

## Panel 2a: End Users: Clinicians, Hospitals, HIEs

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### Overall questions

1. What are the requirements for a centralized infrastructure to implement “one-stop shopping” for obtaining value sets, subsets, and vocabularies for meaningful use?

Assuming a nationwide content sharing portal used primarily for vocabulary content distribution (authoring not included), the following functionalities are proposed:

- (a) Simple methods to browse, search, and download vocabulary content (e.g., value sets, subsets, mappings, synonyms, translations, etc.);
- (b) Flexible tagging methods enabling content-sharers and consumers to identify and find items of relevance;
- (c) Vocabulary content available using standard (or widely used) formats, and augmented with instructions and best practices for implementation and use;
- (d) Simple methods to upload vocabulary content, including proper management of versions and dependencies;
- (e) Simple methods to subscribe to content updates and extensions;
- (f) Simple methods to request changes and report errors and inconsistencies;
- (g) Simple methods to rate the content value (and associated support services);
- (h) Co-existence of open (free) and subscription-based licensing models;
- (i) Proper handling of legal issues related to intellectual property, liability, and indemnification.

2. Which requirements or functionalities are urgent, i.e., absolutely required to support “meaningful use”? Which would be most useful immediately? What would be a staged approach over time to get to the desired end state?

Taking into account the high-level functionalities presented above, the urgent ones include items ‘a’, ‘c’, and ‘i’. Useful functionalities in the short-term include items ‘b’, ‘e’, and ‘f’. Other functionalities listed would be added as part of a future end state, with particularly emphasis on long-term sustainability.

### Detailed Questions

3. Where are you using value sets and subsets? For what domains? How many value sets and subsets?

Value sets and subsets derived from standard vocabularies are used primarily to support data entry, including terminology lookup, and concept classification. The domains being managed using a common terminology infrastructure include problem lists and medication-related concepts, with more recent efforts focusing on bedside documentation. Currently managing 291 sets for problem lists derived from SNOMED, including several describing ‘clinical states’ that are used by clinical decision support

rules, and 23 medication-related sets derived from First DataBank. Most clinical systems at Partners are internally developed and rely on local dictionaries with proprietary codes. Many of these dictionaries are not yet linked to standard vocabularies. Most of the details below pertain to problem list subsets.

4. In your experience with creating, disseminating, updating and/or using value sets, subsets, and entire vocabularies, what works and what does not work?

Efforts that seem to be working include: (a) Access to value sets and subsets is primarily made via software services (APIs); (b) Sets are created and maintained using custom-developed editors; (c) Content review and vetting assisted by subject matter experts. Areas that remain challenging include: (a) Development and maintenance of value sets and subsets is labor-intensive, with periodic reviews triggered by updates to the reference sources; (b) Local extensions are inevitable and relatively common, particularly considering the need to support research activities; (c) Mappings to local codes are also inevitable and common, with continuous efforts to reduce ambiguity while preserving the intended meaning.

5. What human resources does it take to implement and manage value sets, subsets, and entire vocabularies? Informaticists? Clinicians? IT people? How are you organized?

Terminology management activities require the following roles: terminology engineers, clinical informaticians, and subject matter experts (SMEs), with support from project managers and software engineers. Current organization is based on domain-specific teams with these roles. Routinely 10 to 12 employees are directly involved with terminology management activities at the enterprise level, excluding SME panels.

6. What national resources and services could be leveraged to reduce the level of effort required for local implementations? What is the irreducible minimum of local work at an implementation site, or within an organization or system?

At a national level, the following resources and services should be provided: (a) Distribution (sharing) of national value sets and subsets derived from standard vocabularies, along with necessary detailed clinical models, to support data interoperability, quality measures, and clinical decision support; (b) Efficient process to submit requests for additions and modifications to these standard sets and models, ideally with the generation of temporary identifiers that can be subsequently made permanent (or revoked) when review process is completed, with proper reconciliation with standard terminologies (requested extensions should be accessible to others, avoiding duplicate requests); (c) Processes should be implemented using standard APIs and standard exchange format (download and upload).

At a local (organizational) level, significant work remains to create and maintain local extensions, including items submitted but not approved to be included in national sets, and to create and maintain mappings to local code sets.

7. What is your maintenance process? How do you manage updates?

The maintenance process for value sets and subsets accommodates two types of events: update of the source vocabulary and individual requests to add/remove members (or to fix errors). Changes are made using custom-developed editors and are managed using a series of reports that indicate what has changed and where. SMEs are asked to review changes whenever necessary. The subset lifecycle includes the following states: editable, under review, reviewed, ready for release, and released.

8. What metadata do you maintain and how do you maintain versioning?

The details about value sets and subsets generally include name, nickname (programmatic name), description, version, comments, status, category (one or many indicating intended use), creation date, last update date, last release date, and release notes. Versions typically relate to specific versions of the source reference vocabularies.

9. Is there a difference between versioning for clinical documentation vs. versioning for reported measures, i.e., when do you go live with a change in the EHR vs. when do you use the new version for measures?

For the most part, the existing sets are not being used for reporting, at least not in a manner that could create version conflicts. Currently working on unified strategy to share clinical data definitions for documentation, quality measures and reports, and clinical decision support.

10. How do you manage versioning in clinical decision support vs. changes in value sets?

Typically, a subject matter expert who understands the clinical decision support rules is asked to review and validate the changed subsets before these are released for production use.

11. How does an application know which value set is for which purpose? How is the specific context for a value set maintained at the message data element level of specificity? How is the English language intent of the value set context documented and maintained?

Applications have to know ahead of time which sets they want to use and request them by nickname. The intended use of the value set is defined by its category, but it can be further refined using the description or comments fields.

12. What are lessons learned about web links vs. storage of the vocabulary or other artifact in a physical repository?

Did not understand the intended meaning of 'web links' in this context. Current approach includes local content repositories with the appropriate management of local and reference namespaces.

13. How do you manage distribution of updates to multiple sites?

Access and use of value sets and subsets is provided via software services and these services rely on a centralized ('read-only') content source. Not all sites and clinical systems are currently able to consume these services (work in progress).

14. Where is local customization appropriate and how much customization is acceptable?

Local customizations are likely required for supporting new concepts, differences in concept granularity (e.g., pre-coordination), and legacy concepts ('exclusion' sets). These customizations have to comply with terminology management best practices. Extent of customizations seems to depend on local business needs and degree of sophistication of clinical systems, particularly in terms of clinical decision support.

15. How do you manage distribution of updates with local variations and optionality?

Unique subsets? Local mappings?

Local variations are currently managed via distinct (unique) subsets. Reuse can be maximized with modular (nested) subsets.

16. What has to be local in an EHR implementation vs. what can be external in a vocabulary repository?

The long-term plan at Partners is to have all vocabulary content external to EHR applications and accessed via software services. An alternative is to have vocabulary content imported into EHR applications from a common central source.

17. What functions are required that users have not yet appreciated?

Examples of desirable functionality include: (a) Explicit (computable) definition of context of use (for entire set and members of a set); (b) Declarative methods to specify the content of subsets (particularly for complex clinical states); and (c) Collaborative and distributed processes to create and maintain vocabulary content and models beyond organizational boundaries, decreasing the overall cost of implementation and maintenance, while enabling sharing of clinical decision support rules.

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