

Applying Standards to Real-World Healthcare Data

10/31/2019

Brian Carlsen

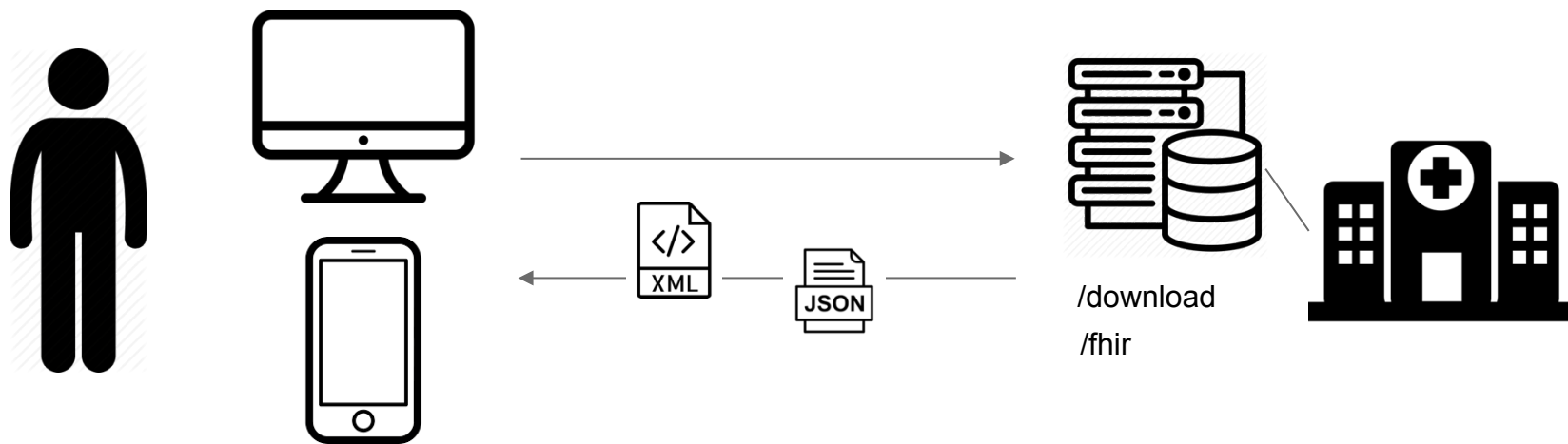
@wcinformatics

Starting Point/Perspective

- Data available to patients
- Outside context of direct treatment or care coordination
- For patients
- For sharing (patient's family and/or professional caregivers)
- For “computable” approaches to leveraging the patient's data

