

The Use of Big Medicare Data and LHC Data Capture Forms in FHIR

Paul Lynch, Ye Wang, Ajay Kanduru, Xiaocheng Luan, Lee Mericle, Shennon Lu,
and Clement McDonald

Lister Hill Center, National Library of Medicine, NIH

AMIA 2017 Annual Symposium
Washington, DC
November 5, 2017

Big Data from Medicare's VRDC aka CMS Enclave

A brilliant approach to big data access with no privacy tears

The Core Honeypot

- ➔ Medicare Part A and Part B (includes coded in office medications) from 1991
 - ✚ Includes encounter events, Diagnoses, surgical procedures (lots of outcomes)
- ➔ Medicare Part D- all out patient prescription from Oct 2006
- ➔ Around 100 M enrollees all together
- ➔ If you focus only on PART A/B/D excluding capitated patients, its about 24 million
- ➔ Vital status (they link to SS death tapes)
- ➔ A per patient database of 50 algorithms defined nearly chronic disease per 50
- ➔ Lots of other info can also be obtained on smaller populations (e.g. Medicaid)

Process For Getting Data

- Make application with study rational and what databases you want
- ResDac (U. of Minneapolis) will help you
 - ✦ <https://www.resdac.org/cms-data/request/cms-virtual-research-data-center>
- Pay fee around \$25 K per year for one seat – cost depends on # of seats)
- Wait for approval or request for revisions (can take 2+ months)
- They set up your computer with special software help you figure out databases you really need

Tools Available for Analysis

- ➔ SAS with an SQL data base
- ➔ STATA
- ➔ Can upload and link (with consents for uploaded patients)
- ➔ Can download but only statistical summary
- ➔ Machine time is free
- ➔ More info:
 - † [http://resdac.umn.edu/sites/resdac.umn.edu/files/Introduction%20to%20the%20Virtual%20Research%20Data%20Center%20\(VRDC\)%20-20-](http://resdac.umn.edu/sites/resdac.umn.edu/files/Introduction%20to%20the%20Virtual%20Research%20Data%20Center%20(VRDC)%20-20-)



Cox Regression: A Most Powerful Tool for Temporal Data

- Typically predicts time to an outcome, e.g. death
- Can take binary, categorical, or continuous covariates
- Accommodates censoring, lost to follow up, etc.
- Can (Usually should) use time varying coefficients
 - † Such variables reflect changes in test values or drug use over time
 - † **Just don't use variables that peak into the future (Like "any" occurrence)**
- Lots of variants on the COX method exist

Cox is Ingenious

- † It pivots on the outcome event (e.g. death) for each patient
- † It develops a statistic for that patient, based on the state of all of the remaining study individuals. So when a patient dies, it looks at the value of all of the other remaining patients AT THAT POINT IN TIME. Generates a statistic for the index patient based on that data
- † Then repeats the process for all other events
- † Finally averages over all of those calculations to figure the hazard due to each covariate

What We Are Looking At NLM

- Unexpected harms (Non-harm) or benefits from treatments (especially drugs)
- Looked at the risk of Alzheimer's from androgen suppression therapy
 - ✚ Paper last year said it was 2-fold. We found almost zero risk¹.
- Looking at risk of PPIs for death (reported to increase death risk by 15-30%)
 - ✚ 15 to 20% of the adult population is taking PPIs –so that be huge bump in death rate.
- Did 12 different analyses using 38 chronic diseases, demographics, Medicare status, rural status, and use of PPIs and of H2 blockers as covariates. See only positive effects of PPIs. (Hope to results publish soon)
- Other studies of metformin (the so called fountain of youth drug), and of statins and BP meds on **Alzheimer's** and death and Opioid abuse
- Working with other big medical databases as well, e.g MIMIC II

1. Baik, S, PhD, Kury F, MD McDonald C, MD. DOI: 10.1200/JCO.2017.72.6109 *Journal of Clinical Oncology* 35, no. 30 (October 2017) 3401-3409.

LHC-Forms





LHC-Forms- how does it work and what can it do?

- ➔ A fast, web open source JavaScript widget program (300kB) generates live forms from JSON form descriptions on the fly
- ➔ Based on Meaningful Use standards
- ➔ Accommodates nested groups and repeating groups of questions
- ➔ Has all of the usual form functions: Skip logic, rich validation checks, auto complete menus, score calculation, etc.
- ➔ Many different layout styles and a responsive design that fits any screen size

LHC forms are standards based

- All 2000+ LOINC panels including hundreds of validated surveys. Are LHC forms
- UCUM for units of measure
- Tied to many external, MU standards, and genetic standard coding systems, including NPI (National Provider Identifier)

Background on Standards Medical forms

- FHIR forms

- FHIR Questionnaire- defines a simple questionnaire without special features such as skip logic
- FHIR SDC Questionnaire – an extension on Questionnaire, with lots of additional features like skip logic – more sophisticated error checking, etc.

- IHE

- Has an SDC form- but it is different from,
https://ihe.net/uploadedFiles/Documents/QRPH/IHE_QRPH_Suppl_SDC.pdf

- LHC forms has a native form definition based on LOINC panels, which we can transform into either of the FHIR questionnaires and possibly into IHE questionnaire

Overall Technology

- Mixture of Web widgets and applications, namely : LHC-Forms Widget, Clinical Table Search Service, Form Builder, UCUM validator
- All software- applications and widgets are written in JavaScript
- Development uses Google AngularJS
- All data (including form definition and content of populated form) is represented as JSON
- Most content stored in ElasticSearch (with Lucene)
<https://www.elastic.co/>
- Size of LHC forms renderer that loads into browser –about 240K to compress



LHC forms and FHI R

LHC-Forms and FHIR SDC Questionnaire

- Most common features are compatible.
 - Form structure, code, name, data types, etc.
 - Most FHIR Questionnaire resources could be loaded into LHC-Forms widget and displayed as actionable forms
 - LHC-Forms form definition data can be exported as FHIR Questionnaire
 - Form data can be exported as FHIR Questionnaire Response or Diagnostic Report
- LHC-Forms has additional features
 - Skip logic, Display control and etc. support more functions

