

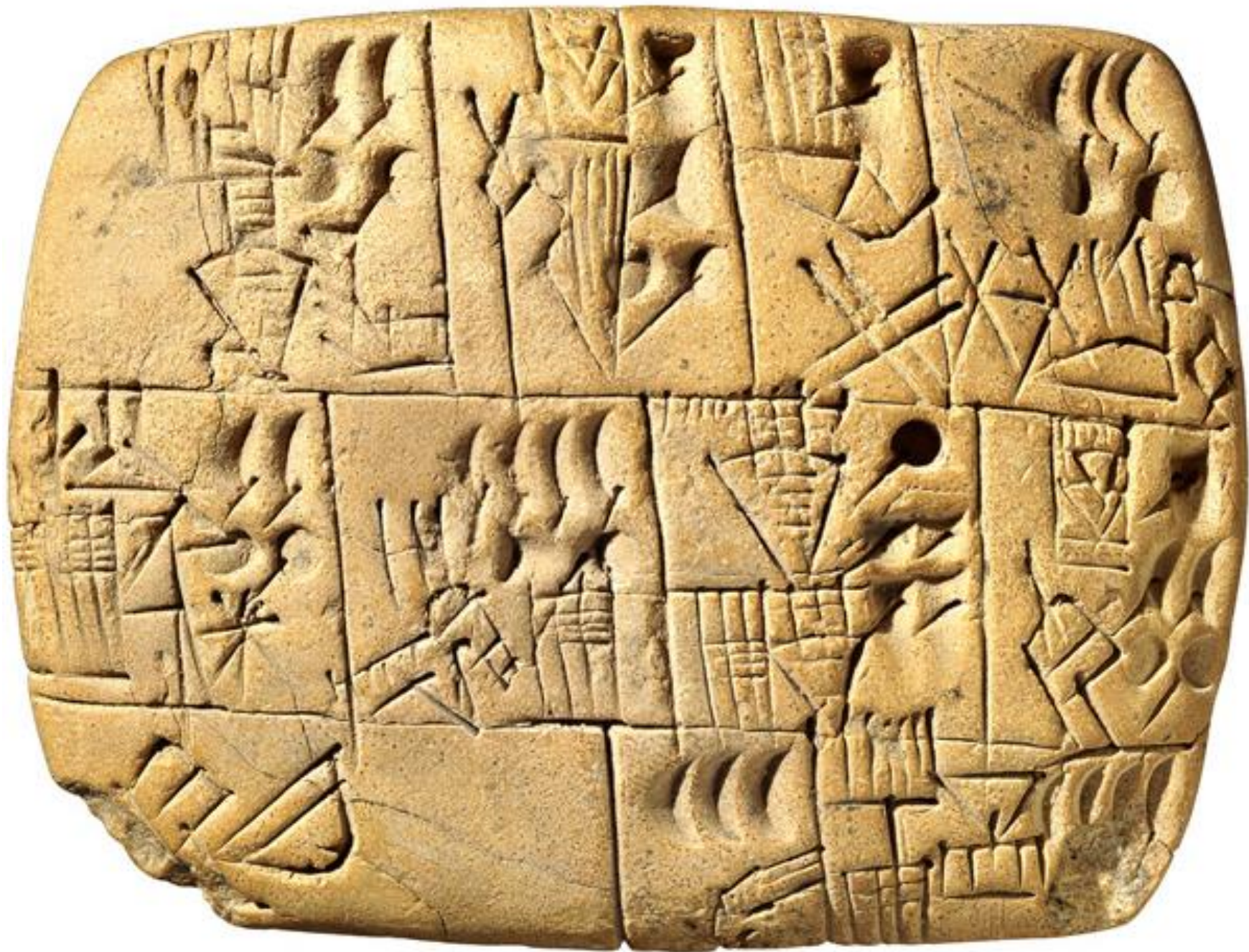
Forms, FHIR and Structured Data Capture

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Senior Standards Architect
NHS Transformation Directorate



about me

- part of a new group lead by Nicholas Oughtibridge in the Transformation Directorate looking at logical models and record standards for care
 - driving coherent record and message designs within the shared care record initiative
 - develop resources to improve the quality of record design, record keeping and record sharing
- working in ISO at both SC32/WG2 (metadata) and TC215 (health informatics) project lead for
 - ISO 21526 – Metadata Registries for Healthcare
 - ISO/IEC 19763-13 – Model for Form Design Registration
 - ISO/IEC 19583-26 XML/JSON Schema for ISO/IEC 11179-3
- UK FHIR logical models group lead
- previously nearly 20 years at University of Oxford/Oxford University Hospitals in Department of Computer Science, Oxford Molecular Diagnostics Centre and the Big Data Institute
 - practical semantic interoperability,
 - devops for clinical data warehousing
 - clinical/lab systems for genomics
 - logical clinical modelling for 100k programme



Mesopotamia, 5,000 BC

Von der Wiege bis zur Bahre — Formulare, Formulare!

