



FHIR[®] Webinar

Case Reporting on FHIR
January 12, 2022

Agenda & Structure

- **House rules, intro, agenda (5')**
- **1: Case Reporting scoping (5')**
 - Lifelong vs time window
- **2: FHIR Fundamentals (15')**
 - Resources, Data types, terminology
 - Profiles
 - FHIR Operations, Capability Statement, REST/Documents
 - FHIR Implementation Guide development process - logical model + profiles, terminology, others (operations, etc)
- **3: Case Reporting purposes (10')**
 - Lifelong vs time window
 - Population / clinical
 - Q&A: Your context / Challenges / ideas?
- **4: Case Reporting Architecture (30)**
 - Architectural pattern(s)
 - Data objects and data flow
- **5: FHIR Questionnaires (5-10)**
- **6: FHIR Structured Data Capture (15)**
- **7: Implementation intro (5)**
 - Layered specification
 - Tooling

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Goals

1. Understand use of terminologies in FHIR
 - how coded data is represented and exchanged in FHIR resources
 - how code systems and value sets in FHIR are defined, identified and used
 - how to specify and use bindings in FHIR models (resources and profiles)
2. Understand Terminology searching and services
 - FHIR terminology-based search capabilities
 - FHIR Terminology Service capabilities

Part 1










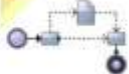


























Scoping



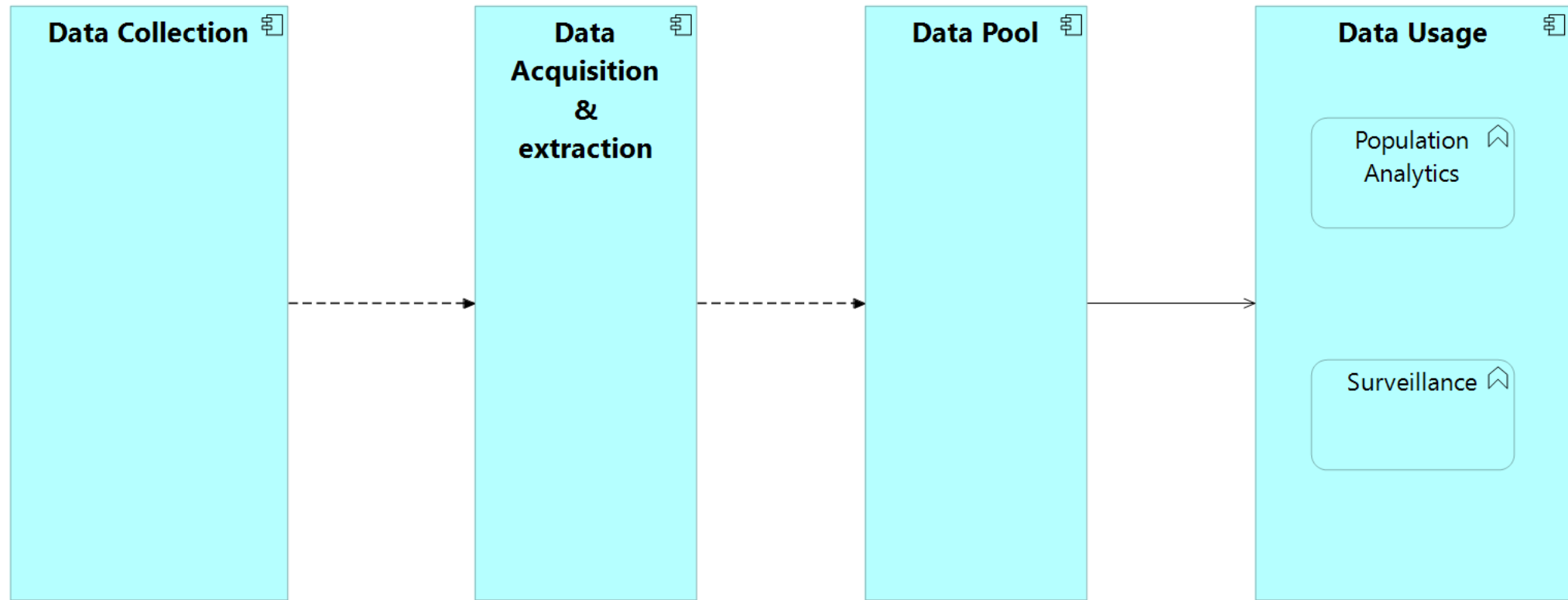
Scope

1. Case Reporting: Data exchange mechanisms for acquiring, maintaining and using data about a patient's case – evolution, treatment...
 - Chronic conditions
 - Infectious diseases
 - Treatments
 - ...any other...

FHIR Applicability

ZFI Zachman Framework						
The Zachman Framework	DATA What	FUNCTION How	NETWORK Where	PEOPLE Who	TIME When	MOTIVATION Why
SCOPE (Contextual) Planner	Things Important to the Business 	Processes the Business Performs 	Locations in which the Business Operates 	Organizations Important to the Business 	Events/Cycles Significant to the Business 	Business Goals/Strategies 
BUSINESS MODEL (Conceptual) Owner	Conceptual Data Model 	Business Process Model 	Business Logistics 	Work Flow Model 	Master Schedule 	Business Plan 
SYSTEM MODEL (Logical) Designer	Logical Data Model 	Application Architecture 	Distributed System Architecture 	Human Interface Architecture 	Processing Structure 	Business Rule Model 
TECHNOLOGY MODEL (Physical) Builder	Physical Data Model 	System Design 	Technology Architecture 	Presentation Architecture 	Control Structure 	Rule Design 
DETAILED REPRESENTATIONS Sub-Contractor	Data Definition 	Program 	Network Architecture 	Security Architecture 	Timing Definition 	Rule Specification 
FUNCTIONING ENTERPRISE	Data 	Function 	Network 	Organization Units 	Schedule 	Strategy 

Basic architecture



Scoping factors

- **Purpose: Patient vs Population**
- **Lifelong vs time window**
- **Condition-focused vs comprehensive**
- **Facility-specific vs nationwide / global**
- **Discussion – your ideas?**

Part 1

FHIR

Fundamentals

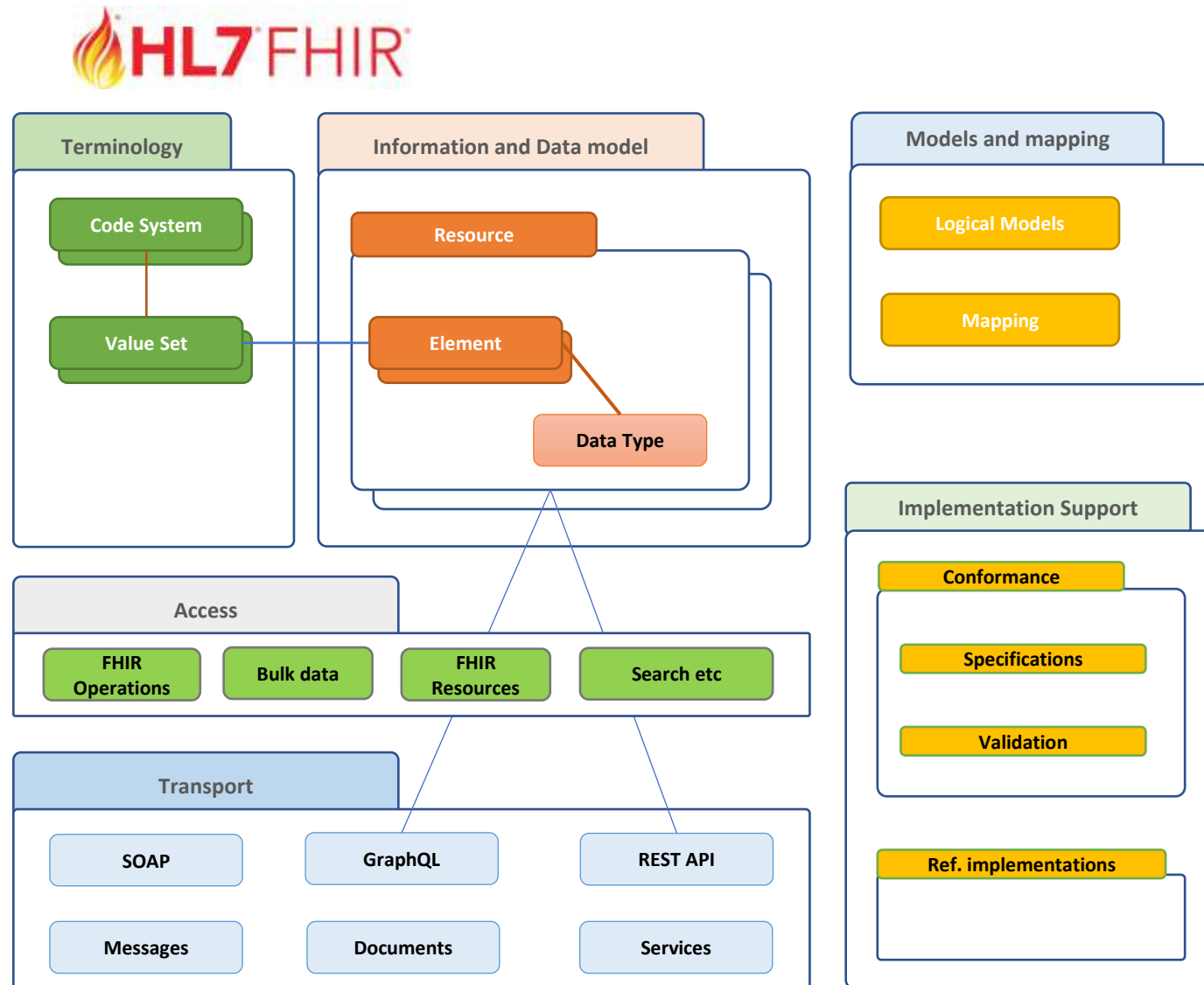
(Review)