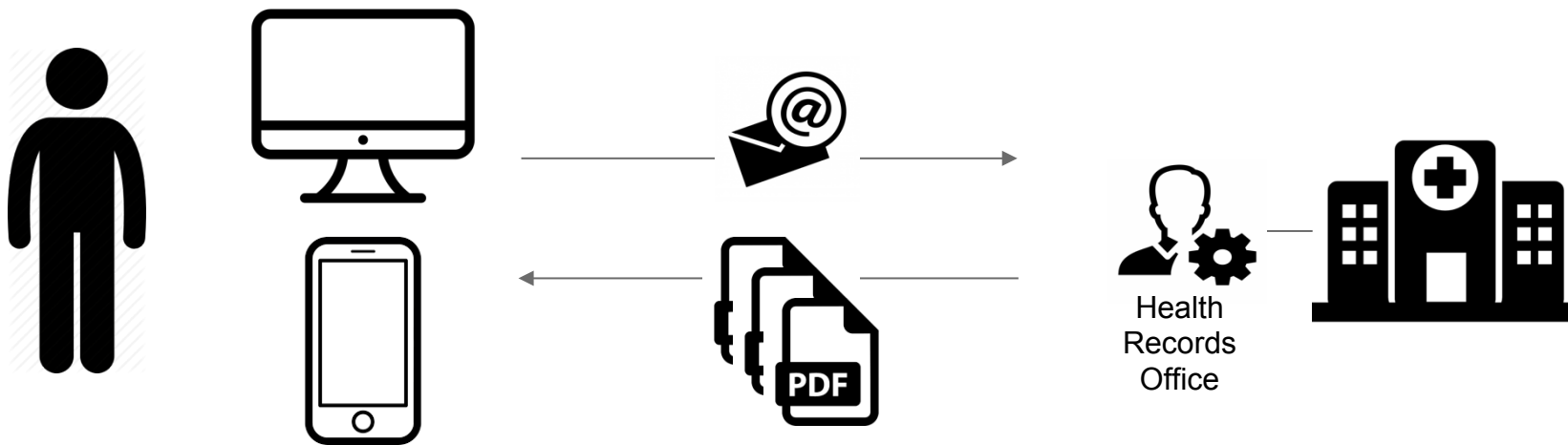
Patient Initiated Data Acquisition

- Download CCDA from patient portal
- Download FHIR JSON from portal endpoint



Patient Initiated Data Acquisition

- Old-style HIM (Health Information Management) department request



Some examples of what you get

application/pdf

Medications - as of this encounter

| Prescription | Sig. | Disp. | Start Date | End Date | Status |
|-----------------------------------|---|-------|------------|------------|--------|
| Warfarin (COUMADIN) 5 mg Oral Tab | Take orally as directed by Anticoagulation Clinic To refill by mail, call 10 days ahead. (888) 218-6245 | 100 | 11/09/2016 | 11/09/2018 | Active |