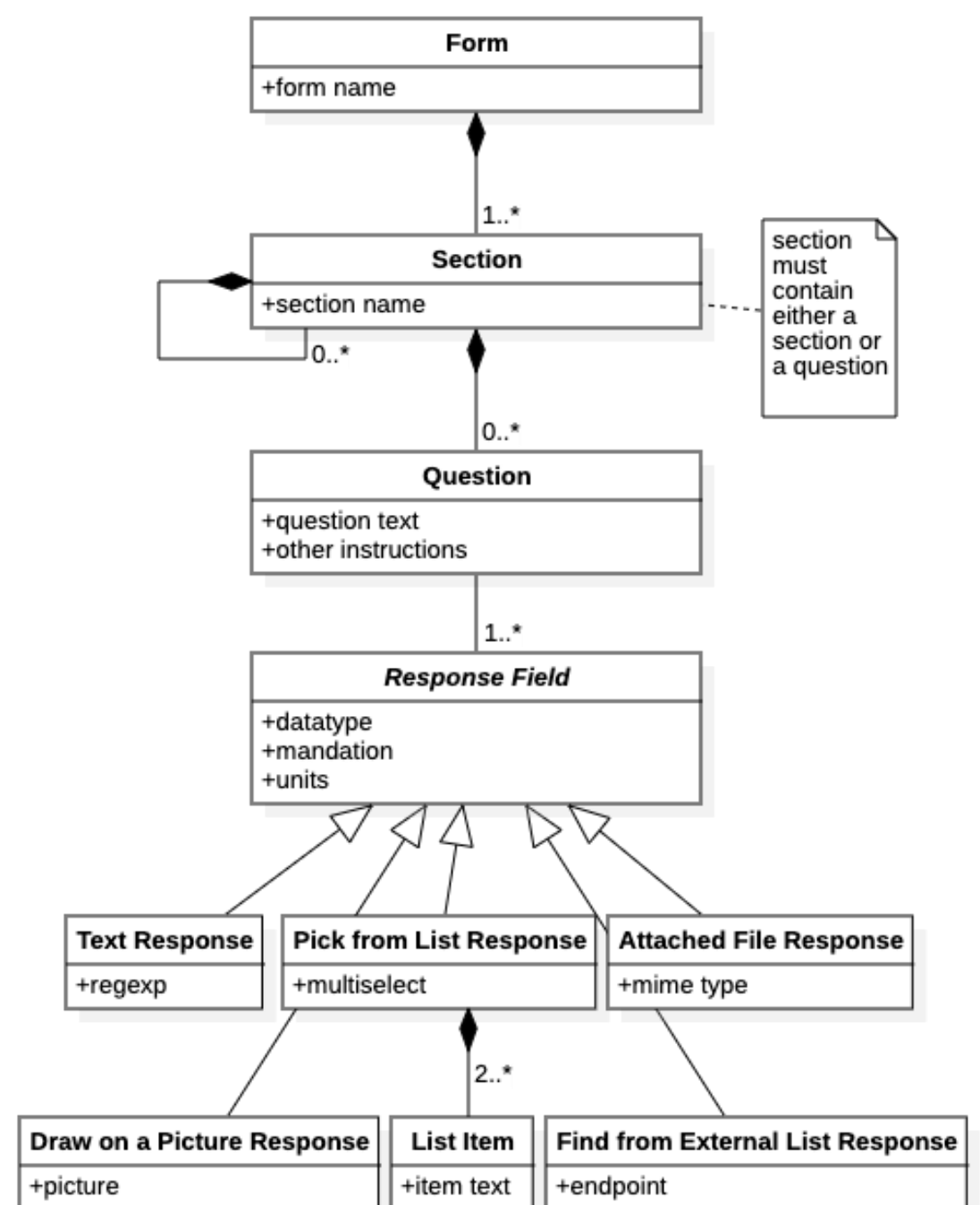
- Oxford Dictionary of English defines a form as: **6** a printed document with blank spaces for information to be inserted: *an application form*
- (if you include a table as a particular kind of form) examples stretch back to 2000 BC, counting sheep and goats in Sumeria
- template legal documents with fill-in spaces were used in ancient Rome, and for collecting census data in China
- mass use required the printing press, and burgeoning bureaucracies certainly took advantage
- from <https://fdiv.net/2021/07/25/unofficial-history-forms>
- encodes expertise, aids creation of complete records

electronic forms

- offer distinct advantages over paper ones
 - do not need a physical medium or real-world storage
 - answers can be typed for automatic processing – regular expressions, integers, selections from pre-defined lists
 - sections and questions can be hidden from the user, and only revealed when necessary
 - pre-defined answer lists can be longer, and have an internal structure
 - can test for (and require) completion
 - metadata can be assigned automatically
 - attribution and non-repudiation can be more reliable
- and disadvantages
 - often split the question from the answer
 - paper lasts longer than electronic media
 - often lower cost of deployment