Main topics

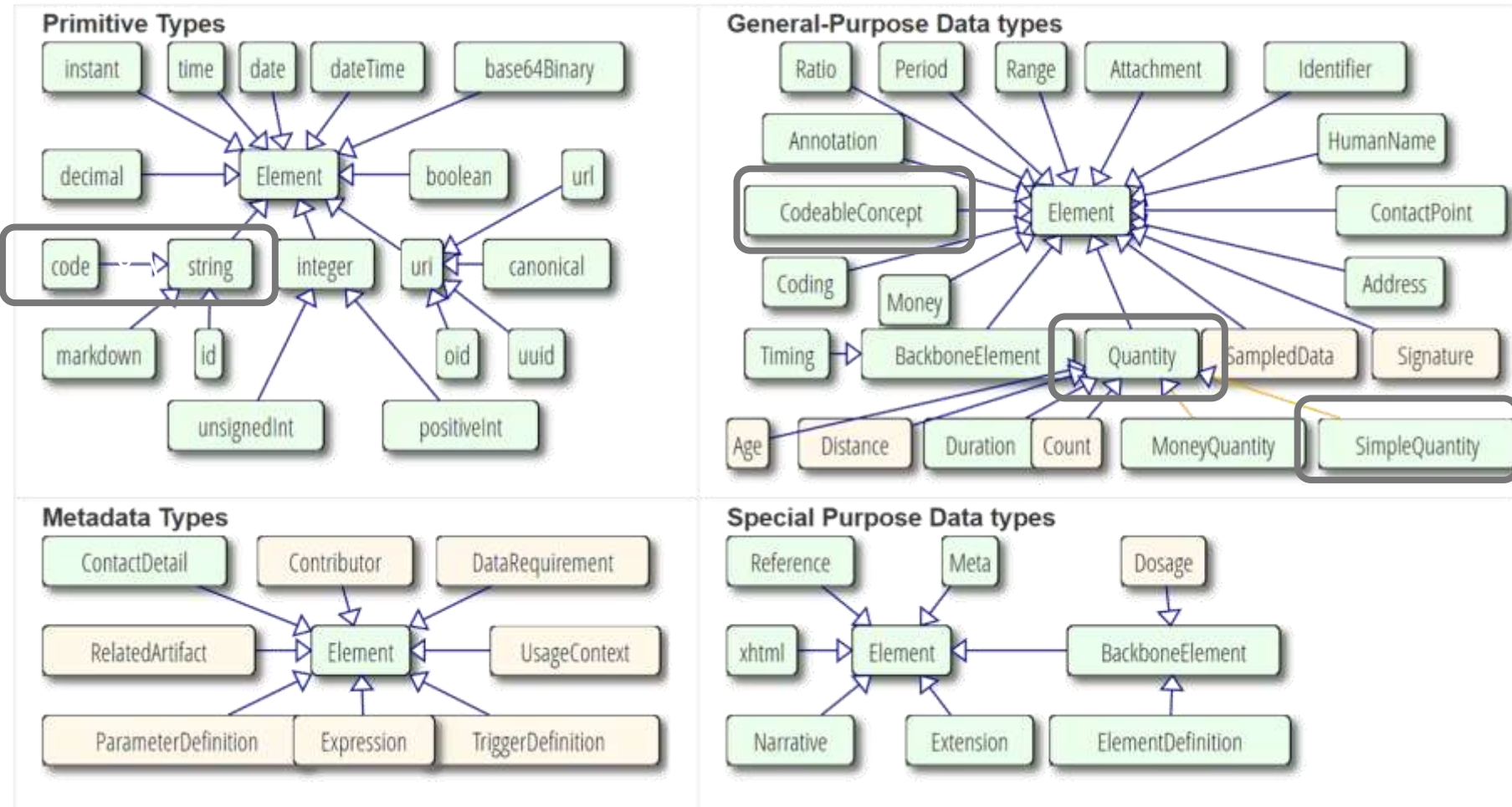
- Resources, Data types, terminology
- Profiles
- FHIR Operations, Capability Statement, REST/Documents
- FHIR Implementation Guide development process - logical model + profiles, terminology, others (operations, etc)

The HL7[®] FHIR[®] standard



Source: HL7 Belgium

Data types



<http://build.fhir.org/datatypes.html>

Primitive Types		XML Representation	JSON representation
FHIR Name	Value Domain		
boolean	true false Regex: <code>true false</code>	xs:boolean, except that 0 and 1 are not valid values	JSON boolean (true or false)
integer	A signed integer in the range -2,147,483,648..2,147,483,647 (32-bit; for larger values, use decimal) Regex: <code>[0]([-+]?[1-9]([0-9])*)</code>	xs:int, except that leading 0 digits are not allowed	JSON number (with no decimal point)
string	A sequence of Unicode characters Note that strings SHALL NOT exceed 1MB (1024*1024 characters) in size. Strings SHOULD not contain Unicode character points below 32, except for u0009 (horizontal tab), u0010 (carriage return) and u0013 (line feed). Leading and trailing whitespace is allowed, but SHOULD be removed when using the XML format. Note: This means that a string that consists only of whitespace could be trimmed to nothing, which would be treated as a null element value. Therefore strings SHOULD always contain non-whitespace content. This data type can be bound to a ValueSet . Regex: <code>[^\\u0013\\u0010\\u0009]*</code> (see notes below)	xs:string	JSON String
decimal	Rational numbers that have a decimal representation. See below about the precision of the number Regex: <code>-?[0]([1-9]([0-9]*)\\.([0-9]+)?([0E]([-+]?[0-9]+)?</code>	union of xs:decimal and xs:double (see below for limitations)	A JSON number (see below for limitations)
uri	A Uniform Resource Identifier Reference (RFC 3986 cf). Note: URIs are case sensitive. For UUID (urn:uuid:53fafa32-fccb-4f8b-8a92-55ee12087707) use all lowercase Regex: <code>JS*</code> (This regex is very permissive, but URIs must be valid. Implementers are welcome to use more specific regex statements for a URI in specific contexts) URIs can be absolute or relative, and may have an optional fragment identifier. This data type can be bound to a ValueSet .	xs:anyURI	A JSON string - a URI
url	A Uniform Resource Locator (RFC 1738 cf). Note: URLs are accessed directly using the specified protocol. Common URL protocols are <code>http(s)://</code> , <code>ftp://</code> , <code>mailto:</code> and <code>ldap://</code> , though many others are defined	xs:anyURI	A JSON string - a URL
canonical	A URI that refers to a resource by its canonical URI (resources with a <code>url</code> property). The <code>canonical</code> type differs from a <code>url</code> in that it has special meaning in this specification, and in that it may have a version appended, separated by a vertical bar (<code> </code>). Note that the type <code>canonical</code> is not used for the actual canonical URLs that are the target of these references, but for the URIs that refer to them, and may have the version suffix in them. Like other URIs, elements of type <code>canonical</code> may also have <code>#fragment</code> references	xs:anyURI	A JSON string - a canonical URL
base64Binary	A stream of bytes, base64 encoded (RFC 4648 cf) Regex: <code>([a-zA-Z0-9+\\/]{4})*</code> There is no specified upper limit to the size of a binary, but systems will have to impose some implementation based limit to the size they support. This should be clearly documented, though there is no computable for this	xs:base64Binary	A JSON string - base64 content
instant	An instant in time in the format YYYY-MM-DDThh:mm:ss.sss+zz:zz (e.g. 2015-02-07T13:28:17.239+02:00 or 2017-01-01T00:00:00Z). The time SHALL specified at least to the second and SHALL include a time zone. Note: This is intended for when precisely observed times are required (typically system logs etc.), and not human-reported times - for those, use date or dateTime (which can be as precise as <code>instant</code> , but is not required to be). <code>instant</code> is a more constrained dateTime. Note: This type is for system times, not human times (see date and dateTime below). Regex: <code>(([0-9]([0-9]([0-9]([1-9]([1-9]([1-9]([1-9]([0-9]([1</code>		

