descriptions into instrument rendering tools like REDCap and FHIR (Fast Healthcare Interoperability Resources)
- Open-source and freely available to the public.
Semantic Instrument Repository Architecture

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API SIR Service

- API SIR
- FUSEKI
- FHIR translator

SIR Editorial Team

- SIR Drupal Module
- Instrument Management
- Instrument Retrieval

Postgres

SIR user on the web

- Canonical representation of instruments
  - HAScO 2.0
  - domain ontologies

SIR user on a FHIR server

- Drupal Service

FHIR Service (Server)
Beyond Mental Health Questionnaires...

- CDC's National Health and Nutrition Examination Surveys (NHANES)
  - Demographics questionnaire, dietary questionnaire, PHQ-9, GAD-7
- FioCruz's National Health Survey (PNS - *Pesquisa Nacional de Saúde*)
- Other surveys
  - National surveys (K-NHANES, …)
  - CDC surveys (National Health Interview Survey, National Survey of Family Growth)
- In the future, we want to expand SIR to allow the incorporation of questionnaires beyond mental health
Ongoing work

● Semantic Instrument Repository deployment at UCLA for supporting the authoring and distribution of the RCADS questionnaire family
  ○ End of May
● Development of the Psychometrics ontology
  ○ Review by domain experts and incorporate feedback
● Development of Semantic Instrument Repository HUB
  ○ A federation of SIRs to allow the decentralized sharing of instruments
    ■ For preserving attribution and storing within each institution policies
  ○ Based on W3C's ActivityPub protocol
Conclusions

- SIR is a semiantically-enabled repository for data acquisition instruments
  - For supporting the authoring, reuse, and distribution of questionnaires
  - Provides a canonical representation of instruments in RDF
    - Utilizes HAScO, VSTOI, and a novel Psychometrics ontology to attach semantics to questionnaire items
  - Supports instrument serialization to common formats, such as FHIR, and PDF
- Learn more about SIR at [https://hadatac.org/sir/](https://hadatac.org/sir/)
- Work partially funded by Tetherless World Constellation, William T. Grant, and National Institute of Mental Health grant #75N95022C00018