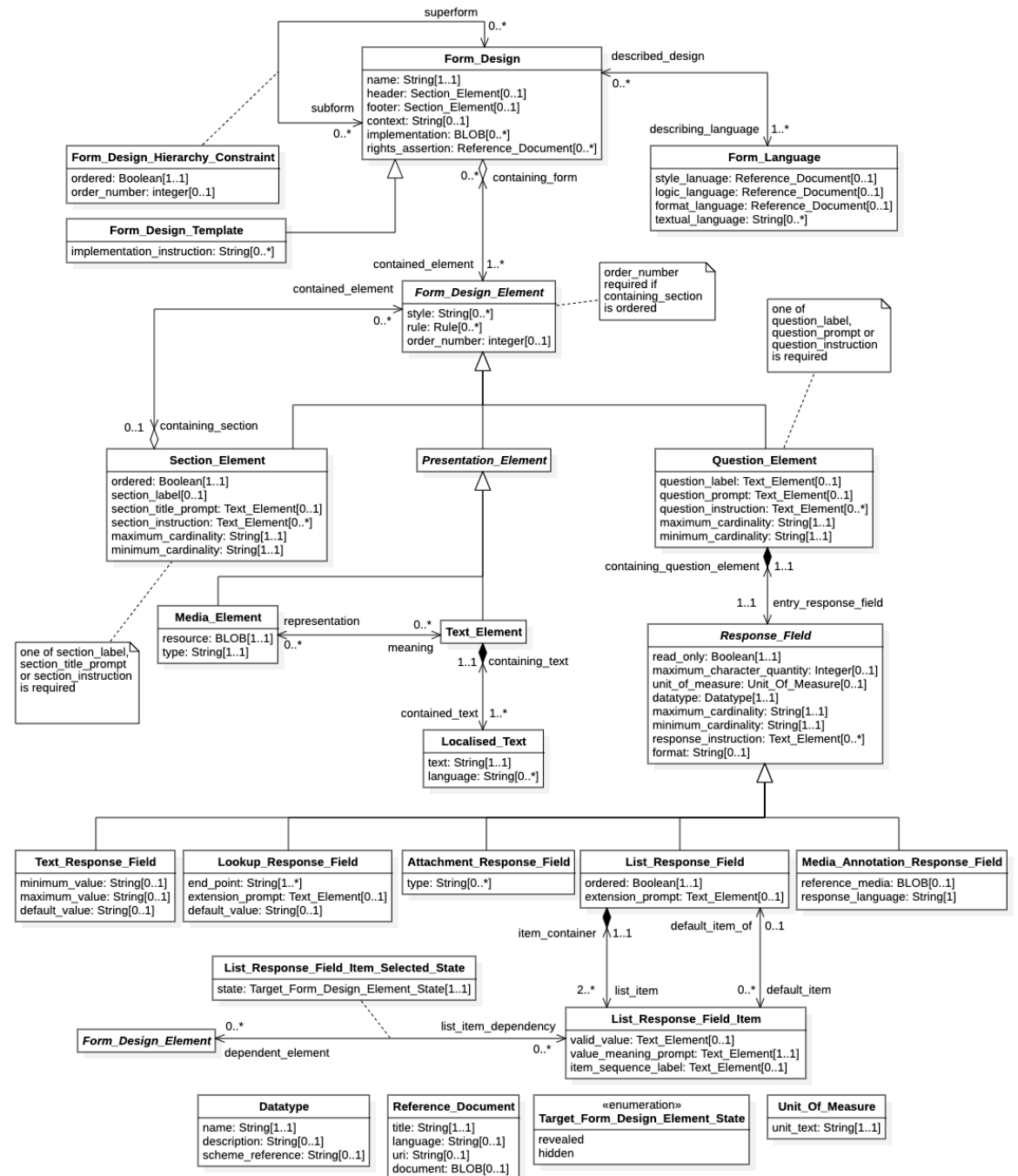
form structure

- a tree of nested sections containing questions with fields for the user's responses
- optionally ordered
- repeating sections (generally) presented as a table
- response fields have a type which constrains styling



ISO/IEC 19763-13

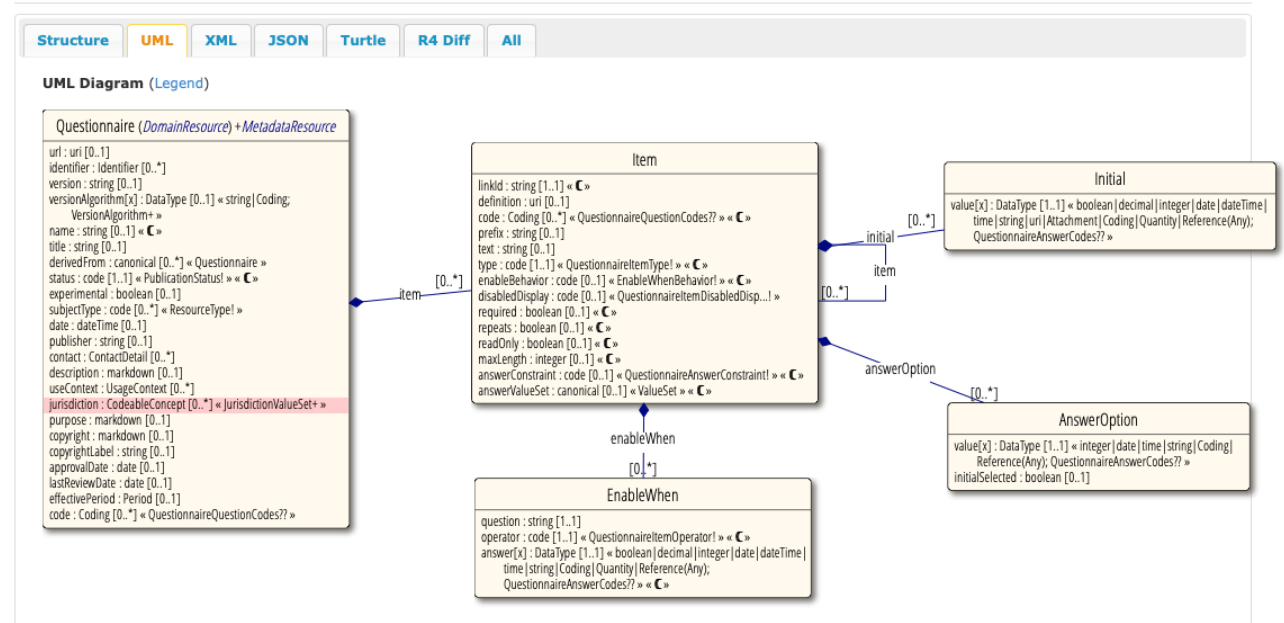
- not only platform neutral, but logical model is kept close to the natural conceptualisation of forms
- also registers paper form designs
- lives within the ISO/IEC 11179 framework – question banks, item mapping, logical models, datasets, identification, naming, classification, conceptual mapping
- part of ISO 21526 metarep
- out of the box support for
 - multilingual forms
 - presentation elements
 - rules
 - skip logic
 - form templating
 - sub-forms