Data types in instances

```
{
  "resourceType" : "Patient",
  "id" : "43961584-bf55-4ddf-9462-a37465fe4440",
  "identifier" : [
    {
      "type" : {
        "coding" : [
          {
            "system" : "http://terminology.hl7.org/CodeSystem/v2-0203/",
            "code" : "MR",
            "display" : "Medical record number"
          }
        ]
      },
      "system" : "http://myhospital.org/identifiers/patients",
      "value" : "P0000001"
    }
  ],
  "name" : [
    {
      "family" : "Doe",
      "given" : [
        "John"
      ]
    }
  ],
  "gender" : "male",
  "birthDate" : "1971-04-28T00:20:00Z"
}
```

Name	Flags	Card.	Type	Description & Constraints
Identifier	I N		Element	An identifier intended for computation Elements defined in Ancestors: id , extension usual official temp secondary old (if known) IdentifierUse (Required)
use	?! I	0..1	code	Description of identifier IdentifierType (Extensible)
type	I	0..1	CodeableConcept	The namespace for the identifier value
system	I	0..1	uri	The value that is unique
value	I	0..1	string	Time period when id is/was valid for use
period	I	0..1	Period	Organization that issued id (may be just text)
assigner	I	0..1	Reference(Organization)	

[? Documentation for this format](#)

Name	Flags	Card.	Type	Description & Constraints
CodeableConcept	I N		Element	Concept - reference to a terminology or just text Elements defined in Ancestors: id , extension
coding	I	0..*	Coding	Code defined by a terminology system
text	I	0..1	string	Plain text representation of the concept

Name	Flags	Card.	Type	Description & Constraints
Coding	I N		Element	A reference to a code defined by a terminology system Elements defined in Ancestors: id , extension
system	I	0..1	uri	Identity of the terminology system
version	I	0..1	string	Version of the system - if relevant
code	I	0..1	code	Symbol in syntax defined by the system
display	I	0..1	string	Representation defined by the system
userSelected	I	0..1	boolean	If this coding was chosen directly by the user

Name	Flags	Card.	Type	Description & Constraints
HumanName	I N		Element	Name of a human - parts and usage Elements defined in Ancestors: id , extension usual official temp nickname anonymous old maiden NameUse (Required)
use	?! I	0..1	code	Text representation of the full name
text	I	0..1	string	Family name (often called 'Surname')
family	I	0..1	string	Given names (not always 'first'). Includes middle names
given	I	0..*	string	This repeating element order: Given Names appear in the correct order for presenting the name
prefix	I	0..*	string	Parts that come before the name
suffix	I	0..*	string	This repeating element order: Prefixes appear in the correct order for presenting the name
period	I	0..1	Period	Parts that come after the name
				This repeating element order: Suffixes appear in the correct order for presenting the name
				Time period when name was/is in use

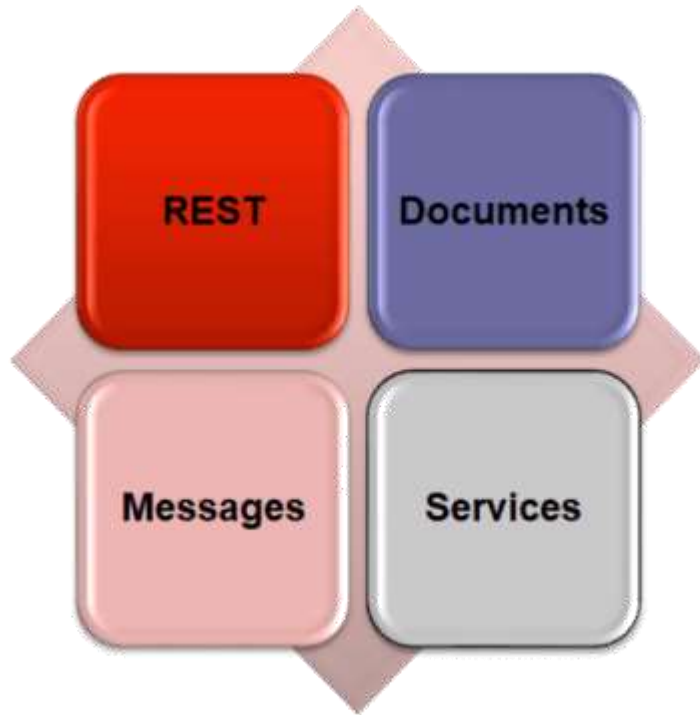
FHIR “special” resource types

- Foundational resources: used to define fundamental aspects of FHIR (resources, maps, operations, capabilities)

Foundation	Conformance	Terminology	Security	Documents	Other
	<ul style="list-style-type: none">• CapabilityStatement N• StructureDefinition N• ImplementationGuide 1• SearchParameter 3• MessageDefinition 1• OperationDefinition N• CompartmentDefinition 1• StructureMap 2• GraphDefinition 1• ExampleScenario 0	<ul style="list-style-type: none">• CodeSystem N• ValueSet N• ConceptMap 3• NamingSystem 1• TerminologyCapabilities 0	<ul style="list-style-type: none">• Provenance 3• AuditEvent 3• Consent 2	<ul style="list-style-type: none">• Composition 2• DocumentManifest 2• DocumentReference 3• CatalogEntry 0	<ul style="list-style-type: none">• Basic 1• Binary N• Bundle N• Linkage 0• MessageHeader 4• OperationOutcome N• Parameters N• Subscription 3

<http://hl7.org/fhir/resourcelist.html>

Exchange paradigms



<http://www.healthintersections.com.au>

FHIR supports four paradigms

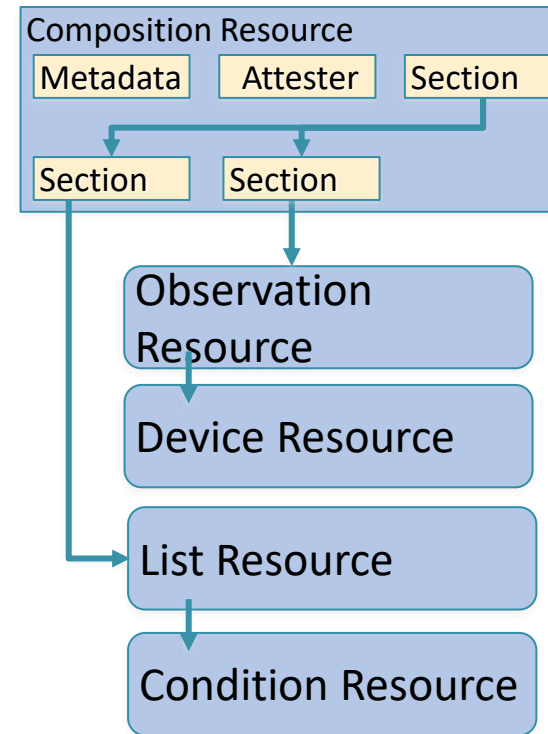
- RESTful API hl7.org/fhir/http.html
- Documents (like CDA) hl7.org/fhir/documents.html
- Services (SOA techniques) hl7.org/fhir/services.html
- Messages hl7.org/fhir/messaging.html
- Subscriptions hl7.org/fhir/subscription.html

REST

- Most common approach
- GET (the “read” verb)
 - GET a single resource: GET Patient/43961584
 - GET a set of resources GET Patient (?...)
 - Response is a resource (a Patient, or a Bundle, or an OperationOutcome)
- POST (create)
- PUT (update)
- DELETE (delete)

Documents

- A Bundle with
 - Type = document
 - 1st Entry is a Composition
 - N entries referenced by Composition
 - Signature and Provenance
- Used for
 - Persistence
 - Stewardship
 - Authentication
 - Context
 - Integrity
 - Human Readability



```
<Bundle>
  <entry>
    <resource>
      <Composition />
    </resource>
  </entry>
  <entry>
    <resource>
      <Observation />
    </resource>
  </entry>
  <entry>
    <resource>
      <Device />
    </resource>
  </entry>
  <entry>
    <resource>
      <List/>
    </resource>
  </entry>
  <entry>
    <resource>
      <Condition/>
    </resource>
  </entry>
</Bundle>
```