text/plain

Warfarin (COUMADIN) 5 mg Oral Tab

Take orally as directed by
Anticoagulation Clinic To refill by
mail, call 10 days ahead. (888) 218-6245

11/09/2016 Start

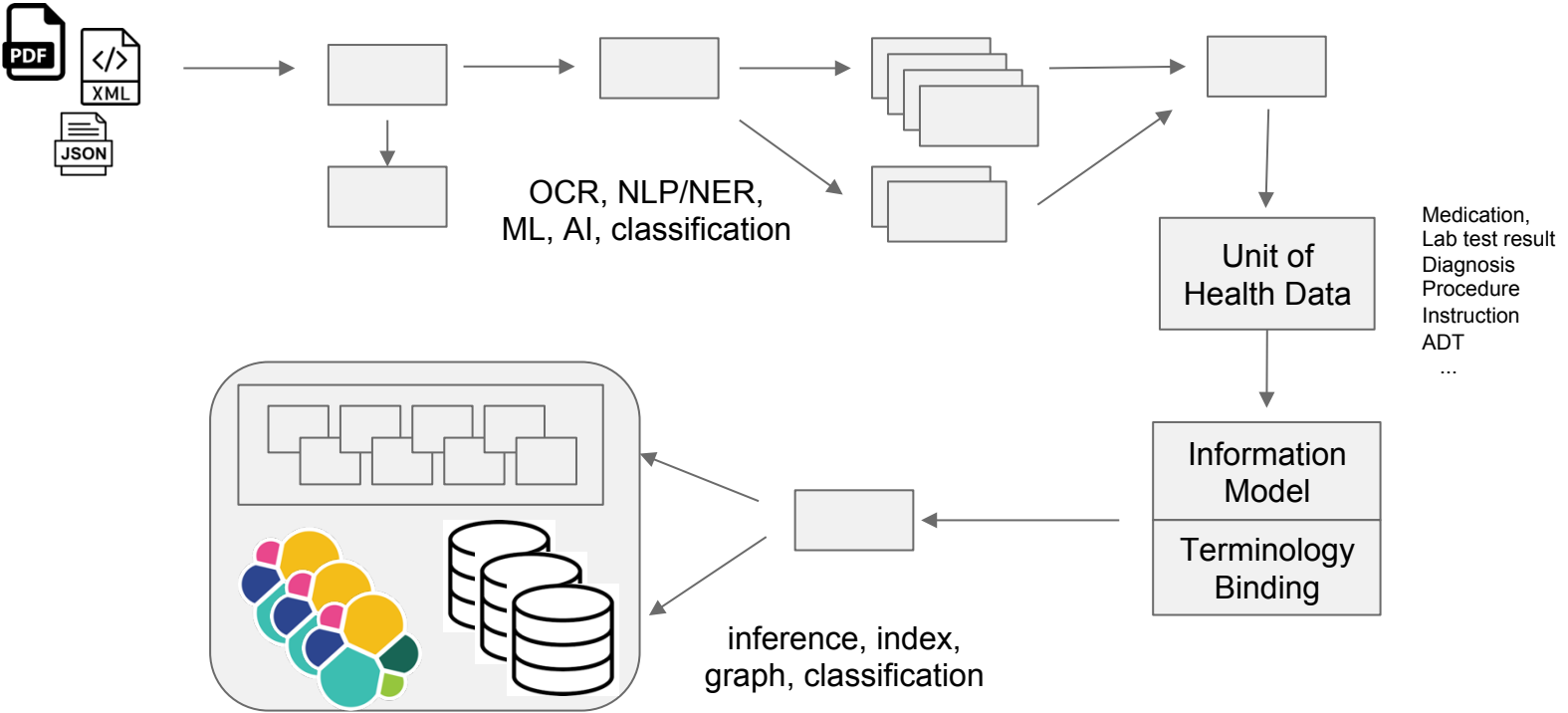
application/xml

```
<consumable typeCode="CSM">
  <manufacturedProduct classCode="MANU">
    <templateId root="2.16.840.1.113883.10.20.22.4.23"/>
    <templateId root="2.16.840.1.113883.10.20.22.4.23" extension="2014-06-09"/>
    <manufacturedMaterial>
      <code code="855332" codeSystem="2.16.840.1.113883.6.88"
        codeSystemName="RxNorm"
        displayName="Warfarin 5 Mg Oral Tab">
```