FHIR Questionnaire

- looks simple – well, not really ...
- questionnaire class is mostly metadata about the questionnaire
- item class has an enumerated typing attribute with the following kinds
 - group – an item with no direct answer but should have at least one child item – i.e. a Section
 - display – text for display that will not capture an answer or have child items – i.e. a presentation element or some ancillary section/question instruction text
 - question - which has further subtypes
- a whole bunch of rules to enforce structure and prevent nonsense definitions

2.5.5 Resource Content



Questionnaire rules translated

Display items

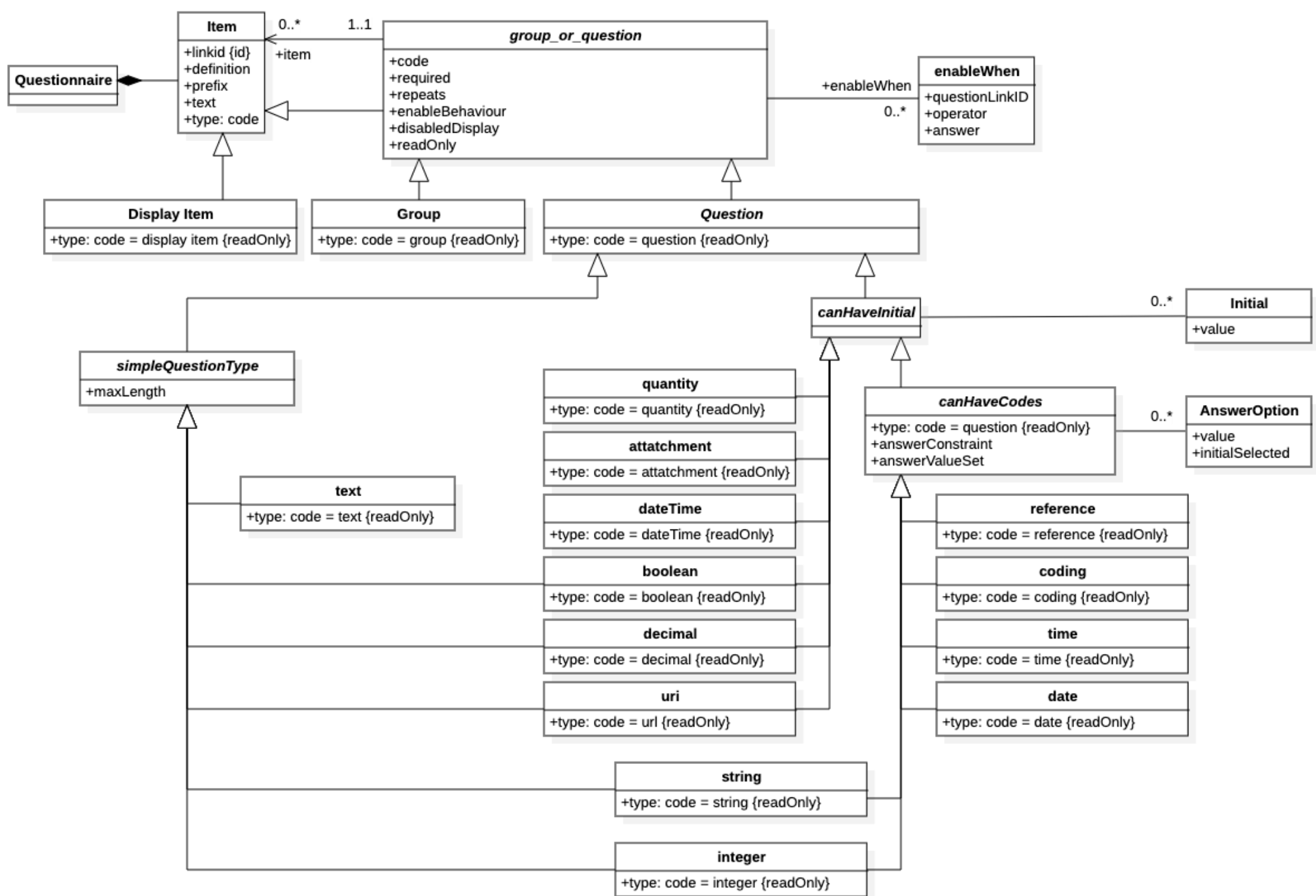
- Display items cannot have child items
- Display items can't have data
 - Display items cannot have a "code" asserted
 - Required and repeat aren't permitted for display items
 - Read-only can't be specified for "display" items
 - Initial values can't be specified for (groups or) display items

Groups

- Groups can't directly have data
 - Initial values can't be specified for groups (or display items)
- Groups are containers and should contain other items
 - Group items must have nested items when Questionnaire is complete
 - Warning: Groups should have items

Questionnaire rules translated (cont ...)