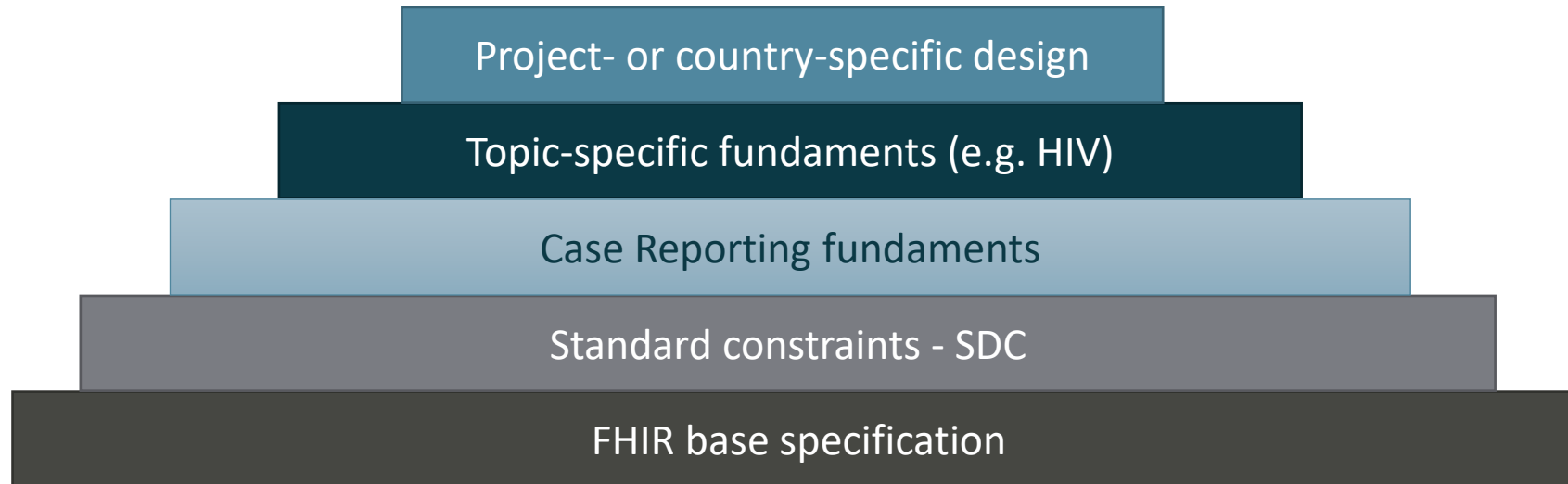
Yellow arrows indicate the relationships between the XML elements: from the Composition element to the Observation, Device, and List elements, and from the List element back to the Composition element.

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Reg. U.S. TM Office.

<http://build.fhir.org/documents>

Layered FHIR specifications

- Different levels of specification
 - Look for already existing guidance...
 - ...or help build it
- A specification can add constraints and extensions to the specification it depends on



FHIR specifications – Implementation Guides

- Define the use cases
 - Define the data
 - Functionally – Logical models
 - Technically – FHIR profiles
- } • terminology

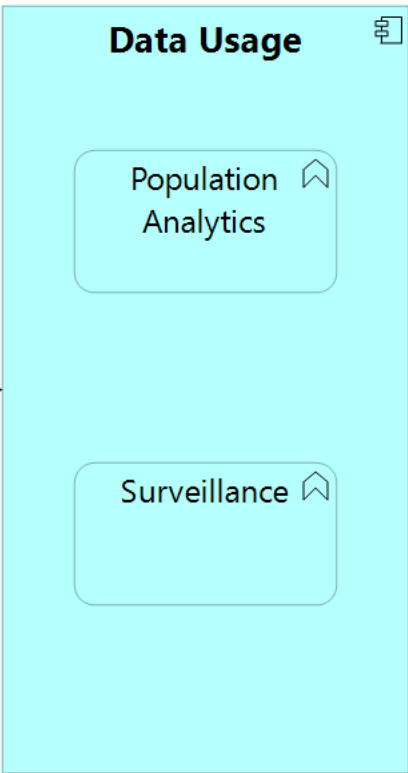
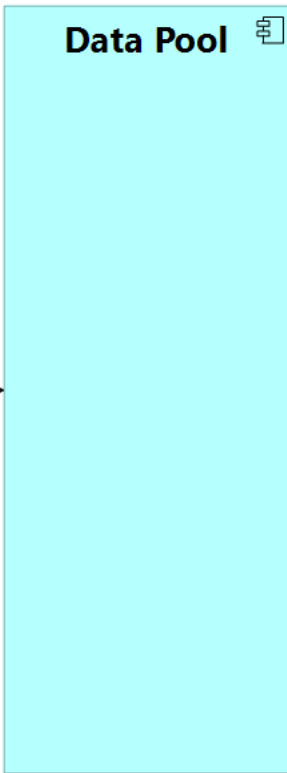
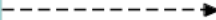
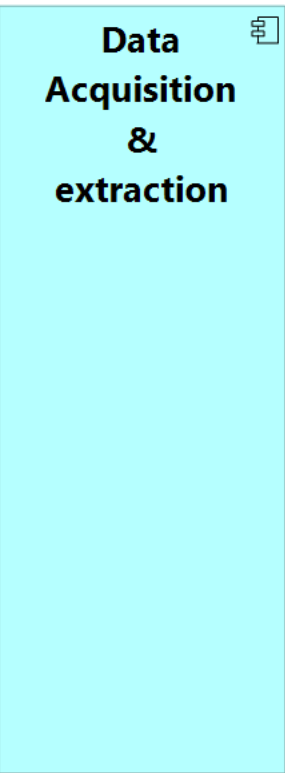
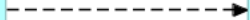
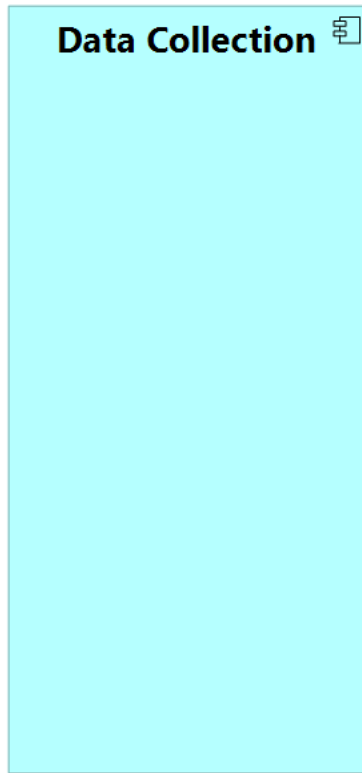
Case Reporting Architecture

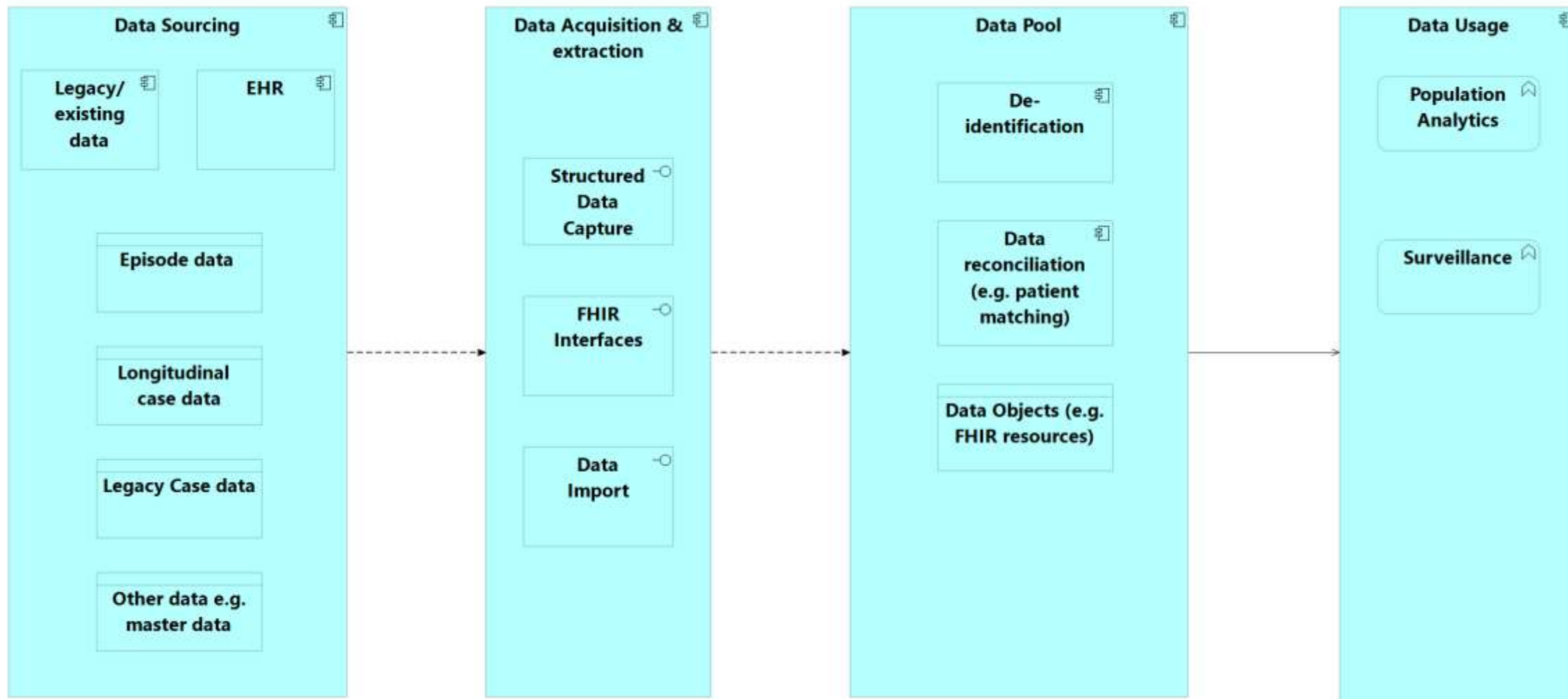


Case Reporting requirements

- Observe how a patient's condition evolves
- Track chronic / epidemic diseases...
- ... or short-term episodes