LHC forms via SMART on FHIR



Add New Listing

Your Listings

Search



Login



LHC-Forms on FHIR

Lister Hill National Center for Biomedical Communications (LHNCBC)

Website

Try App

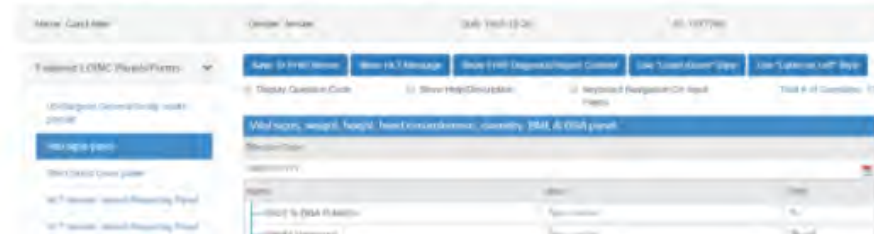
Contact

LHC-Forms (a.k.a. "LForms") is a widget that generates input forms, based on definition files, for Web-based applications or to integrate into electronic health records (EHRs), personal health records (PHRs), and mobile health apps. The input forms support repeating sections and questions, hiding and showing questions via skip logic based on the user's answers to other questions, coded answer lists, scored answers, and more.



LHC-Forms

SMART on FHIR Demo with LOINC Panels/Forms



LHC forms direct to FHIR

- Integrates with plain 'ole FHIR servers- HAPI works well for us
 - <https://fhirtest.uhn.ca/>

Options

Encoding

(default) XML JSON

Pretty

(default) On Off

Summary

(none) true text data count

Server

Server Home/Actions



You are accessing the public FHIR server **UHN/HAPI Server (STU3 FHIR)**. This server is hosted elsewhere on the internet but is being accessed using the HAPI client implementation.

⚠ This is not a production server! Do not store any information here that contains personal health information or any other confidential information. This server will be regularly purged and reloaded with fixed test data.



Walk through of direct to FHIR option

What we will show is an application that controls the use of different LHC Forms tied to an example FHIR server with most of the Tables/Objects (called resources in FHIR), such as patients, orders, etc. that you would find in an EMR. Gives us an Ecosystem in which to use FHIR. Can LHC forms equally well with SMART on FHIR

Note the URL

The screenshot shows a web browser window with the title "LHC-Forms". The address bar displays a secure connection to <https://lhc-forms.lhc.nlm.nih.gov/demo-app>. The page header includes the LHCNCBC logo and the text "LHC-Forms". Below this is a dark blue banner with "FHIR Demo App" on the left and a "Sign In" button on the right. The main content area features a large blue box with the text "Please sign in first." The footer contains links for "Copyright", "Privacy", "Accessibility", and "Freedom of Information Act", along with the "USA.gov" logo and text. At the bottom, it lists "U.S. National Library of Medicine", "[U.S. National Institutes of Health](#)", and "U.S. Department of Health and Human Services".