- For questions
 - A question cannot have both answerOption and answerValueSet
 - No local extensions to a valueset
 - Only coding, decimal, integer, date, dateTime, time, string or quantity items can have answerOption or answerValueSet
 - Options or codes simply don't make sense for references or Boolean answers
 - Maximum length can only be declared for simple question types
 - Is only appropriate for simple question types – are you going to have a maximum length for a coded field?
 - If one or more answerOption is present, initial cannot be present. Use answerOption.initialSelected instead
 - initial is a property related to non-list items only
 - If there are more than one enableWhen, enableBehavior must be specified
 - ... otherwise it gets very complex very quickly
 - Can only have multiple initial values for repeating items
 - ... otherwise where would you put them?
 - Can only have answerConstraint if answerOption or answerValueSet are present. (This is a warning because extensions may serve the same purpose)
 - answer constraint is about fill-in values, so makes no sense if there's nothing to fill in



ISO forms vs. Questionnaire

- enableWhen gating mechanism is defined in data for numerics – ISO expects a code fragment – i.e. enableBehaviour – except for list responses
- questionnaire model looks more like an implementation in a relational structure, despite expecting serialisation in json – ISO is firmly document oriented
- ISO doesn't easily let you hide data from your user – you can make it read only, but you'd have to hide it with code or style
- ISO supports styling elements, layout out of the box
- HL7's historic position on typing, coding and valuesets complicates some things that would otherwise be quite simple
- ISO explicitly supports question/section ordering, seems questionnaire assumes document order
- ISO has a bigger tag set for representing text that isn't a question but has meaning – better human semantics
- ISO does media markup – pain maps, radiography annotation ...
- ISO lives in a very rich environment for describing data at rest – data elements and datasets (11179), ontologies/terminologies (19763-3), data models (19763-12) ...
- questions (and sections) in questionnaire are not a separately identifiable resource – in ISO they are, better supporting compositional modelling

Structured Data Capture

- SDC extends Questionnaire in several ways
 - *Workflow* – how Questionnaire definitions are used in information systems
 - *Finding forms* – how does a user locate the form they need to complete
 - *Rendering* – layout, tables, colours, addressed in ISO forms
 - *Enhanced behaviour* – addressed in ISO forms
 - *Automatic population* – finding appropriate data from an EPR to part fill
- *Data extraction* – mapping responses to other parts of the FHIR API
- *Modular forms* – getting the kind of design benefits one might expect from openEHR
- *Adaptive forms* – hiding the form design from the form runner
- Offers some of the wider ISO infrastructure, but focussed on data gathering applications in healthcare
- Not to the rigour of openEHR
- Some pdf-spec where ISO Forms is modelled

ISO/IEC SC32/WG2 vs HL7

- data elements pre-coordinate the value domain, and thus lists of valid values and value meanings
 - expectation is to declare a set of data elements covering permitted representations
 - data element transformations registered alongside the data elements
- ISO 11197-3 very 3rd NF belying deep origins in tabular data submissions to US Agencies
- ‘bureaucratic’ / built in governance
- interop friendly out of the box – simple graphs of identifiers are all that is required for processing
- agnostic w.r.t. clinical, social and eGov
- HL7 data elements by default are more like SC32 data element concepts: data elements are post coordinated in the data instance
 - fast
 - flexible
- ...but perfectly possible to allow someone to say complete nonsense
- any transformation /normalisation graph requires more logic
- ... unless you nail down your profile, which is neither fast nor flexible
- focussed on the clinical end of care

Why does the comparison matter?

- FHIR is quick, and where are the runners for ISO-Forms?
 - ISO is intended for exchanging definitions in a platform neutral way from existing systems, including paper – Questionnaire is a useful and very usable subset, but you may lose some structure from an existing implementation
 - over-generalisation of the FHIR model makes it a little more opaque than the ISO-Forms model, so reading the ISO model will help developers understand how to implement both
- working transformation from Mauro ISO-Forms profile to Questionnaire demonstrated, inverse under development
 - can bank form designs, connect them to logical models, and recommend them for use
- provides a completeness check on the specification

Recap ...