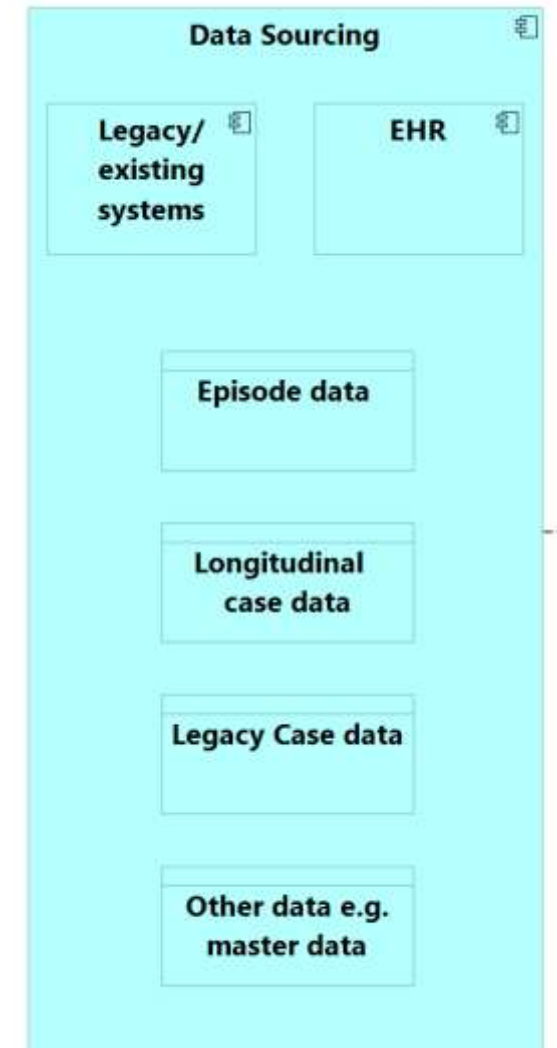
Case Reporting Architecture components





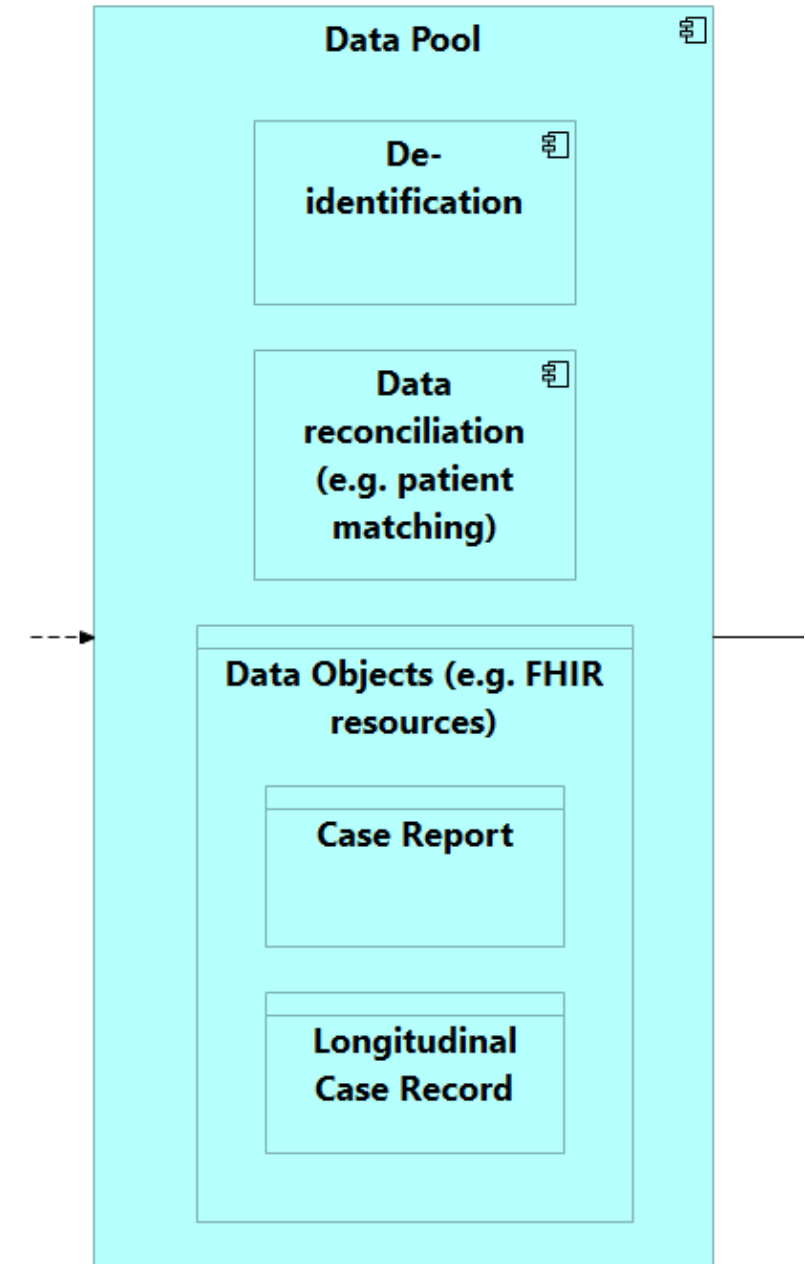
Data Sourcing

- What data is there? What can be acquired?
 - Patient episode data (treatment, medication, visit report...)
 - EHR existing data
 - Legacy data
 - (Other data)
- When is it acquired?
 - Each event / visit
 - History



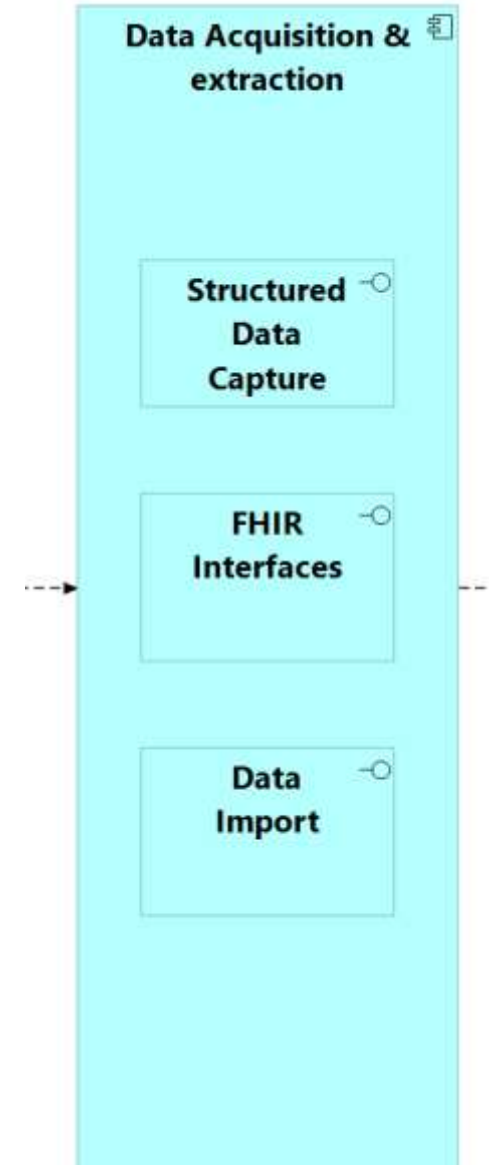
Data Pool

- Data objects – can be FHIR native or not
- Data functions
 - Data processing/reconciliation
 - De-identification
- Storage format – not end format



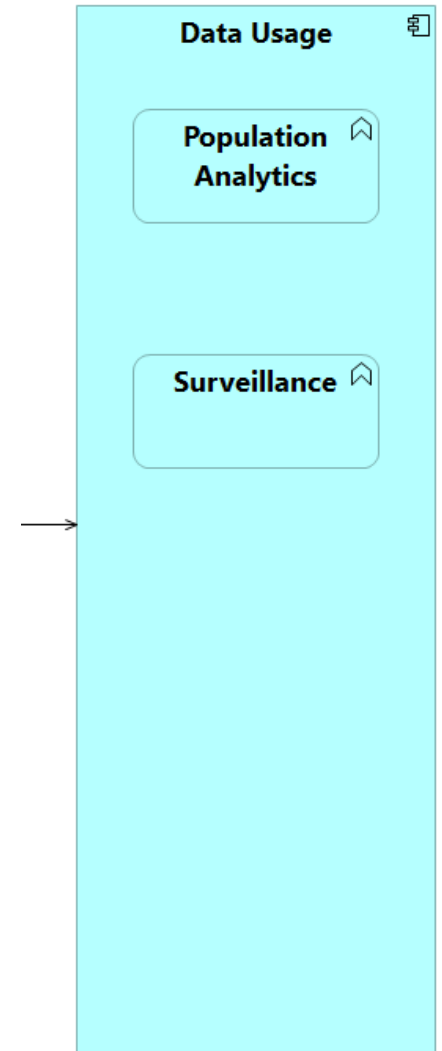
Data Acquisition

- Data acquisition getting data into the **Storage format**
- Depends on how data is to be acquired
 - User entry e.g. Patient, nurse...
 - From existing systems e.g. EHRs



Data Usage

- Population data / analytics
 - Dedicated architecture
 - Existing specification
- Surveillance / trigger events
 - Can use e.g. FHIR Subscriptions



Data Structures

Data Objects

- Data input
 - Patient episode
 - Patient history
 - EHR data
 - Legacy data
 - (Other data e.g. product data)

Data objects

- Case reports could be presented as FHIR resources
 - Even better packed in a Bundle per Event / per Patient
- However, sometimes what we have is other data...
 - Some previously captured data – CSV/others
 - Standardized data (CDA,...)
- ...or we need to capture it



Why use forms?