LHC-Forms

Secure | <https://lhc-forms.lhc.nlm.nih.gov/demo-app>

LHCNCBC

LHC-Forms

FHIR Demo App

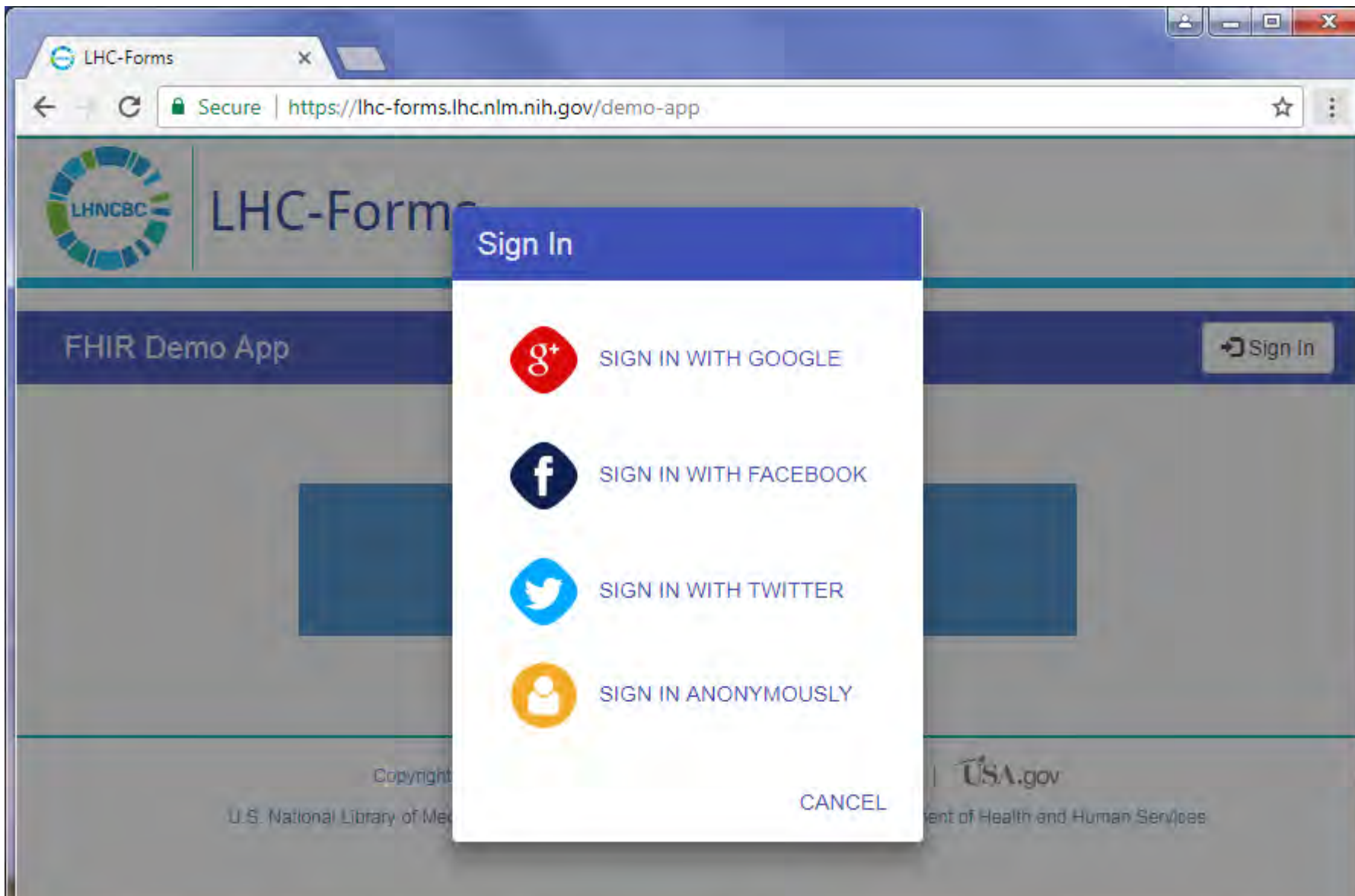
Sign In

Please sign in first.

Copyright | Privacy | Accessibility | Freedom of Information Act | USA.gov

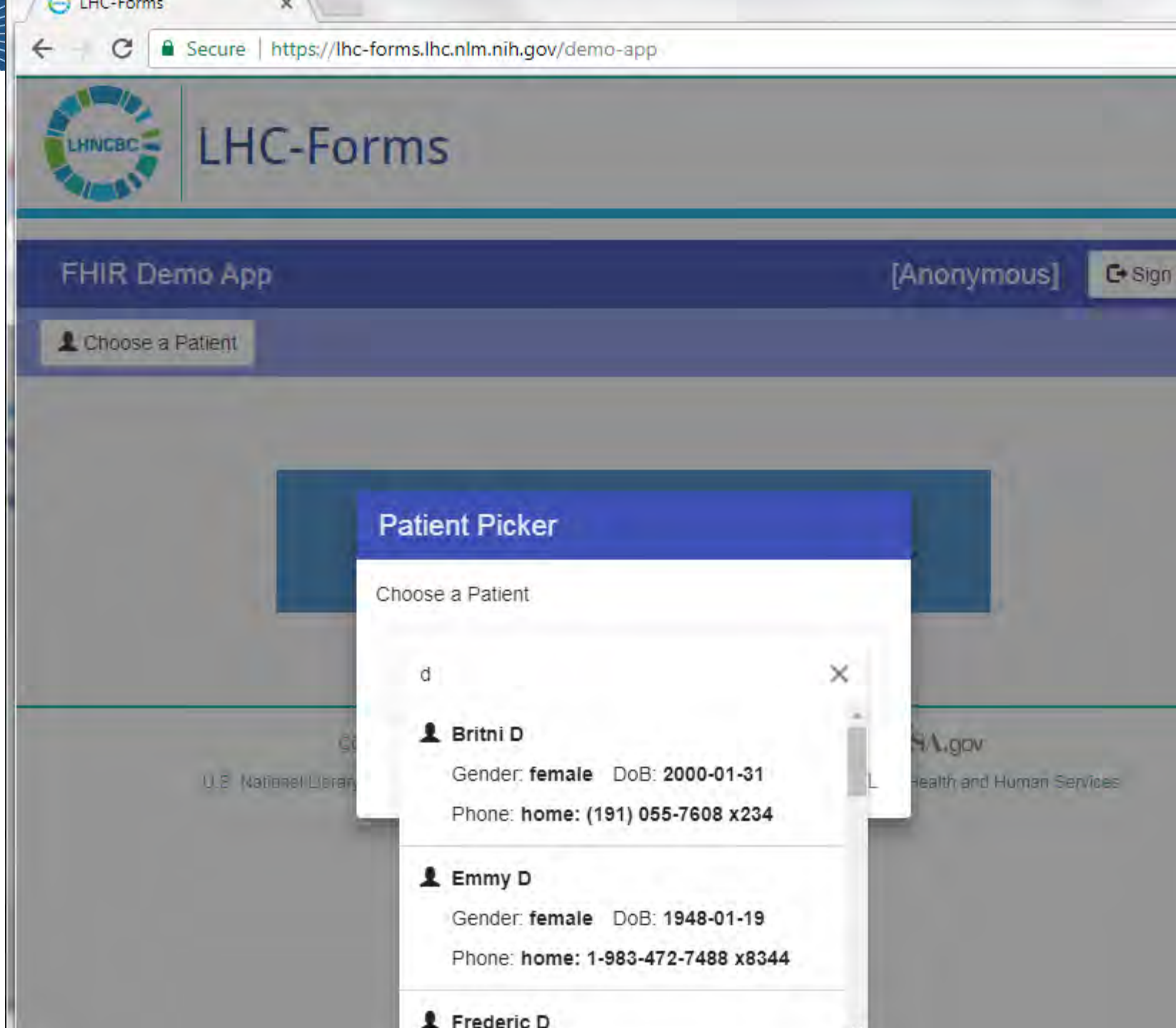
U.S. National Library of Medicine | [U.S. National Institutes of Health](#) | U.S. Department of Health and Human Services

Sign in if you want to save what you do. All standards sign ins work



Pick a patient

- ➔ Autocomplete choice from the Hapi FHIR server



Pick A form

- Can pull a previously saved form for review and/or editing
- Can pull a new form

The screenshot shows a web browser window with the address bar displaying "https://lhc-forms.lhc.nlm.nih.gov/demo-app". The page features the LHC-Forms logo and title. Below the header, a dark blue bar contains the text "FHIR Demo App" and "[Anonymous]" with a "Sign Out" button. A light blue bar below this displays user information: "Name: Daniel J", "DoB: 1995-02-22", "Gender: male", and "Phone: mobile: 800-504-6466", along with a "Change" button. The main content area is divided into two sections. The first section, titled "Saved Patient Data (Questionnaire Response)", lists two items: "US Surgeon General family health portrait [10/27/2017 10:10:34]" and "Vital signs, weight, height, head circumference, oximetry, BMI, & BSA panel [10/26/2017 10:10:09]". The second section, titled "Featured LOINC Panels/Forms", lists four items: "US Surgeon General family health portrait", "Vital signs panel", "Short blood count panel", and "HL7 Genetic Variant Reporting Panel".