- First half: mainly of interest to architects and devs working with the Questionnaire model itself rather than particular questionnaires
 - What is a form
 - What does ISO/IEC think is a computable representation of a form
 - Compare the FHIR Questionnaire model with the ISO/IEC model
 - Some general and detailed observations about the specifications
- Second half: for business analysts, people making questionnaires, and wanting to structure their data capture
 - How do you use it
 - How does it work with the term server

- My Project >
- interOPEN test v
- Licenses**
- Members
- Settings
- + New Project

FHIR Platform

FHIR platform name *

interOPEN training

Goal

Research



Hosting



Self-hosted



Google Cloud Platform



Amazon Web Services

Development

Max storage size 2GB
Free for 2 weeks

Production

Highly available installation with
max storage size 500Gb

High Load Production

Custom deployment on request

Select Aidbox version *

Latest

Recommended version

Edge

Newest version

Instance URL *

interopentraining

.aidbox.app

FHIR Version

5.0.0



Configuration projects ⓘ

Select a pre-built config project if needed



Aidbox SDC Forms

You can [specify an open Github repository](#) instead

Get Support

Documentation

Book a meeting

Start 14 days trial

Cancel

 My Project >

 interOPEN test ▾

Licenses

Members

Settings

 New Project

interOPEN test licenses

New license


interOPENtraining


interopen.aidbox.app 

Standard

Active

14 days left

 Get Support

 Documentation

Book a meeting



This feature is in the beta stage. UI and data format may change! For feedback and ideas join the [discussion](#)

Community notebooks

Getting Started: CRUD Community ⋮
 This notebook will help you create, read, update, and delete resources in Aidbox

Getting Started: Custom Resources Community
 Guide on work with custom resources

Getting Started: SQL Basics Community
 Work with Aidbox database

Getting Started: Search Community
 Aidbox search API overview

API Construtor: Patient specific access CRUD Community
 Patient specific access CRUD demo on Devbox

Aidbox Forms Community
 This notebook will help you to create test patient, test encounter and test observation.

Aidbox Terminology Community
 Aidbox approach to terminologies

Aidbox Terminology Basics Community
 Presented by Nikolay Ryzhikov on Online FHIR meetup #7: FHIR Terminology Services

Bulk API Community
 New Bulk api, differences & examples

CCDA Converter API Demo Community
 Description

Create AccessPolicy Community
 Create AccessPolicy for users with a specific role

Create AccessPolicy Community
 Create AccessPolicy for users with a specific role

- Notebooks
- Resources
- APIs
 - Operations
 - REST Console
 - GraphQL
- Auth
- Profiles
- Terminology
- Database
- Workflow Engine
- Subscription Topics

- Aidbox Forms
- Apps
- HL7 v2

- Documentation
- Support
- Logout



CREATE FORM

+ Add Widget

ReSPECT



ReSPECT

1. Personal Details

Full Name

NHS/CHI/Health and Care Number

LinkId

bf51553c-887d-4721-bb48-5abc883e

Text

NHS/CHI/Health and Care Number

Hidden Required

Include code?

Extract to Observation

Populate

RULES

Calculated Expression

?

Enable When

+ Add Widget

Group	Text	Textarea
URL	Display	Integer
Decimal	Quantity	Date
Time	Datetime	Choice
Open Choice	Checkbox	Attachment
Reference		

Details

Health and Care Number

Load Questionnaire

Save Questionnaire

Convert to Aidbox Forms DSL

Show Q

Show QR

introductory demo

Accessing master data

This FHIR Questionnaire accesses the NHS Scotland Terminology server via a proxy, and requests items from the DM+D drug database

```
{
  "resourceType": "Questionnaire",
  "title": "Demo form",
  "status": "draft",
  "item": [
    {
      "extension": [
        {
          "url": "http://hl7.org/fhir/StructureDefinition/terminology-server",
          "valueUrl": "https://beta.scot.dc4h.link/auth-proxy/fhir"
        },
        {
          "url": "http://hl7.org/fhir/StructureDefinition/questionnaire-itemControl",
          "valueCodeableConcept": {
            "coding": [
              {
                "system": "http://hl7.org/fhir/questionnaire-item-control",
                "code": "autocomplete",
                "display": "Auto-complete"
              }
            ],
            "text": "Auto-complete"
          }
        }
      ],
      "linkId": "medication",
      "text": "dm+d VMP",
      "type": "choice",
      "answerValueSet": "https://dmd.nhs.uk/ValueSet/VMP"
    }
  ]
}
```

Master data

This is the rendering of the form – as you can see it is an auto-complete control so you can type part of a drug name to find the term you want to use. The terminology server could be used in any application to provide a central source of master data items – NHSE additionally plans on using it for locations, organisations, services and staff

The screenshot displays the LHC FHIR Tools website. At the top, the NIH logo and 'National Library of Medicine' are visible, along with the text 'LHC FHIR Tools' and 'Tools, widgets, and services for HL7 FHIR applications'. A navigation bar includes links for 'FHIR Tools', 'LHC-Forms Demo', 'Form Builder', 'Clinical Table Search Service', and 'FHIR SDC SMART App'. The main content area features a 'Demo form' section with a search input field containing 'asp'. A dropdown menu lists various aspirin-related terms: 'Aspirin powder', 'Aspirin 100mg capsules', 'Aspirin 150mg suppositories', 'Aspirin 25mg capsules', 'Aspirin 300mg suppositories', 'Aspirin 75mg tablets', and 'Nasal aspirator'. A 'See more items (Ctrl Ret)' link is also present. The footer contains social media icons, contact information for the National Library of Medicine, and links to 'Web Policies', 'FOIA', 'HHS Vulnerability Disclosure', and 'NLM Support Center'.

