

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

- What was the Structured Data Capture project?
- What does the SDC implementation guide support?
- Potential use-cases for Structured Data Capture?
- Mapping strategies
- Where is SDC going next?

Background

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

CodeSystem & ValueSet

- From a Questionnaire perspective:
 - Allow defining sets of answers that are shared or are externally managed
 - Codes have both computable and human friendly views
 - Can have numeric weights for calculations

SDC – the original project

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

How to find FHIR SDC?

- <http://hl7.org>

Level 5 Providing the ability to



Clinical Reasoning

External Links:

Implementation Guides

Specifications based on the FHIR

- [Published by HL7, Affiliate Foundation](#)
- [Other IGs \(FHIR Wiki\)](#)

Specification	Category	Authority	Editions
US Core : Base US national implementation guide	Base National Specifications	HL7/US	<ul style="list-style-type: none"> ○ STU ○ CI Build
AU Base : Base Australian national implementation guide	Base National Specifications	HL7/AU	<ul style="list-style-type: none"> ○ Sept Connectathon ○ CI Build
CCDA on FHIR : US Realm Implementation Guide (IG) addressing the key aspects of Consolidated CDA (C-CDA) required for Meaningful Use (MU). This IG focuses on the clinical document header and narrative constraints necessary for human readability, and references the Data Access Framework (DAF) implementation guide for coded data representation	Clinical Documentation	HL7/US	<ul style="list-style-type: none"> ○ Ballot ○ CI Build
SDC (Structured Data Capture) : Defines expectations for sharing of Questionnaires and answers, including mechanisms for automatically populating portions of a questionnaire based on embedded mappings to underlying data elements	Data Collection	HL7/US	<ul style="list-style-type: none"> ○ STU2 ○ CI Build
SDC Data Elements Registry : Defines expectations for sharing of data elements between registries	Data Collection	HL7/US	<ul style="list-style-type: none"> ○ STU2 ○ CI Build
US Lab : US Realm Laboratory ordering and reporting between ambulatory care setting and the laboratory and laboratory reporting to public health jurisdictions	Diagnostics	HL7/US	<ul style="list-style-type: none"> ○ DSTU2

SDC Use-cases – Data Elements

- Data Elements are a common notion, particularly in the research community
 - Defines the meaning of a discrete piece of data, the type and potentially the allowed values
 - Encourages consistency of data capture – particularly within questionnaires (e.g. CRFs – Case Report Forms)
- Need
 - Standard way to share data elements between data element repositories
 - National Library of Medicine, Federal Drug Administration, National Cancer Institute
 - Want to be aligned with ISO 11179

SDC Use-cases Questionnaire

- Questionnaire, like other resources, is “simple” and highly flexible
 - To support research, cancer reporting, etc. need more sophistication
 - Tight control over appearance/rendering
 - Flow control over what questions appear when
 - Need to set minimum expectations for systems
 - What elements must be present?
 - What elements (and extensions) must be supported?
 - Ensure a minimum baseline of capability to allow support for forms o ‘reasonable’ capability

Use Cases - QuestionnaireResponse

- Filling out questionnaires is:
 - Time consuming (repeatedly answering the same questions when data is already 'known' by the system)
 - Error-prone (transcription errors, missed data)
- It would be nice if a questionnaire could automatically be filled in with data already known
 - User fills in whatever is not automatically filled in
 - User can still review/correct/suppress pre-filled data

Use Cases - QuestionnaireResponse

- Not all systems will support rendering “complex” questionnaires
- Need a way to allow an EHR to support users still filling out those Questionnaires
 - Provide the HTML to render in an internal browser
 - Provide a link to a website where the user can fill in their answers
- In both cases, still want to support populating the response with existing known data

