

Questionnaires & Structured Data Capture (SDC)

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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.
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Objectives

- Understand where FHIR Questionnaires should and shouldn't be used
- Be able to differentiate the role of the FHIR core specification and the SDC implementation guide
- Identify some of the additional rendering and behavioral capabilities of SDC questionnaires
- Know the different mechanisms for performing questionnaire “population” and “extraction”
- Be able to explain how adaptive questionnaires work

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+
 - What was your birth year? Answer: integer
What was your birth month? Answer: integer
 - Etc.
- Other resource question:
 - Patient.birthDate? Answer: date (yyyy, yyyy-mm, yyyy-mm-dd)

In general

- 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

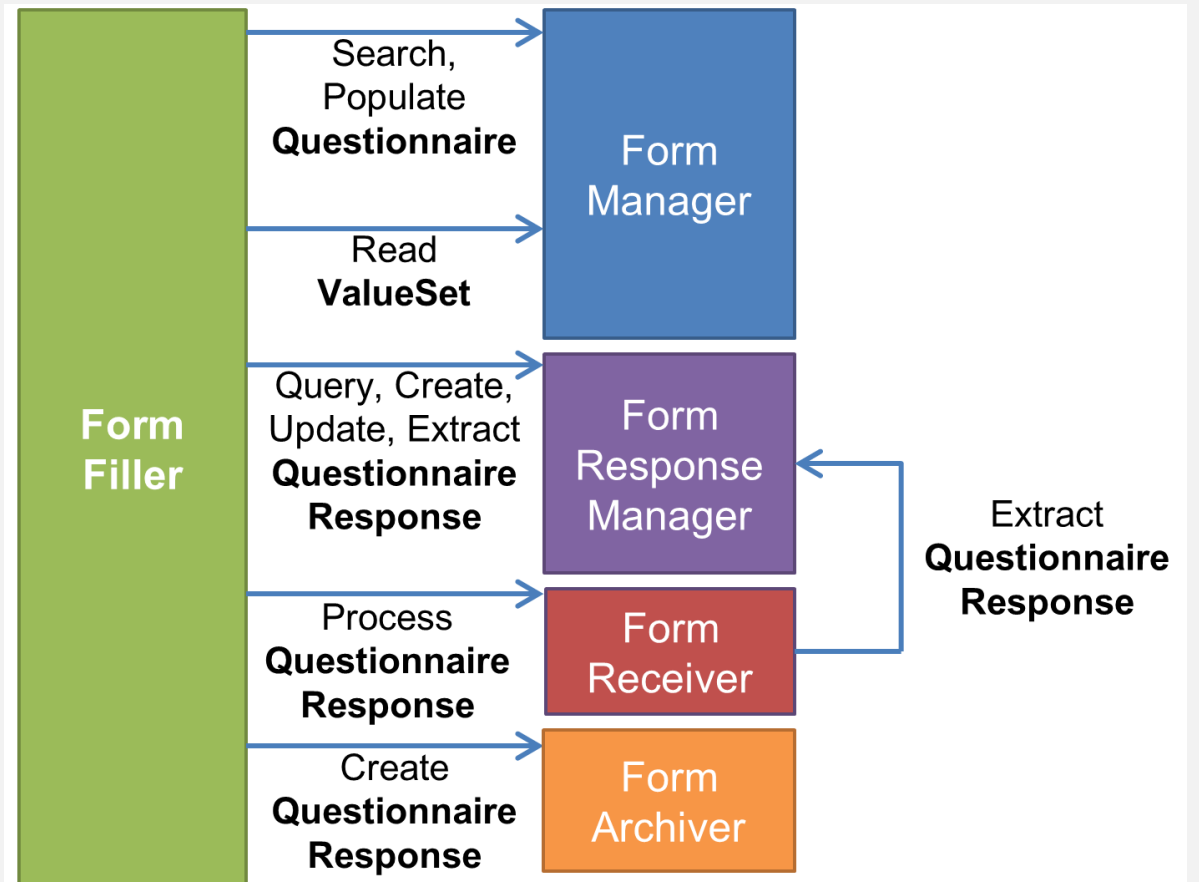
Argonaut Questionnaire

- 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?



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

OR

C. If you have **pain that stops you** from completing your training/practice in **Achilles tendon loading sports**, for how long can you train/practise?

NIL	1-10 mins	11-20 mins	21-30 mins	>30 mins	POINTS
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0	2	5	7	10	

TOTAL SCORE (/100) %

913 843-0462

Last Name	First Name	Phone
White	Johnson	408 496-7223
Green	Marjorie	415 986-7020
Carson	Cheryl	415 548-7723
O'Leary	Michael	408 286-2428
Straight	Dean	415 834-2919
Smith	Meander	913 843-0462
Bennet	Abraham	415 658-9932
Dull	Click to Select Item	415 836-7128

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 use 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
 - 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.

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

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:
 - [http://wiki.hl7.org/index.php?title=FHIR Structured Data Capture](http://wiki.hl7.org/index.php?title=FHIR_Structured_Data_Capture)

Questions / Discussion?

- <http://build.fhir.org/ig/HL7/sdc>
- <https://github.com/HL7/sdc>
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