application/fhir+json

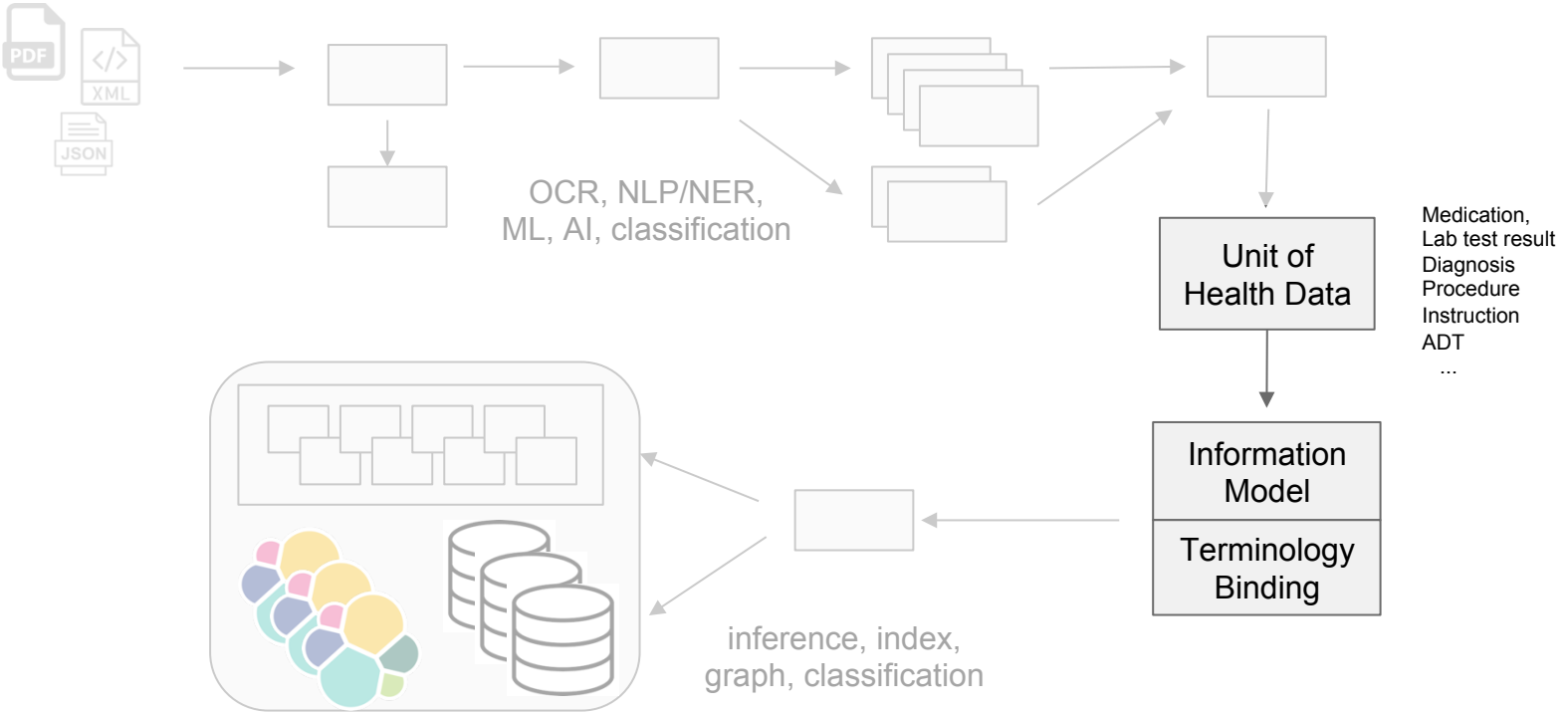
```
...
"code": {
  "coding": [
    {
      "system": "http://www.nlm.nih.gov/research/umls/rxnorm",
      "code": "855332",
      "display": "Warfarin 5 Mg Oral Tab",
      "userSelected": false
    }
  ]
},
"isBrand": false
...
```

Data Processing Pipeline



We've taken everything out of the health system and are trying to figure out what it says.

Data Processing Pipeline



We are not going to worry about the before or after, just what to do with the low level data points

Healthcare Data Points - Statements

- Consider the smallest units of information available for rendering into “statements”.
- Statements are *someone* saying *something* about *someone else* with dates, values, and context.
- Information models, like FHIR, can be used to model what kinds of things can be said.
- Terminologies, like SNOMED, can be used to bind semantics to shared (and standard) meanings.
- Important to take a strong stand on how to divide responsibility between the information model and SNOMED.

Terminology-to-Information-Model Binding

| Terminology Model | What, How, and Why | |
|--------------------------|--|---|
| +++ | Disease, Symptom, Sign, Procedure, Body structure, Morphology, Substance, Drug, Device, Organism | |
| ++ | Semantic constraints Refinement of concepts (e.g. severity, laterality) | |
| + | + | Clinical situations (context), Present/Absent/Uncertain, Family history, Past history, Requested/Planned/Done |
| ++ | Relationships between record entries Structural constraints on classes or attributes | |
| +++ | Dates, Times, Durations, Quantities, Text and markup, Instances of People, Organizations, and Places | |
| Structural Model | What, How, and Why | |

Consider this example...

application/pdf

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- *Kaiser (organization)* said *something* about *someone else* with dates, values, and context

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- *Kaiser (organization)* said *something* about *Brian Carlsen (Patient)* with dates, values, and context

Consider this example...

application/pdf

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- *Kaiser (organization)* said *Brian Carlsen (Patient)* is prescribed *Warfarin 5 mg Oral Tablets* starting 11/09/2016 and valid through 11/09/2018, with medication instruction “Take orally....”

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application/pdf

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- On 11/13/2018 *Kaiser (organization)* said *Brian Carlsen (Patient)* is *prescribed Warfarin 5 mg Oral Tablets* starting 11/09/2016 and valid through 11/09/2018, with medication instruction “Take orally....”