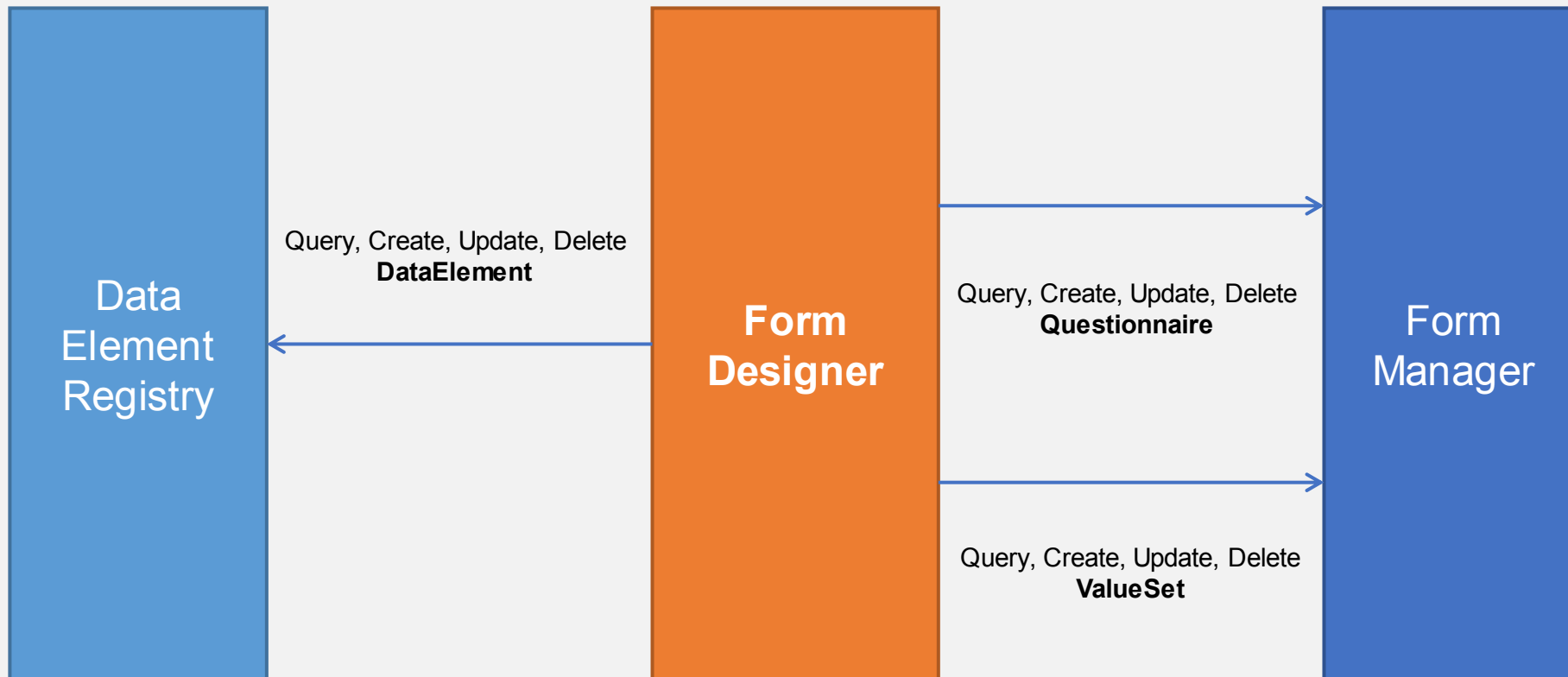
Pre-pop and Auto-pop

- Pre-population
 - An EHR or other data entry system solicits a 3rd party to fill in questionnaire with information submitted to that third party and/or information the third party already holds
- Auto-population
 - An EHR or other data entry system fills in questionnaire with information it holds itself

Pre-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

SDC overview



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

Enabling Questionnaire population

- Extension linking to data element with mapping
- ConceptMap linking Questionnaire questions to data elements with mappings
- Concept map linking Questionnaire questions to source data

What made SDC U.S.-specific?

- The SDC-DE (Data Element Maintenance) IG includes U.S.-specific vocabulary bindings
- The main SDC IG is generic however
 - Fully appropriate to use outside the U.S.

FHIR SDC vs. IHE SDC

- SDC work had already started in IHE prior to ONC funding the FHIR effort
- IHE SDC
 - Focuses only on Questionnaire, not DataElement
 - Leverages the IHE RFD (Request Forms for Data Capture) spec
 - Defines a custom XML syntax that combines form definition and results capture
 - FHIR used to do this, but changed based on implementer feedback
 - Has evolved largely independently of the FHIR spec

SDC – Phase II

SDC Phase II

- Funded by U.S. National Library of Medicine
- Focused just on the forms aspect of SDC
 - I.e. not ISO 21090 data element exchange (SDC-DE)

SDC Phase II Scope

- Update the SDC implementation guide to align with R4
- Remove dependency on US-specific terminology bindings and make the IG international
- Add additional rendering/control capabilities
 - More control over “enable when”
 - Calculated elements
 - Enhanced query capability for dynamic answer lists
 - Questions in grids
 - Etc.

SDC Phase II Scope (cont'd)

- Revamp how mappings supporting pre-population are managed to better support FHIR
 - And to use technologies implementers want to use...
 - Explore StructureMap, FHIRPath
 - Drop ConceptMap, use of DataElement?
- Add ability to export QuestionnaireResponses into FHIR resources
 - Give guidance on how this fits into management of complex data structures
 - E.g. Pregnancy record, birth record, etc.
- Align with Argonaut Questionnaire work
 - SDC will be a superset

To participate

- 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://hl7.org/fhir/us/sdc>
- <http://build.fhir.org/ig/HL7/sdc>
- <https://github.com/HL7/sdc>

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