LHC-Forms

Secure | https://lhc-forms.lhc.nlm.nih.gov/demo-app

LHC-Forms

FHIR Demo App [Anonymous] Sign Out

Name: Daniel J Gender: male
DoB: 1995-02-22 Phone: mobile: 800-504-6466 Change

Saved Patient Data (Questionnaire Response)

US Surgeon General family health portrait [10/27/2017 10:10:34]

Vital signs, weight, height, head circumference, oximetry, BMI, & BSA panel [10/26/2017 10:10:09]

Featured LOINC Panels/Forms

US Surgeon General family health portrait

Vital signs panel

Short blood count panel

HL7 Genetic Variant Reporting Panel

→ Here we show a new form for vital signs with no data yet entered

LHC-Forms

Secure | https://lhc-forms.lhc.nlm.nih.gov/demo-app

LHNCBC LHC-Forms

FHIR Demo App [Anonymous]

Name: Daniel J Gender: male DoB: 1995-02-22 Phone: mobile: 800-504-6466 Change

Saved Patient Data (Questionnaire Response)

US Surgeon General family health portrait [10/27/2017 10:10:34]

Vital signs, weight, height, head circumference, oximetry, BMI, & BSA panel [10/26/2017 10:10:09]

Featured LOINC Panels/Forms

User created Forms (Questionnaire)

Search LOINC Panels/Forms

Show FHIR SDC Questionnaire Show FHIR SDC QuestionnaireResponse Update on FHIR Server Delete from FHIR Server

Show FHIR DiagnosticReport Show HL7 Message

☐ Display Question Code ☐ Show Help/Description ☐ Keyboard Navigation On Input Fields Total # of Questions: 12

Vital signs, weight, height, head circumference, oximetry, BMI, & BSA panel

Name	Value	Units
SaO2 % BldC Oximetry	Type a value	%
Weight Measured	Type a value	lbs
Head Circumf OFC by Tape measure	Type a value	cm
Bdy height	Type a value	Select one
Bdy height lying	Type a value	Select one
Body temperature	Type a value	Cel
BP dias	Type a value	mm[Hg]
BP sys	Type a value	mm[Hg]
Heart rate	Type a value	{beats}/min
Resp rate	Type a value	{breaths}/min

One LOINC pane (v2 genetics)

- Here we show data entered into the genetics report form
- The output examples below based on this content

1 Discrete genetic variant panel	
Variant category	Simple Variant
Genetic variant coding system	ClinVar Variants
Discrete genetic variant	NM_000492.3(CFTR):c.1040G>C (p.Arg347Pro)
Transcript specification	
Gene studied	CFTR
Transcript RefSeq ID	NM_000492.3
DNA change c.HGVS	c.1040G>C
Amino acid change p.HGVS	p.Arg347Pro
DNA change [Type]	Select one or type a value
Amino acid change [Type]	Select one or type a value
Genomic specification	
Genomic reference sequence	NC_000007.13
Genomic DNA change (gHGVS)	Type a value
Genomic ref allele	G
Genomic allele start-end	117180324^117180324
Genomic alt allele	C
Other optional codes related to a discrete genetic variant	
Haplotype Name	Type a value
dbSNP ID	rs77932196

Load existing form from local file

Save captured data to local file

Show JSON OF form itself (SDC questionnaire)

Show entered data as FHIR Questionnaire Response in JSON

Show entered data as FHIR Diagnostic report in JSON

Show entered data as HL7 V2 delimited file

Load From File

Save To File

Show FHIR SDC Questionnaire

Show FHIR SDC QuestionnaireResponse

Show FHIR DiagnosticReport

Show HL7 Message

Theme: Default

☐ Display Question Code

☐ Show Help/Description

☐ Keyboard Navigation On Input Fields

Total # of Questions: 107

Master HL7 genetic variant reporting panel (2017-06-06)