- AllergyIntolerance
- Condition
- Encounter
- FamilyMemberHistory
- MedicationStatement
- Observation
- Patient
- 100+ other resources

or

- QuestionnaireResponse

Forms for display

NAME: _____

FOLDER NO.: _____

BIRTH DATE: _____

CLINIC/DOCTOR: _____

TELEPHONE NO: _____

HISTORY *

Obstetric history

Year	Gestation (weeks)	Delivery	Weight	Sex	L = Live IUD = intra-uterine death END = early neonatal death LND = late neonatal death ID = infant death	Complications

Description of complications

Age P G

Medical and general history

Medication

Operations

Allergies

Smoking: Yes No Counselling _____

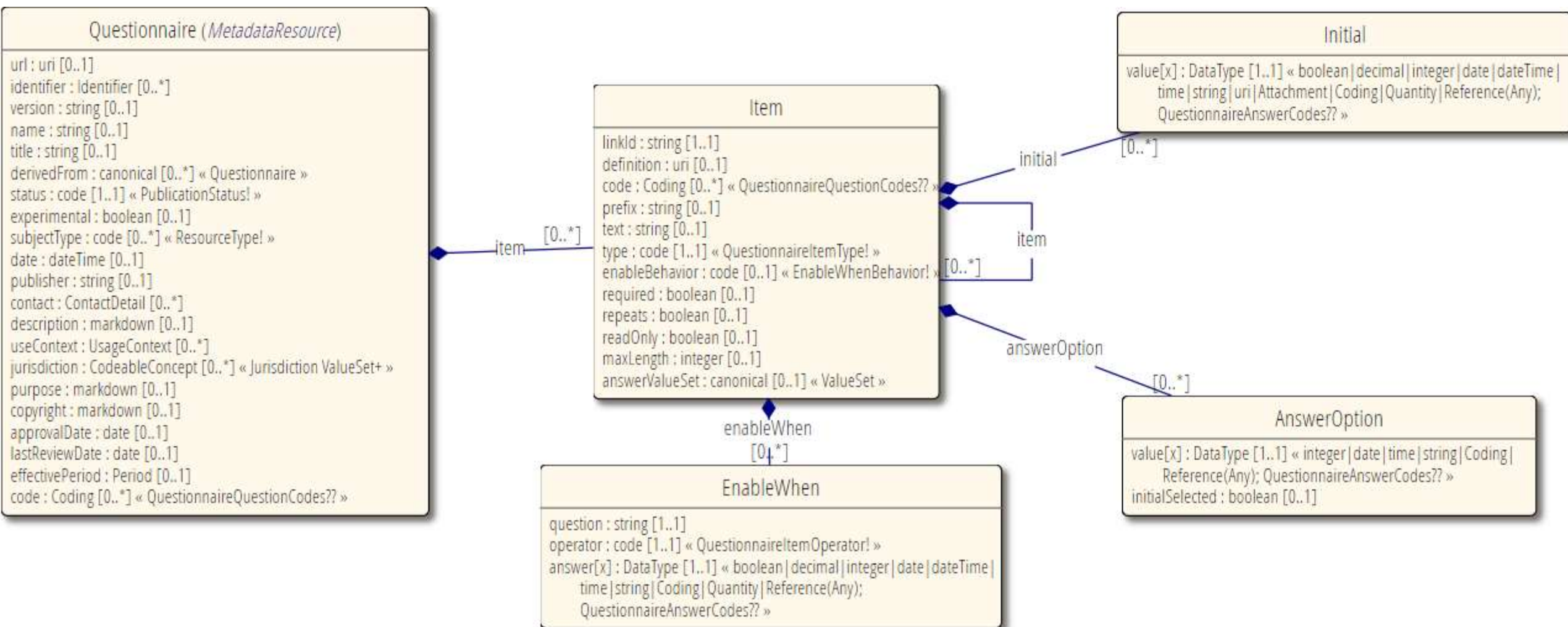
EXAMINATION *											
						Date					
		D		M		M		Y		Y	
Height _____						Weight _____					
BP _____						Hb _____					
Urine _____											
General _____											
Thyroid _____						Breasts _____					
Heart _____											
Lungs _____											
Abdomen _____						SF - Measurement 					
Other _____											
Vaginal Examination											
V + V _____											
Cervix _____											
Uterus _____											
Abdomen _____											
NAME 											
SPECIAL INVESTIGATIONS *											
VDRL _____				TPHA _____				FTA - Abs _____			
Rx received 1st _____				2nd _____				3rd _____			
Bloodgroup and Rb _____											
Cytology _____											
MSU _____											
RVD				Test accepted: Yes No				Precautions: Yes No			
Other _____											

PLAN											
Antenatal Care						Labour					
GESTATIONAL AGE											
LMP		D	D	M	M	Y	Y	Certain		Yes	No
Cycle								Contraception		Yes	No
								Type			
SONAR						Date					
		D	D	M	M	Y	Y				
BPD						mm				weeks	
FL						mm				weeks	
Placenta											
Other											
EDD		according to: dates / sonar / both / uncertain									
Day	Day	Month	Month	Year	Year						
Future family planning											
* Note problems from history, examination and special investigations on problem list											

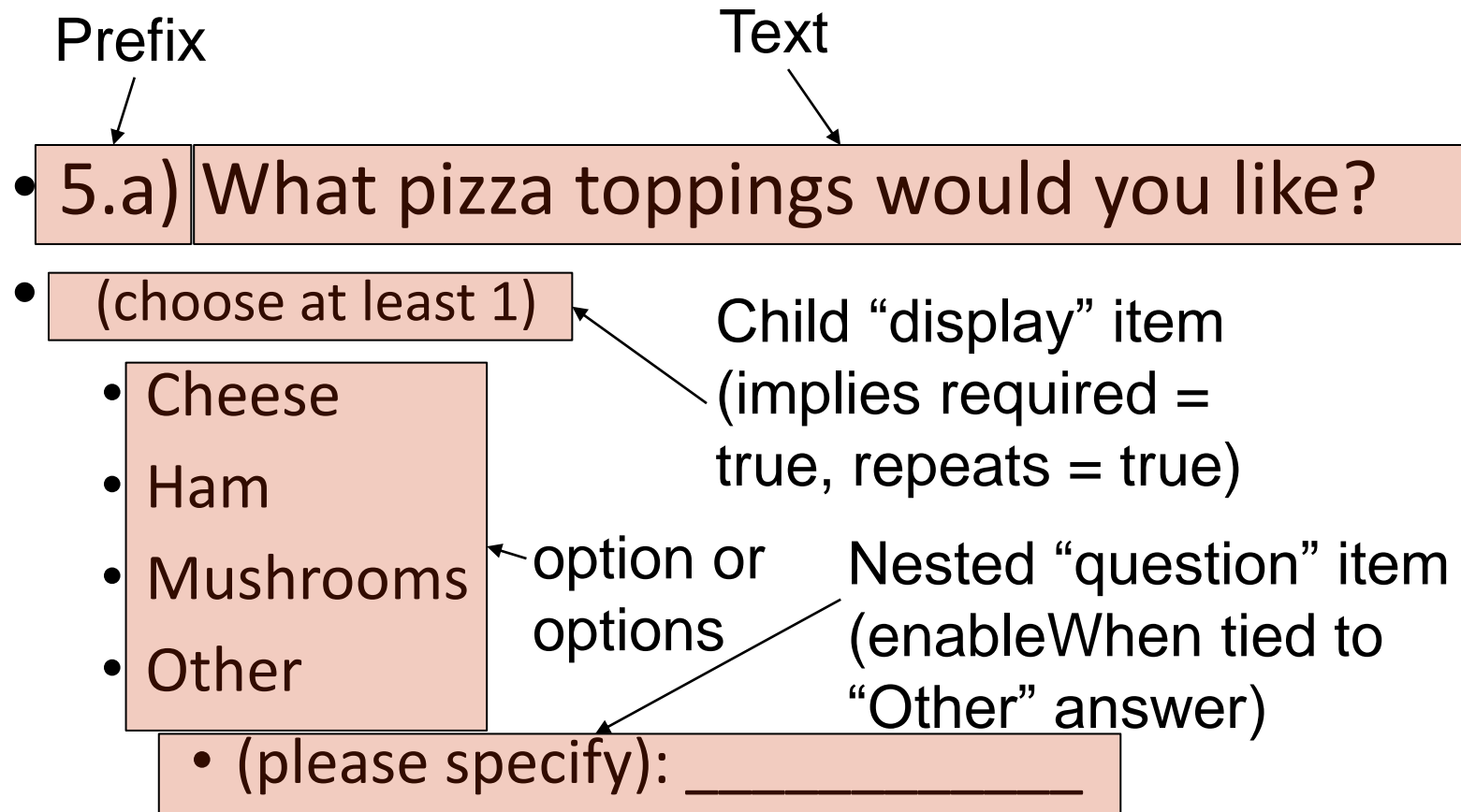
Forms provide:

- Tight control over user experience:
 - How questions are phrased
 - What answer choices are permitted
 - What gets asked when (and in what order)
 - User interface 'appearance'
 - i.e. Consistency in data capture
- Full flexibility in what data is captured and how
- Very simple data model

Questionnaire



Anatomy of a Question



Linking Questionnaire to QuestionnaireResponse

Questionnaire

```
<item>
  <linkId value="G1"/>
  <text value="Test questions"/>
  <type value="group"/>
  <repeats value="true"/>
  <item>
    <linkId value="Q1"/>
    <text value="What is your name?"/>
    <type value="string"/>
  </item>
  <item>
    <linkId value="Q2"/>
    <text value="What is your quest?"/>
    <type value="string"/>
  </item>
  <item>
    <linkId value="Q3"/>
    <text value="What is your favorite colour?"/>
    <type value="string"/>
  </item>
</item>
```

QuestionnaireResponse

```
<item>
  <linkId value="G1"/>
  <text value="Test questions"/>
  <item>
    <linkId value="Q1"/>
    <text value="What is your name?"/>
    <answer>
      <valueString value="Sir Lancelot of Camelot"/>
    </answer>
  </item>
  <!-- ... -->
</item>
<item>
  <linkId value="G1"/>
  <text value="Test questions"/>
  <item>
    <linkId value="Q1"/>
    <text value="What is your name?"/>
    <answer>
      <valueString value="Sir Robin of Camelot"/>
    </answer>
  </item>
  <!-- ... -->
</item>
```


Structured Data Capture (SDC)

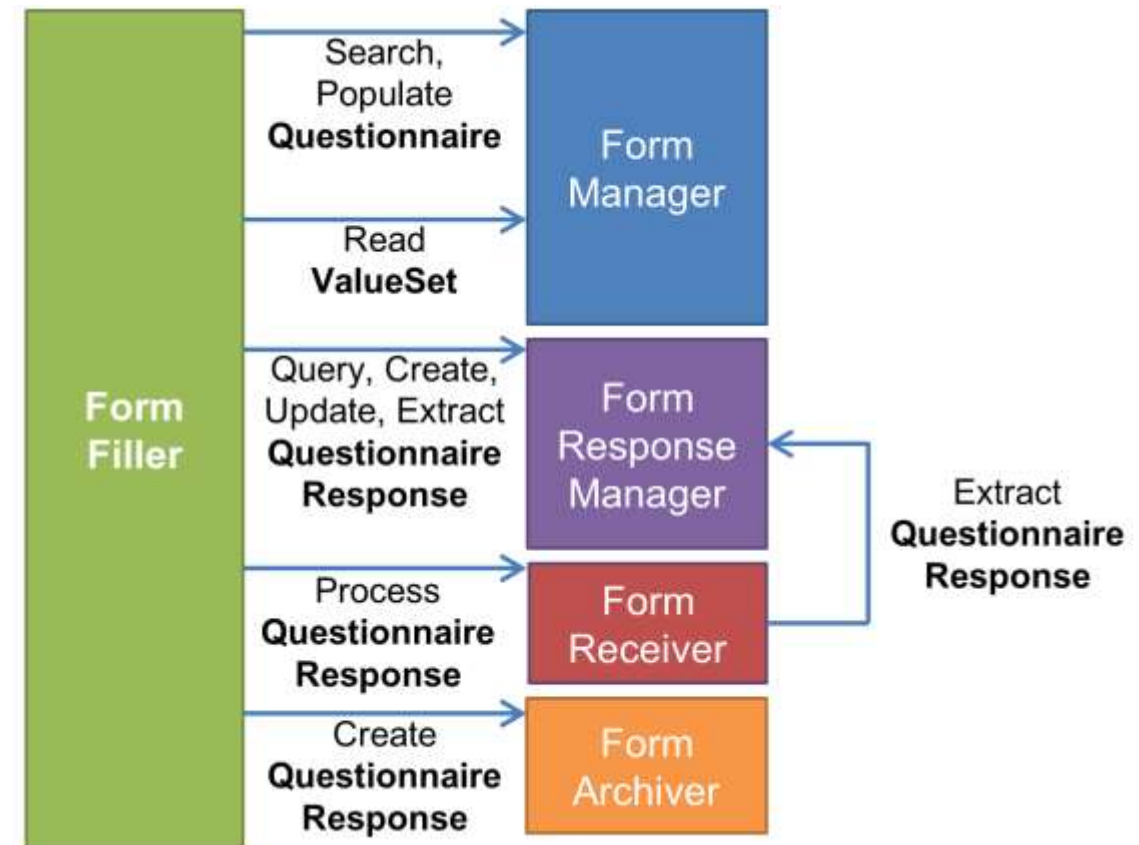


What is Structured Data Capture (SDC)?

- Standardize/enhance capabilities of FHIR Questionnaires:
 - Workflow
 - Complex form rendering - <https://build.fhir.org/ig/HL7/sdc/rendering.html>
 - Complex form behavior - <https://build.fhir.org/ig/HL7/sdc/behavior.html>
 - Automatically populating forms - <https://build.fhir.org/ig/HL7/sdc/behavior.html>
 - Automatically extracting form data - <https://build.fhir.org/ig/HL7/sdc/extraction.html>
 - Adaptive forms - <https://build.fhir.org/ig/HL7/sdc/adaptive.html>
 - Form composition - <https://build.fhir.org/ig/HL7/sdc/modular.html>

Questionnaire (complex) workflow and actors

- How do you find a form?
- How do you retrieve allowed values?
- How do you manage form completion?
- How do you submit a form?
- How do you ask someone to complete a form?
- How do you track whether they've filled it out?
- How do you derive one form from another?



SDC as enabler of standard tools

- <https://confluence.hl7.org/display/FHIRI/SDC+Implementations>
- Example: <https://lhcfirms.nlm.nih.gov/lforms-fhir-app/>

Data Extraction

Data extraction

3 mechanisms to be explored later

- Observation-based extraction
- Definition-based extraction
- Structure-map based extraction
 - $\$extract$ operation

Structure-map extraction

- Uses FHIR mapping language -
 - <https://www.hl7.org/fhir/mapping-language.html>
- Easily gets rather complex
 - we're working on making it more accessible

Structure-map extraction

- Uses FHIR mapping language -
 - <https://www.hl7.org/fhir/mapping-language.html>
- Easily gets rather complex
 - we're working on making it more accessible