valueset inline

```
"answerOption": [  
  {  
    "valueCoding": {  
      "system": "http://snomed.info",  
      "code": "144321000000100",  
      "display": "Released to family"  
    } /valueCoding  
  }, /answerOption[0]  
  {  
    "valueCoding": {  
      "system": "http://snomed.info",  
      "code": "144311000000106",  
      "display": "Disposed of as anatomical waste"  
    }, /valueCoding  
    "initialSelected": true  
  } /answerOption[1]  
]
```


valueset by uri

```
{
  "resourceType": "Questionnaire",
  "title": "Demo form",
  "status": "draft",
  "item": [{
    "extension": [{
      "url": "http://hl7.org/fhir/StructureDefinition/terminology-server",
      "valueUrl": "https://beta.scot.dc4h.link/auth-proxy/fhir"
    }, {
      "url": "http://hl7.org/fhir/StructureDefinition/questionnaire-itemControl",
      "valueCodeableConcept": {
        "coding": [{
          "system": "http://hl7.org/fhir/questionnaire-item-control",
          "code": "autocomplete",
          "display": "Auto-complete"
        }], /coding
        "text": "Auto-complete"
      } /valueCodeableConcept
    }], /extension
    "linkId": "medication",
    "text": "care professional staff group",
    "type": "choice",
    "answerValueSet": "https://beta.datadictionary.nhs.uk/valueSet/care_professional_staff_group__maternity_"
  }] /item
}
```

valueset by refset

```
{
  "resourceType": "Questionnaire",
  "title": "Demo form",
  "status": "draft",
  "item": [{
    "extension": [{
      "url": "http://hl7.org/fhir/StructureDefinition/terminology-server",
      "valueUrl": "https://beta.scot.dc4h.link/auth-proxy/fhir"
    }, {
      "url": "http://hl7.org/fhir/StructureDefinition/questionnaire-itemControl",
      "valueCodeableConcept": {
        "coding": [{
          "system": "http://hl7.org/fhir/questionnaire-item-control",
          "code": "autocomplete",
          "display": "Auto-complete"
        }], /coding
        "text": "Auto-complete"
      } /valueCodeableConcept
    }], /extension
    "linkId": "medication",
    "text": "early intervention in psychosis",
    "type": "choice",
    "answerValueSet": "http://snomed.info/sct?fhir_vs=refset/991311000000100"
  }] /item
}
```

skip logic

skip by valueset selection

```
], /code
"text": "Subject Relationship Context",
"enableWhen": [
  {
    "question": "7109611871902",
    "operator": "=",
    "answerBoolean": false
  } /enableWhen[0]
], /enableWhen
"answerValueSet": "http://snomed.info/sct/900000000000207008?fhir_vs=ecl%2F%3C125676002"
}, /item[2]
```

Advanced fields ^

Conditional display **i**

Question i	Operator i	Answer i
Default context?	=	<input type="checkbox"/>
+ Add another condition		

Show this item when **i**

Snomed CT

This tool will also allow you to send ECL to an ontosever to return valuesets, and set skips conditional on ontosever returns – ‘temporal’ is an ECL constraint with the form builder querying the term server at design time to find the terms allowing ‘when’ to be revealed



Home | LHC-Forms E

LHC-Forms is a wide documentation.

Genetic Forms

Featured Forms

Personal Health Record

US Surgeon General family health portrait

Mental RFC assessment form

Heart ultrasound (echocardiogram)

Weight & height tracking panel

Vital signs panel

U.S. standard certificate of death - 2003 revision

Patient-Reported Outcomes with LASIK Symptoms and Sa

LC

Bi

Se

Conn



Data type **i** choice

Answer list source **i** Answer options SNOMED answer value set Answer value set URI

Answer value set **i** Note that this option also sets the terminology server option below (under "Advanced fields").

Enter SNOMED ECL **i**: ecl/ < 410510008

Select SNOMED edition: International Edition (900000000000207008)

Select SNOMED version: Any version

Formatted answerValueSet URI:
http://snomed.info/sct/900000000000207008?fhir_vs=ecl%2F%3C+410510008

Answer list layout **i** Drop down Auto-complete Radio Button

Situation with explicit context

Finding or procedure? finding procedure

Default context? **?** Yes No Not Answered

Subject Relationship Context Subject of record

Temporal Past - specified

When? 4: Past - specified

Finding

Associated Finding

Finding * Headache

Severity Severe

Advanced fields ^

Conditional display **i**

Question i	Operator i	Answer i
Temporal	=	Current - specified
Temporal	=	Past - specified