Date Done

Time Done

Where Done

Comment

MM/DD/YYYY



Type a value

Select or type a value



Type a value

Name

Value

Units

Form configuration

Choose kind of mutations targeted

☒ Discrete variants

☒ Complex variants

☒ Pharmacogenomics

Select one or more

Choose region of interest specification

☒ Specific targeted mutations



Click HL7 and you get this almost most of the message

Click Questionnaire response and get this-JSON- It extends for a long way below

HL7 OBR & OBX Segments

Please note that this is still a work in progress, and the code system values might be incorrect in some places.

```
OBR|1|81247-9^Master HL7 genetic variant reporting panel (2017-06-06)^LN|
OBX|1|CNE|XXXXX-12^Choose kind of mutations targeted^LN|a|C01^Discrete variants^LN|
OBX|1|CNE|XXXXX-12^Choose kind of mutations targeted^LN|b|C02^Complex variants^LN|
OBX|1|CNE|XXXXX-12^Choose kind of mutations targeted^LN|c|C04^Pharmacogenomics^LN|
OBX|2|CNE|XXXXX-10^Choose region of interest specification^LN|a|C01^Specific targeted mutat
OBX|2|CNE|XXXXX-10^Choose region of interest specification^LN|b|C02^Range targeted in the r
OBX|3|CNE|83005-9^Variant category^LN|2a|LA26801-3^Simple Variant^LN|
OBX|4|CWE|82122-3^Genetic variant coding system^LN|2a|CLINVAR-V^ClinVar Variants^LN|
OBX|5|CWE|81252-9^Discrete genetic variant^LN|2a|7110^NM_000492.3(CFTR):c.1040G>C (p.Arg347
OBX|6|CWE|48018-6^Gene studied^LN|2a|1884^CFTR^HGNC-Symb|
OBX|7|CWE|51958-7^Transcript RefSeq ID^LN|2a|NM_000492.3^NM_000492.3^RefSeq-T|
OBX|8|CWE|41103-3^DNA change c.HGVS^LN|2a|c.1040G>C^c.1040G>C^HGVS.c|
OBX|9|CWE|48005-3^Amino acid change p.HGVS^LN|2a|p.Arg347Pro^p.Arg347Pro^HGVS.p|
OBX|10|CWE|48013-7^Genomic reference sequence^LN|2a|NC_000007.13^NC_000007.13^RefSeq-G|
OBX|11|ST|69547-8^Genomic ref allele^LN|2a|G|
OBX|12|NR|81254-5^Genomic allele start-end^LN|2a|117180324^117180324|
OBX|13|ST|69551-0^Genomic alt allele^LN|2a|C|
OBX|14|CNE|81255-2^dbSNP ID^LN|2a|7110^rs77932196^dbSNP|
OBX|15|CWE|48001-2^Cytogenetic (chromosome) location^LN|2a|^^^^^^^7q31.2|
OBX|16|CWE|81259-4^Probable associated phenotype^LN|2a|CN169374^not specified^Medgen-Dis|
OBX|17|CNE|83005-9^Variant category^LN|3a.1a|LA26801-3^Simple Variant^LN|
OBX|18|CWE|82122-3^Genetic variant coding system^LN|3a.1a|CLINVAR-V^ClinVar Variants^LN|
```

FHIR SDC QuestionnaireResponse Content

```
},
{
  "linkId": "/81250-3/48018-6/1/1",
  "text": "Gene studied",
  "answer": [
    {
      "valueCoding": {
        "system": "http://loinc.org",
        "code": "1884",
        "display": "CFTR"
      }
    }
  ]
},
{
  "linkId": "/81250-3/51958-7/1/1",
  "text": "Transcript RefSeq ID",
  "answer": [
    {
      "valueCoding": {
        "system": "http://loinc.org",
        "code": "NM_000492.3",
        "display": "NM_000492.3"
      }
    }
  ]
},
{
  "linkId": "/81250-3/41103-3/1/1",
  "text": "DNA change c.HGVS",
  "answer": [
    {
      "valueCoding": {
        "system": "http://loinc.org",
        "code": "c.1040G>C",
```



Click FHIR Diagnostic Report and get this (only shows partial message)

```
{
  "resourceType": "DiagnosticReport",
  "id": "81247-9-juypxugwf",
  "status": "final",
  "code": {
    "coding": [
      ...
      {
        "id": "XXXXX-10-ld6fmc8hwy9",
        "status": "final",
        "code": {
          "coding": [
            {
              "system": "http://loinc.org",
              "code": "XXXXX-10"
            }
          ],
          "text": "Choose region of interest specification"
        },
        "valueCodeableConcept": {
          "coding": [
            {
              "system": "http://loinc.org",
              "code": "C01",
              "display": "Specific targeted mutations"
            }
          ],
          {
            "system": "http://loinc.org",
            "code": "C02",
            "display": "Range targeted in the reference sequence"
          }
        ]
      }
    ],
    "text": "ClinVar Variants"
  },
  {
    "resourceType": "Observation",
    "id": "81252-9-4evwjg9v3d",
    "status": "final",
    "code": {
      "coding": [
        {
          "system": "http://loinc.org",
          "code": "81252-9"
        }
      ],
      "text": "Discrete genetic variant"
    },
    "valueCodeableConcept": {
      "coding": [
        {
          "system": "http://loinc.org",
          "code": "7110",
          "display": "NM_000492.3(CFTR):c.1040G>C (p.Arg347Pro)"
        }
      ],
      "text": "NM_000492.3(CFTR):c.1040G>C (p.Arg347Pro)"
    },
    {
      "resourceType": "Observation",
      "id": "48018-6-pjkdllkrn4",
      "status": "final",
      "code": {
        "coding": [
          {
            "system": "http://loinc.org",
            "code": "48018-6"
          }
        ],
        "text": "Gene studied"
      },
      "valueCodeableConcept": {
        "coding": [
          {
            "system": "http://loinc.org",
            "code": "1884",
            "display": "CFTR"
          }
        ],
        "text": "CFTR"
      },
      {
        "resourceType": "Observation",
        "id": "51958-7-i32tjamztpk",
        "status": "final",
        "code": {
          "coding": [
            {
              "system": "http://loinc.org",
              "code": "51958-7"
            }
          ],
          "text": "Transcript RefSeq ID"
        },
        "valueCodeableConcept": {
          "coding": [
            {
              "system": "http://loinc.org",
              "code": "NM_000492.3",
              "display": "NM_000492.3"
            }
          ],
          "text": "NM_000492.3"
        },
        {
          "resourceType": "Observation",
          "id": "83005-9-yled6ihq58",
          "status": "final",
          "code": {
            "coding": [
              {
                "system": "http://loinc.org",
                "code": "LA26801-3",
                "display": "Simple Variant"
              }
            ],
            "text": "Simple Variant"
          },
          {
            "resourceType": "Observation",
            "id": "82122-3-gp14b9abh7n",
            "status": "final",
            "code": {
              "coding": [
                {
                  "system": "http://loinc.org",
                  "code": "82122-3"
                }
              ],
              "text": "Genetic variant coding system"
            },
            "valueCodeableConcept": {
              "coding": [
                {
                  "system": "http://loinc.org",
                  "code": "CLINVAR-V",
                  "display": "ClinVar Variants"
                }
              ]
            }
          ]
        }
      ]
    }
  ]
}
```



Examples from among the 2000+ forms



Associated Tools

- ** Clinical table linker for auto complete look-up when values come from big external tables
- ** Units validator and converter
- ** Form builder for creating new or editing existing forms

Secret Sauce in Clinical Table linker

- † Via the URL, users can specify what fields in the external table are searched, and which answers are returned as part of selection grid, and which are stored in the index value field as hidden variables
- † Other fields in the form can use these hidden variables as answer lists, default values, or help messages.
- † Explore the tables we have created so far at:
<https://clin-table-search.lhc.nlm.nih.gov/>
- † Tables include IDC9, ICD10, genetic tables (ClinVar, dbSNP, etc.), RxTerms, NPI , etc.