Mapping

```
map "http://hl7belgium.org/matchbox/fml/extractfindrisc" = "extractfindrisc"

uses "http://hl7.org/fhir/StructureDefinition/QuestionnaireResponse" alias QuestionnaireResponse as source
uses "http://hl7.org/fhir/StructureDefinition/Observation" alias Observation as target

group QuestionnaireResponse(source src : QuestionnaireResponse, target tgt : Observation) {
  src.item as item where linkId.value in ('findriscScore') -> tgt as scoreresult then item(item, scoreresult) "r1";
  src.item as item where linkId.value in ('findriscScore') -> tgt as scoreresult then patient(item, scoreresult) "r2";
}

group item(source src, target tgt: Observation) {
  src -> tgt.code as code then itemcoding(src, code) "x1";
  src -> tgt.status = "final" "x2";
  src -> tgt.value = (src.answer.valueDecimal) "x3";
}

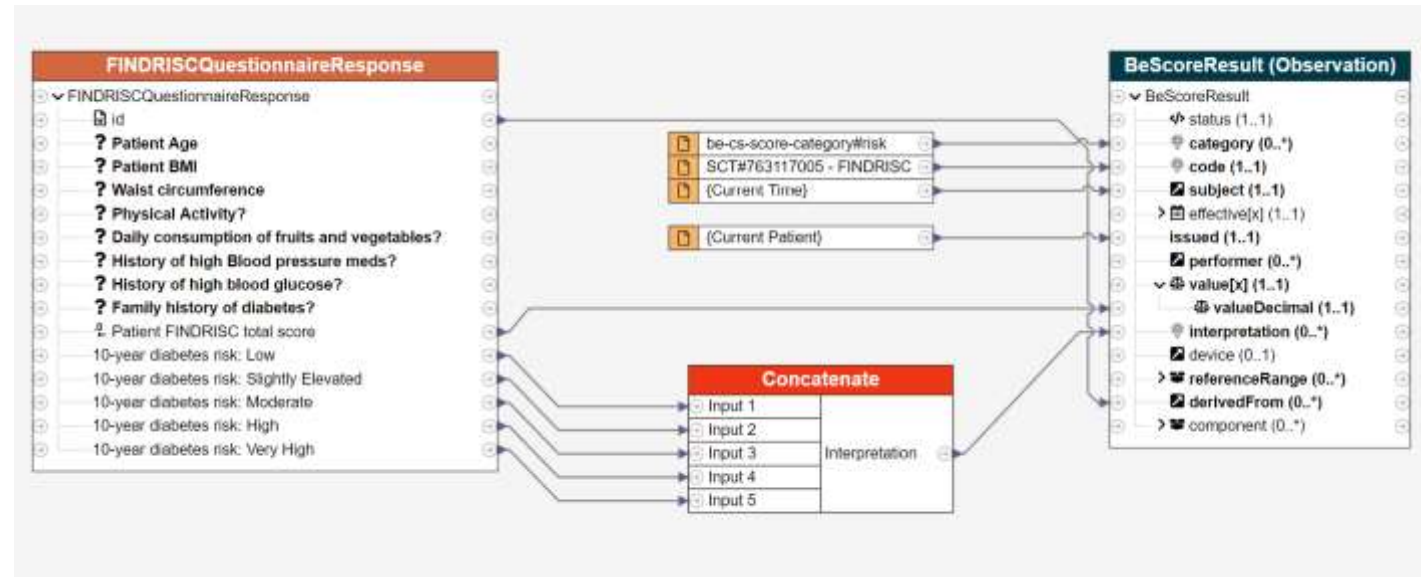
group patient(source src, target tgt: Observation) {
  src -> tgt.subject as patref then patientid(src, patref) "x4";
}

group patientid(source src, target tgt: Reference) {
  src -> tgt.identifier as patid then idvalue(src, patid) "x5";
}

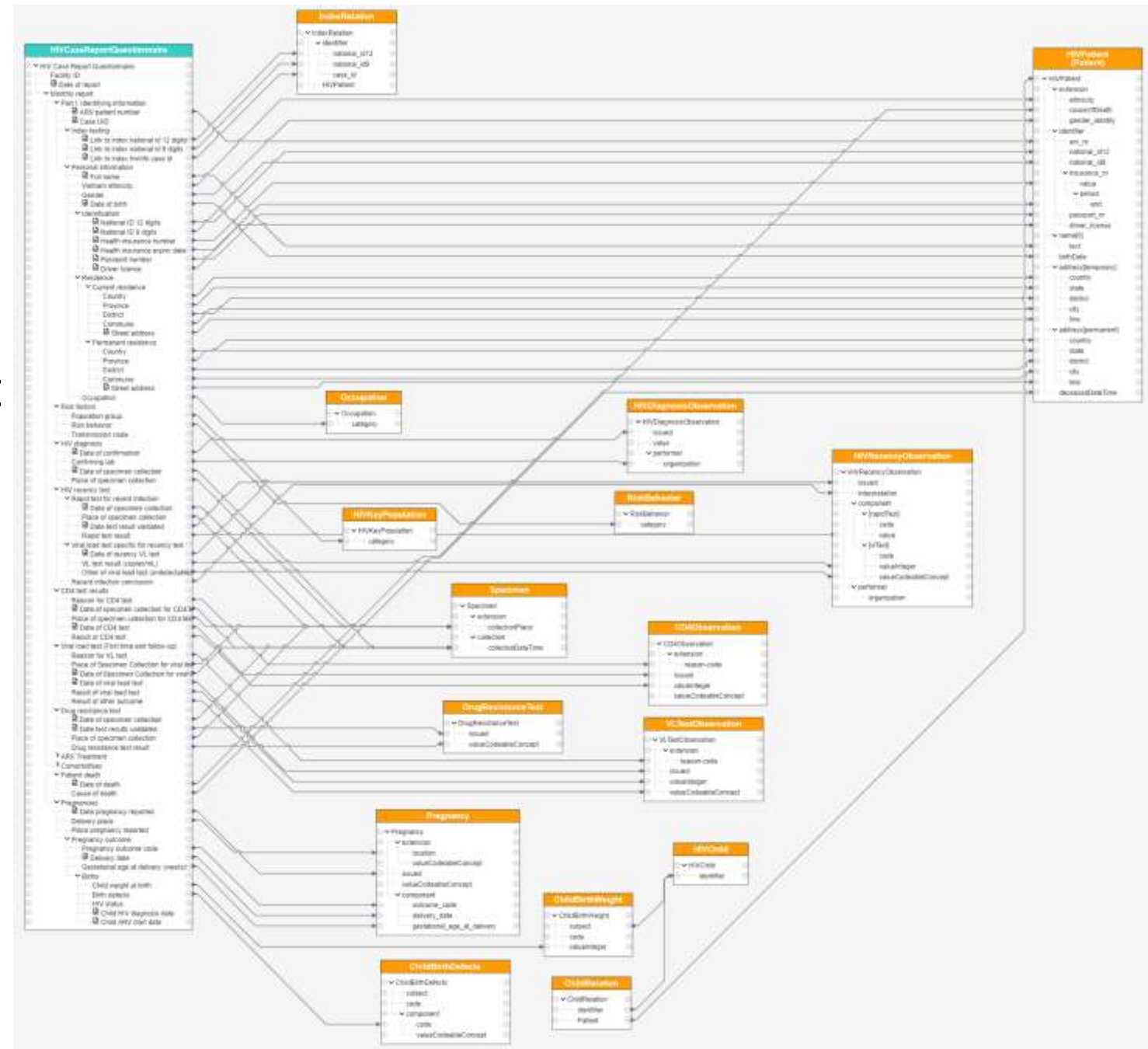
group idvalue(source src, target tgt: Identifier) {
  src -> tgt.value = (src.answer.valueDecimal) "x6";
}

group itemcoding(source src, target tgt: CodeableConcept) {
  src -> tgt.coding as y then codingcode(src, y) "x7";
}

group codingcode(source src, target tgt: Coding) {
  src -> tgt.code = '763117005' "x8";
  src -> tgt.system = 'http://snomed.info/sct' "x9";
  src -> tgt.display = 'FINDRISC (Finnish Diabetes Risk Score) score' "x10";
}
```



- + Wrapped in a Document



Implementation Introduction

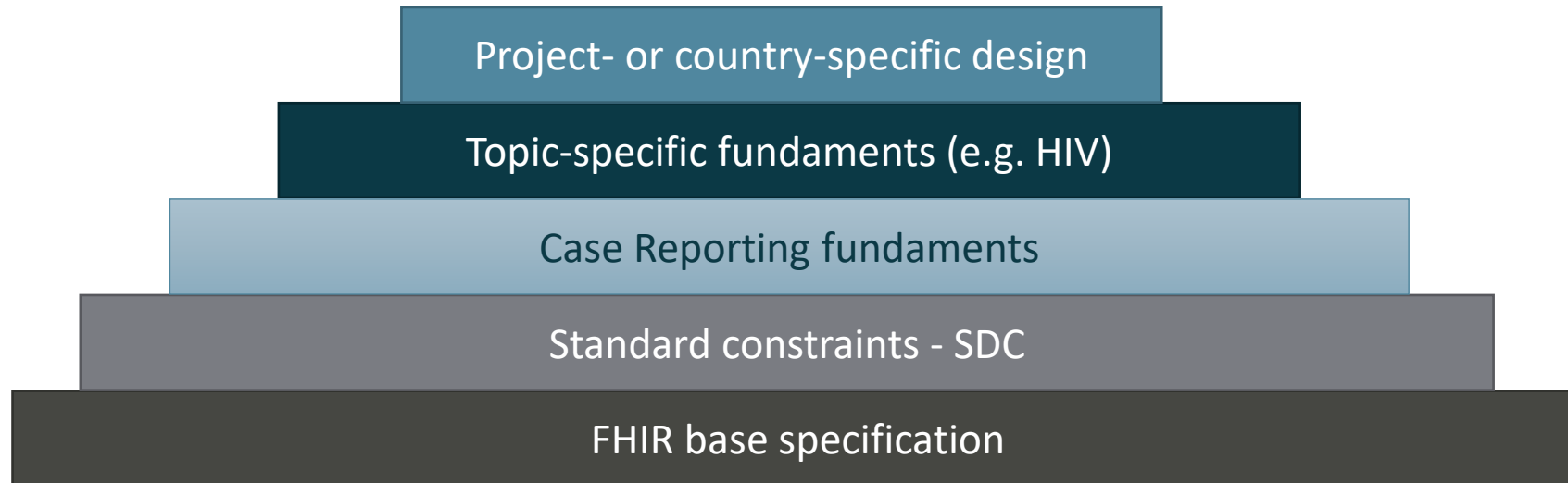


Tooling

- Implementation Guide
- LHCForms
- HAPI
- Matchbox

Layered FHIR specifications

- Different levels of specification
 - Look for already existing guidance...
 - ...or help build it
- A specification can add constraints and extensions to the specification it depends on



Q&A, ideas



Get in touch, be active

- Check with others (at chat.fhir.org or community.fhir.org)
- Create (or ask someone to create) a change request
- Join a FHIR® event like DevDays (devdays.com), discuss
- Join a FHIR® connectathon, test and provide feedback

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Demo and hands-on

- <https://lhcforms.nlm.nih.gov>
- <http://ui.hl7.beda.software>
- <http://smartqedit4.azurewebsites.net>