+ Add another condition

Show this item when **i**

All conditions are true Any condition is true

Form transformation

This questionnaire started life as an openEHR operational template (i.e. form), was imported into Mauro Data Mapper – a metadata registry/model catalogue – as XML, marked up with the ISO Form model and exported as a JSON FHIR Questionnaire

```
1 {
2   "resourceType" : "Questionnaire",
3   "id" : "Mental Health Triage from OpenEHR Template",
4   "meta" : {
5     "versionId" : "1",
6     "lastUpdated" : "2023-03-03T03:05:07.9531803+00:00"
7   }, /meta
8   "text" : {
9     "status" : "generated"
10  }, /text
11  "item" : [
12
13
14    {
15      "linkId" : "988a63de-935d-4ea8-84d4-30420bddaec7",
16      "text" : "GAD-7",
17      "type" : "group",
18      "required" : true,
19      "repeats" : false,
20      "definition" : "Generalised Anxiety Disorder (GAD-7) questionnaire.",
21      "item" : [
22        {
23          "linkId" : "2ec61c77-bcb4-425e-8e65-54a140e52aea",
24          "text" : "Point in time",
25          "type" : "group",
26          "required" : true,
27          "repeats" : false,
28          "definition" : "A specific date and/or time which may be explicitly defined in a template or at run-time.",
29          "item" : [
30            {
31              "linkId" : "fb22e3a7-0a79-43aa-8804-0281e54addbb",
32              "text" : "Becoming easily annoyed or irritable",
33              "definition" : "A specific date and/or time which may be explicitly defined in a template or at run-time.",
34              "type" : "string",
35
36              "repeats" : false
37            } /item[0]
38          ]
39        },
40        {
41          "linkId" : "91e24cce-2473-4244-9ed0-b8a5e8735e9c",
42          "text" : "Being so restless it is hard to sit still",
43          "definition" : "A specific date and/or time which may be explicitly defined in a template or at run-time.",
44          "type" : "string",
45
46          "repeats" : false
47        }
48      ]
49    }
50  ]
51 }
```

LHC-Forms is a widget that renders input forms, based on definition files (FHIR Questionnaires), for web-based applications. This page provides a demo with some sample forms. For information on including the widget in your own website, see the [developer documentation](#).

- Genetic Forms >
- Featured Forms v
 - [Personal Health Record](#)
 - [US Surgeon General family health portrait](#)
 - [Mental RFC assessment form](#)
 - [Heart ultrasound \(echocardiogram\)](#)
 - [Weight & height tracking panel](#)
 - [Vital signs panel](#)
 - [U.S. standard certificate of death - 2003 revision](#)
 - [Patient-Reported Outcomes with LASIK Symptoms and Satisfaction \(PROWL-SS\)](#)
- LOINC Panels with score rules >
- Big LOINC Panels >
- Search LOINC Panels >

Load From File
Save To File
Show Form Data As ... v

GAD-7 *

Point in time *

- Becoming easily annoyed or irritable
- Being so restless it is hard to sit still
- Feeling afraid as if something awful might happen
- Feeling nervous, anxious or on edge
- Not being able to stop or control worrying
- Total score
- Trouble relaxing
- Worrying too much about different things

Patient Health Questionnaire-9 (PHQ-9) *

Point in Time *

- Appetite
- Death/Self-harm
- Feeling Bad About Yourself
- Feeling Down
- Interest/Pleasure
- Sleep Issues
- Slowness/Fidgety
- Tired/Little Energy
- Trouble Concentrating
- PHQ-9 Score

Story/History *

Any event *

- Symptom/Sign *
 - Symptom/Sign name

JSON for a FHIR Questionnaire

Here you can see the form rendered using the open source NLM FHIR Questionnaire tool, with the valueset rendered as a dropdown control

FHIR Questionnaire Response

- Data collected with a questionnaire can be communicated with instances of the Response resource
- Some FHIR servers will receive and store Response instances
- Could prove very useful supporting departmental workflows quickly
 - Aidbox allows you to compose tabular views on FHIR resources
 - Relatively easy to replace an Excel-based workflow with something more robust
- An EPR is more than a FHIR server instance, so take care over scope and spec

... and the
response
data from
completion

National Library of Medicine
Lister Hill National Center for Biomedical Communications

LHC FHIR Tools
Tools, widgets, and services for HL7 FHIR

Tools | LHC-Forms Demo | Form Builder

LHC-Forms is a widget that renders input forms. For more information, see the [developer documentation](#).

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- Patient-Reported Outcomes with LASIK Symptoms and Satisfaction (PROWL-SS)
- DINC Panels with score rules
- Big LOINC Panels
- Search LOINC Panels

FHIR SDC QuestionnaireResponse Content

```
{
  "resourceType": "QuestionnaireResponse",
  "meta": {
    "profile": [
      "http://hl7.org/fhir/uv/sdc/StructureDefinition/sdc-questionnaireresponse|3.0"
    ],
    "tag": [
      {
        "code": "lformsVersion: 35.0.3"
      }
    ]
  },
  "status": "completed",
  "authored": "2024-02-28T14:30:31.018Z",
  "item": [
    {
      "linkId": "988a63de-935d-4ea8-84d4-30420bddaec7",
      "text": "GAD-7",
      "item": [
        {
          "linkId": "2ec61c77-bcb4-425e-8e65-54a140e52aea",
          "text": "Point in time",
          "item": [
            {
              "answer": [
                {
                  "valueString": "often"
                }
              ],
              "linkId": "fb22e3a7-0a79-43aa-8804-0281e54adbb",
              "text": "Becoming easily annoyed or irritable"
            },
            {
              "answer": [
                {
                  "valueString": "often"
                }
              ],
              "linkId": "91e24cce-2473-4244-9ed0-b8a5e8735e9c",
              "text": "Being so restless it is hard to sit still"
            },
            {
              "answer": [
                {
                  "valueString": "never"
                }
              ]
            }
          ]
        }
      ]
    }
  ]
}
```

(sdc demo)

Questions?