Clinical Table Search Service: Demo page

Autocompletion Demo for the Alleles API

This page allows you to try the [Alleles](#) API and see the effects of different choices for search and display fields (specified with the "sf" and "df" query string parameters, as described on the [API documentation](#) page) on returned data, which is shown in the autocompletion list below.

Example autocompleter

The following autocompleter was constructed using the fields specified below.

[Show developer info](#)

Database:

The "Search" checkboxes control which data fields the autocompleter searches, and the "Display" checkboxes control which data fields show up in the autocompletion list. If none are checked, a default selection will be used.

Field	Search	All	Default	Display	All	Default	Description
AlternateAllele			<input type="checkbox"/>			<input type="checkbox"/>	The value of the AlternateAllele field in the source file.
AlternateAllele_lbl			<input type="checkbox"/>			<input type="checkbox"/>	The value of the AlternateAllele field in the source file, but prefixed with "Alt=".
AlleleID			<input type="checkbox"/>			<input type="checkbox"/>	The ID of the allele as taken from the AlleleID column of the source file.
AminoAcidChange			<input type="checkbox"/>			<input type="checkbox"/>	This is the amino acid change (starting with "p.") parsed from the Name field.
Chromosome			<input type="checkbox"/>			<input type="checkbox"/>	The chromosome number, taken from the Chromosome field in the source file, but prefixed with "chr".
ChromosomeAccession			<input type="checkbox"/>			<input type="checkbox"/>	The chromosome accession number, taken from the ChromosomeAccession field in the source file.
Cytogenetic			<input type="checkbox"/>			<input type="checkbox"/>	The cytogenetic location of the allele, taken from the "Cytogenetic" field in the source file.
dbSNP			<input type="checkbox"/>			<input type="checkbox"/>	The "rs" ID number from dbSNP, taken from the "RS# (dbSNP)" field in the source file.
GeneID			<input type="checkbox"/>			<input type="checkbox"/>	The gene ID from NCBI's gene database.
GeneSymbol			<input type="checkbox"/>			<input type="checkbox"/>	This is the GeneSymbol field listed in the source file. It is the symbol for the gene that overlaps the variant.
GenomicLocation			<input type="checkbox"/>			<input type="checkbox"/>	This is an HL7-style concatenation of the Start and Stop fields, i.e., Start^Stop.
hgnc_id			<input type="checkbox"/>			<input type="checkbox"/>	A unique ID provided by the HGNC for each gene with an approved symbol. Although standard HGNC IDs are of the format HGNC:n, where n is a number, we have removed the "HGNC:" prefix, so that these values are just numbers.
HGVS_c			<input type="checkbox"/>			<input type="checkbox"/>	The "HGVS (c.)" field from the source file. (The "RefSeq cDNA-based HGVS expression".)
HGVS_p			<input type="checkbox"/>			<input type="checkbox"/>	The "HGVS (p.)" field from the source file. (The "RefSeq protein-based HGVS expression".)

UCUM-LHC: Unit Validation and Conversion

- For “Unified Code for Units of Measure” (UCUM)
- Website: <https://lhncbc.github.io/ucum-lhc/>
- Library can be downloaded from GitHub or installed with “bower”
- Library supports:
 - Validation of unit expressions
 - Conversion of values between different unit expressions
- Unit codes in UCUM are not always what one would expect, but there are synonyms
 - Some UCUM syntax is not in common vernacular, e.g. [lb_av], but synonyms ([lb_av] = pounds) will guide the users
- Some special syntax: “.” = multiplication, * = exponentiation

Form Builder -After selecting a seed form

list of all of the form questions at the start and their hierarchy

User can add questions or remove levels and re-order questions within a level

Detailed attributes about the current question. In this case, the first one in the heirarchy. Can edit cardinality, skip logic, validation checks etc

Full live form for what has been created so far. Will look just like it would look in real use. This space can also show the JSON output that underlie the form

For

Save

Title

ADD

INC

1 Vital signs, weig...

1.1 SaO2 % BldC Oximetry

1.2 Weight Measured

1.3 Head Circumf OFC ...

1.4 Bdy height

1.5 Bdy height lying

1.6 Body temperature

1.7 BP dias

1.8 BP sys

1.9 Heart rate

1.10 Resp rate

1.11 BSA Derived

1.12 BMI

1 Vital signs, weight, height, h
BSA panel [74728-7]

Name	Value	Units
Text ?	Vital signs, weight, height, h	
Coding System ?	LOINC	
Code ?	74728-7	
Local code ?	Type a value	
Question instructions ?	This panel was created to co	
Repeat this item? ?	Select one	
Add conditional show/hide logic? ?	No	


PRE

Name	Value	Units
Vital signs, weight, height, head circumference, oximetry, BMI, & BSA panel ?		
SaO2 % BldC Oximetry	Type a number	%
Weight Measured	Type a value	
Head Circumf OFC by Tape measure	Type a number	cm
Bdy height	Type a value	
Bdy height lying	Type a number	Select c
Body temperature	Type a value	
BP dias	Type a number	mm[Hg]
BP sys	Type a number	mm[Hg]
Heart rate	Type a number	{beats}/mi
Resp rate	Type a number	{breaths}/i



Example forms that illustrate the capabilities

"Matrix" style with Radio buttons-PROMIS Social isolation form

PROMIS item bank - social isolation - version 2.0 ©					
Date Done	Time Done	Where Done	Comment		
MM/DD/YYYY 	Type a value	Select or type a value ▼	Type a value		
	Never	Rarely	Sometimes	Usually	Always
People get the wrong idea about my situation ©	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel isolated even when I am not alone ©	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that people avoid talking to me ©	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel detached from other people ©	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that some of my friends avoid me ©	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that some of my family members avoid me ©	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that I am alone in my interests and ideas ©	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that people barely know me ©	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel like a stranger to those around me ©	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I find that friends or relatives have difficulty talking with me about my health ©	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that people are around me but not with me ©	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel isolated from others ©	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel left out ©	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that I am no longer close to anyone ©	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Surgeon Generals family health history as an LHC-Form

Illustrates repeating groups of nested questions.

