Questionnaires & Structured Data Capture (SDC)

Lloyd McKenzie, Gevity Consulting
Who am I?

• Name: Lloyd McKenzie
• Company: Gevity
• Background:
  • One of FHIR’s 3 initial editors
  • Co-chair MnM, FMG & FHIR Infrastructure
  • Technical lead for ONC’s FHIR SDC project
    • Same role for NLM-funded internationalization/update project
  • Heavily involved in HL7 and healthcare exchange for last 19 years
    • v2, v3, CDA, etc.
• lmckenzie@gevityinc.com
Objectives

• What are FHIR Questionnaires for?
• FHIR vs. SDC IG
• What does SDC provide?
What are Questionnaires for?
Questionnaire

• Used to represent forms/surveys/case report forms/etc.
• Can capture any sort of information
  • clinical, administrative, financial, research, public health, ...
• Hierarchical collections of questions
  • May include ‘groups’ and instructions/guidance
  • Control over allowed answer optionality, repetition, data type, options
  • Some elements might be conditional
    • e.g. “if question 2=female, then display question 5”
QuestionnaireResponse

• A single (fully or partially) completed form
• Ties to exactly one Questionnaire
• Lets you see and compare “raw” data
• Can’t be used for direct query based on answer values
  • Too hard to manage context implicit in instructions/other questions
• Data is not comparable if captured based on different Questionnaires
Example

• Questionnaire question:
  • “When were you born?” Answer: string
  • “How old are you (in years)?” Answer: integer/decimal
  • “How old are you?” Answer:
    (a) 0-18; (b) 19-30; (c) 31-50; (d) 51+
    Answer: integer
  • “What was your birth year?”
    “What was your birth month?”
    Answer: integer
  • Etc.

• Patient question:
  • Patient.birthDate? Answer: date (yyyy, yyyy-mm, yyyy-mm-dd)
Questionnaire usage

• Questionnaire
  • Raw data capture or tight control over display
  • Retain “source of truth” for data
  • Generic mechanism for non-FHIR aware systems

• Other resources
  • Search
  • Decision support
  • Consistency of representation independent of source

• In many cases, you may need both
What is SDC?
Original Structured Data Capture (SDC)

- U.S. Office of the National Coordinator for Healthcare (ONC) initiated project
- Parallel efforts in IHE (custom schema) and FHIR
- FHIR effort had 2 focuses
  - Standardizing the sharing of data elements (IS 11179-aligned)
  - Supporting standardization of Questionnaire usage and enabling pre-population and auto-population
- Separate FHIR IGs created for each
SDC Phase II

• Funded by US National Library of Medicine

• Scope:
  • Update the SDC implementation guide to align with R4
  • Make the IG international in scope
  • Add new rendering/control capabilities
  • Figure out a population/extraction mechanism that’s workable

• Targeting Standard for Trial Use (STU) ballot opening in April
Why SDC?

• Base FHIR resources
  • almost everything optional
  • Focus is “what do most systems do?”
    • Most systems includes lots of very limited systems
  • Provides base level interoperability across all systems

• SDC implementation guide
  • Sets “higher” expectations for systems dealing with more sophisticated forms
  • Provides confidence that forms will be rendered and will capture data as intended
SDC defines 6 things

• Standard workflow models and roles for managing, discovering and completing forms
• Sophisticated rendering capabilities
• Sophisticated behavior/flow control capabilities
• Pre-populate/auto-populate forms
• Extract resources from forms
• Adaptive forms

• Systems choose what to adapt
Capabilities defined by

- Describing conformance expectations around existing extensions
- Defining new extensions
- Documenting (and providing examples) showing how the capabilities can be used for real-world healthcare scenarios
Where can SDC be useful?

• Submitting forms for clinical research
• Submitting public health forms
• Submitting and processing electronic insurance claims (pre-authorizations, special authorizations, etc.)
• Any area where questionnaires/forms are a standard mechanism for data collection
Argonaut Questionnaire

• What questionnaire capabilities should U.S. EHRs support?
• Much simpler than SDC – but aligned
• Expectation is that more complex (SDC) forms will be handled through SMART on FHIR apps
SDC capabilities
SDC Workflow

• Who are the participants?
• What do they do?
• What’s the base metadata for searching?
Form rendering

- Embedded HTML
- Table rendering
- Sliders
- Item-level labels

- Form translation
- Question grids
- Form translation
Complex behavior

- Calculated fields (e.g. scores)
- Calculated decision points
  - E.g. Display question 5 IIF cumulative score <0.3
- Calculated default values
- Multi-column drop-downs
Population operations

• $populate
  • Get back a QuestionnaireResponse

• $populatehtml
  • Get back HTML with active submit button

• $populatelink
  • Get back URL to site displaying interactive (and partially populated) form
Form population

• Don’t make user fill in what’s already in the EHR/other systems
• Contents of forms must be “computably” derivable from standardized data
• SDC Phase II focus is FHIR-based data, not CDA
Multiple population levels

• **Full population**: Answer automatically filled in
  - E.g. Patient’s name, gender, address

• **Choice selection**: Possible choices for answer
  - E.g. “List all potentially relevant concomitant medications”

• **Answer context**: Information to help user formulate an answer
  - E.g. “Has the patient had similar procedures in the past?”
3 data representation approaches

• **Observation-based**
  • Question/group tied to specific question code (e.g. LOINC)

• **FHIRPath based**
  • Pass in context (Patient, Encounter, other?)
  • Perform queries to set context for Questionnaire/group
  • FHIRPath to calculate variables
  • Question/group context tied to specific FHIRPath

• **StructureMap**
  • Formal mapping from QuestionnaireResponse to completed Questionnaire
Extraction

• User has filled in a Questionnaire
  • How do I make that data available to:
    • Decision support
    • Available using standard profiles (Argonaut, Australian core, etc.)
    • Discoverable by queries?
  • Need to move data into “regular” resources
    • Observation, Encounter, MedicationStatement, etc.

• $extract operation
Extraction approach

• Leverage same technologies as population
  • Observation
  • StructureDefinition

• Also support “Definition”-based
  • Link questions/groups to particular profiles and profile elements
Adaptive forms

• Hide the complexity of the questionnaire logic
• Hit the server with “answers so far”
• Server returns an updated questionnaire adding one more question
• Supported by Argonaut Questionnaire

• $nextQuestion operation
Current state

• Hope to go to ballot in May 2019
• Publish as STU in late 2019
• Actively testing at connectathon
• SMART on FHIR app ~50% done
• Still work to do defining examples, determining conformance requirements
To participate in SDC

• Weekly calls, 5 Eastern
• Details (and minutes) available from the FHIR wiki:
Questions / Discussion?

• [http://build.fhir.org/ig/HL7/sdc](http://build.fhir.org/ig/HL7/sdc)
• [https://github.com/HL7/sdc](https://github.com/HL7/sdc)

• [https://chat.fhir.org/#narrow/stream/102-questionnaire](https://chat.fhir.org/#narrow/stream/102-questionnaire)

• lmckenzie@gevityinc.com