Proband can have many diagnoses with dates AND many relatives who also have many diagnoses and dates

US Surgeon General family health portrait [54127-6]

Date Done

Time Done

Where Done

Comment

MM/DD/YYYY

Type a value

Select or type a value

Type a value

Name

Value

Units

My health history [54126-8]

Name [54125-0]

Mr good doctor

Gender [54131-8]

Male

Birth Date [21112-8]

12/16/1944

{mm/dd/yyyy}

Twin [54132-8]

No

Adopted [54128-4]

Yes

Parents related [54135-9]

No

Body height [8302-2]

70

Weight [29463-7]

70

Race [54134-2]

2106-3. White

Ethnicity [54133-4]

Unknown/No answer

1.1 Diseases history panel [54137-5]

History of diseases [54140-9]

Diabetes - type 2 (adult, non-insulin-independent)

Age range at onset of disease [54130-0]

30-39

1.2 Diseases history panel [54137-5]

History of diseases [54140-9]

Congestive heart failure (CHF)

Age range at onset of disease [54130-0]

OVER 60

Add another "Diseases history panel"

1 Family member health history [54114-4]

Relationship to patient [54136-7]

GRNDDAU. Granddaughter

Name [54138-3]

mary

Gender [54123-5]

Female

Living? [54139-1]

Yes

Date of Birth [54124-3]

12/20/1190

{mm/dd/yyyy}

Current Age [54141-7]

Type a number

a

Twin [54121-9]

No

Adopted [54122-7]

No

multiple repeats per person recording

OV

Can multiple values per field

Medications assessed [51963-7]

* Ampicillin

* coumarin

Search for or type values

Gene(s) assessed [48018-6]

* CFTR

* AAGAB

* FDXACB1

Search for values

make multiple
setions in one
field. Remove them
by clicking on x

PHQ-9 Depression survey with score computed on the fly

As an LHC-Form

PHQ-9 quick depression assessment panel [44249-1] ©

Date Done

Time Done

Where Done

Comment

MMDD/YYYY

Type a value

Select or type a value

Type a value

Name

Value

Units

Over the last 2 weeks, how often have you been bothered by any of the following problems?

[44257-4] ©

Little interest or pleasure in doing things? [44250-0] ©

1. Several days

Feeling down, depressed, or hopeless? [44255-8] ©

2. More than half the days

Trouble falling or staying asleep, or sleeping too much [44259-0] ©

1. Several days

Feeling tired or having little energy [44254-1] ©

1. Several days

Poor appetite or overeating [44251-7] ©

1. Several days

Feeling bad about yourself-or that you are a failure or have let yourself or your family down [44258-2] ©

1. Several days

Trouble concentrating on things, such as reading the newspaper or watching television [44252-5] ©

0. Not at all

Moving or speaking so slowly that other people could have noticed. Or the opposite-being so fidgety or restless that you have been moving around a lot more than usual [44253-3] ©

0. Not at all

Thoughts that you would be better off dead, or of hurting yourself in some way [44280-8] ©

1. Several days

Patient health questionnaire 9 item total score [44281-6] ? ©

8

(score)

How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? [89722-7] ? ©

Selection

form adds up the score for the answers given

<https://lhc-forms.lhc.nlm.nih.gov/>



Secret sauce : Code stored in one field can generate code answer lists for succeeding fields- to be illustrated on the PHR form

Enter Lasix oral and get selection menu of available pill sizes

<input type="checkbox"/>	Z-PAK (Pack)	Q	Stopped	▼	mixed Pack	tal
<input type="checkbox"/>	Beclomethasone (Nasal)	Q	Active	▼	40 mcg/puff Metered dose sp	1 p
<input type="checkbox"/>	LA SIX (Oral Pill)	Q	Active	▼	Select one or type a value	Ty

1: 20 mg Tab
 2: 40 mg Tab
 3: 80 mg Tab

Add another 'Medications'

Allergies and Other Dangerous Reactions

Name

action



Secret sauce: Genetics form. Load variant ID and it fills in values for many other fields

Before

Genetic variant coding system [02122-9]

Discrete genetic variant [81252-9]

Transcript specification

Gene studied	Transcript RefSeq ID	DNA change c.HGVS	Amino acid change p.HGVS	DNA change type	Amino acid change type
<input type="text" value="Search for or type a value"/>	<input type="text" value="Search for or type a value"/>	<input type="text" value="Search for or type a value"/>	<input type="text" value="Search for or type a value"/>	<input type="text" value="Select one or type a value"/>	<input type="text" value="Select one or type a value"/>

Genomic specification

Genomic reference sequence	Genomic DNA change (gHGVS)	Genomic ref allele	Genomic allele start-end	Genomic alt allele
<input type="text" value="Search for or type a value"/>	<input type="text" value="Type a value"/>	<input type="text" value="Type a value"/>	<input type="text" value="Type a value"/>	<input type="text" value="Type a value"/>

After

Discrete genetic variant [81252-9]

Transcript specification

Gene studied	Transcript RefSeq ID	DNA change c.HGVS	Amino acid change p.HGVS	DNA change type	Amino acid change type
CFTR	NM_000492.3	c.1373G>T	p.Gly458Val	SNV	<input type="text" value="Select one or type a value"/>

Genomic specification

Genomic reference sequence	Genomic DNA change (gHGVS)	Genomic ref allele	Genomic allele start-end	Genomic alt allele
NC_000007.13	<input type="text" value="Type a value"/>	G	117188858^117188858	T



Choices of combo boxes, radio buttons, check boxes and grids when appropriate

Braden scale skin assessment panel

Date Done

Time Done

Where

MM/DD/YYYY

Type a value

Select

Name

Sensory perception Braden Scale

?

⊞

⚙

☒ Const

☐ No impairment

Moisture exposure Braden Scale

?

⊞

⚙

☐ Constantly moist

☐ Very moist

☐ Occasionally moist

☐ Rarely moist

Physical Activity Braden Scale

?

⊞

⚙

☐ Bedfast

☐ Chairfast

☐ Walks occasionally

☐ Walks frequently

Physical mobility Braden Scale

?

⊞

⚙

☐ Completely immobile

☐ Very limited

☐ Slightly limited

☐ No limitation

Nutrition Intake Pattern Braden Scale

?

⊞

⚙

☐ Very poor

☐ Probably inadequate

☐ Adequate

☐ Excellent

Friction+Shear Braden Scale

?

⊞

⚙

☐ Problem

☐ Potential problem

☐ No apparent problem

Braden Scale Total Score

⊞

Type a value

{score}

Pressure ulcer risk Braden Scale

?

⊞

⚙

☐ Very high

☐ High

☐ Moderate

☐ Mild

☐ No risk

☐ Combo box

☒ Radio buttons

Display format

In 6 columns

gear gives choice of combo box or buttons and the

gear clicked



Responsive design-example from HL7 V2 genetics reporting form

Wide screen

Full narrative report [51969-4]

Variant ISCN [81291-7]

Versions of Coding Systems [divider04t]

Human reference sequence assembly [62374-4]

☐ NCBI35
 ☐ NCBI36
 ☐ GRCh37
 ☐ GRCh38
 ☐ OTHER:

HGVS version [ID] [81303-0]

Skinny screen

Variant ISCN [81291-7]

Versions of Coding Systems [divider04t]

Human reference sequence assembly [62374-4]

☐ NCBI35
 ☐ NCBI36
 ☐ GRCh37
 ☐ GRCh38
 ☐ OTHER:

HGVS version [ID] [81303-0]

A personal health record in one form

Save To File

Use "Label Above" Style

Use "Label on Left" Style

Show HL7 Message

☐ Display Question Code☒ Show Help/Description☐ Keyboard Navigation On Input Fields

Total # of Questions: 44

Personal Health Record ⚙

Medical Conditions

	Medical condition		Status	Started	Stopped	Description/Comment
-	Chest pain	🔍	Active ▼	04/20/2016 📅	MM/DD/YYYY 📅	Sounds anginal. Worrse with exertion, but young and no family history
-	Pneumonia - bronchial	🔍	Inactive ▼	03/17/2017 📅	04/22/2016 📅	Treated wish Zpack on ambulatorybais
-	Hay fever (allergic rhinitis)	🔍	Active ▼	03/20/2012 📅	MM/DD/YYYY 📅	Every spring
-	bac	🔍	Select one or t▼	MM/DD/YYYY 📅	MM/DD/YYYY 📅	Type a value

Add another 'Medical Conditions'

Medications

	Medication name	Status	Strength	Instructions	Started	Stopped	Why stopped	Resupply
-	Z-PAK (Pack)	🔍 Stopped ▼	mixed Pack	take until gone	03/17/2016 📅	04/22/2016 📅	Finished the prescription ▼	MM/DD/YYYY 📅
-	Beclomethasone (Nasal)	🔍 Active ▼	40 mcg/puff Metered dose sp▼	1 puff twice day in season	03/20/2012 📅	MM/DD/YYYY 📅	Select one or type a value ▼	MM/DD/YYYY 📅

Add another 'Medications'

Allergies and Other Dangerous Reactions

	Name	Reaction	Started	Comment
-	Pollen	▼ Sneezing or stuffy nose ▼	▼ 03/15/2017 📅	Worse when maple trees bloom
-	Select one or type a value	▼ Select one or type a value ▼	▼ MM/DD/YYYY 📅	Type a value

Add another 'Allergies and Other Dangerous Reactions'

Form Builder

URLS for exploring

(Ye Wang, Paul Lynch, Ajay Kanduru, Lee Mericle, Xiaocheng Luan, Clem McDonald)

✈ LHC-Forms

- † Project page: <https://lhncbc.nlm.nih.gov/project/lforms>
- † Software download and documentation: <https://lhncbc.github.io/lforms>
- † Demo site: <https://lhc-forms.lhc.nlm.nih.gov/>

✈ Lister Hill Table Connector (for autocompletion)

- † <https://clin-table-search.lhc.nlm.nih.gov/>
- † <http://lhncbc.github.io/autocomplete-lhc>
- † <https://github.com/lhncbc/autocomplete-lhc>

✈ Form Builder

- † <https://lhc-formbuilder.lhc.nlm.nih.gov>

✈ Units of measure (UCUM) validator and converter

- † <http://lhncbc.github.io/ucum-lhc/>

URLS for exploring - cont.

(Ye Wang, Paul Lynch, Ajay Kanduru, Lee Mericle, Clem McDonald)

✈ JSON & Screenshot of genetic form (use Chrome)

- ✚ Screenshot: <http://lhncbc.github.io/lforms/samples/genetic-panel/screenshot.png>
- ✚ - Form as FHIR Questionnaire: <http://lhncbc.github.io/lforms/samples/genetic-panel/fhir-questionnaire.json>
- ✚ - Form response as FHIR Questionnaire Response: <http://lhncbc.github.io/lforms/samples/genetic-panel/fhir-questionnaire-response.json>
- ✚ - Form response as FHIR Diagnostic Report: <http://lhncbc.github.io/lforms/samples/genetic-panel/fhir-diagnostic-report.json>
- ✚ - LHC-Forms format (with user data): <http://lhncbc.github.io/lforms/samples/genetic-panel/lforms-data.json>

We would be interested in collaborators!