Choosing Information Models and Terminology

- FHIR is a default starting point for most projects these days
 - But you do have the DSTU2, STU3, R4 choice that needs to be made
- FHIR lets you say the same thing legitimately in a variety of different ways.
- FHIR has limitations on the kinds of things you can say
- FHIR “extensibility” mechanisms effectively negate its solution to syntactic interoperability when used
- SNOMED is a good point on terminology side.
- SNOMED requires post-coordination to effectively say certain things.
- SNOMED has a well-defined extensibility mechanism for content gaps
- Need to think about what kinds of questions you want to be able to ask of the data
- Need to think about other national standards (e.g. RXNORM, LOINC in US)

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Back to this example...

application/pdf

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- Implement as a FHIR “MedicationStatement” resource
- Choose **319735007 |Product containing precisely warfarin sodium 5 milligram/1 each conventional release oral tablet (clinical drug)|**
- Brand name not representable in SNOMED
- Dosing instruction can be captured, as can start/end dates and “status”
- As there is a “disp” column with a value of 100, could consider rendering as a “MedicationDispense” ->

Real World Data Sometimes Missing Information

application/pdf

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- If FHIR MedicationStatement, what would “category” be?
 - Inpatient, outpatient, community, patientspecified
- If FHIR MedicationStatement, what do we do with “Disp.” of 100?
- If using SNOMED, what do we do about “COUMADIN”?
- And frankly, what does it actually mean?
- And remember - this is a very simple example.

Expand SNOMED concept models?

- In theory, if SNOMED metamodel was “expanded” enough, it would be possible to represent the entirety of the semantics of a statement as SNOMED
- With concrete domains, it would be possible to have attributes link to the underlying dates.

```
< 319735007 |Product containing precisely warfarin sodium 5 milligram/1 each conventional  
      release oral tablet (clinical drug)| :  
12345 | Has assertion date (attribute)| = '11-nov-2018'  
12346 | Has start date (attribute)| = '09-nov-2016'  
12347 | Has end date (attribute)| = '09-nov-2018'  
12348 | Has clinical status (attribute)| = 55561003 |Active (qualifier value)|
```

- But ...

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Consider another example...

text/plain

The patient underwent a right thyroid lobectomy for a 6 mm papillary thyroid cancer.

- *someone* said *something* about *someone else* with dates, values, and context

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The patient underwent a right thyroid lobectomy for a 6 mm papillary thyroid cancer.

- *Healthcare Provider #1* said *something* about *“the patient”* with dates, values, and context

Consider another example...

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The patient underwent a right thyroid lobectomy for a 6 mm papillary thyroid cancer.

- *Healthcare Provider #1* said *“the patient”* underwent a right thyroid lobectomy *FOR papillary thyroid cancer INVOLVING a 6mm tumor* on a date specified elsewhere in the document.

Consider another example...

text/plain

The patient underwent a right thyroid lobectomy for a 6 mm papillary thyroid cancer.

- *Healthcare Provider #1* said *“the patient”* underwent a right thyroid lobectomy FOR papillary thyroid cancer INVOLVING a 6mm tumor on a date specified elsewhere in the document.
- There are really 3 things going on here
 - Procedure - **744855001 |Excision of right lobe of thyroid gland (procedure)|** with a procedure context of “performed”.
 - Condition - **363478007 |Malignant tumor of thyroid gland (disorder)|** with a morphology of **442172002 |Papillary neoplasm (morphologic abnormality)|**
 - Observation - **263605001 |Tumor size (observable entity)|** of 6mm

Consider another example...

text/plain

The patient underwent a right thyroid lobectomy for a 6 mm papillary thyroid cancer.

```
graph LR; A[6 mm] -- tumor size for --> B[papillary thyroid cancer]; C[right thyroid lobectomy] -- reason for procedure --> B;
```

- *Healthcare Provider #1* said *“the patient”* underwent a right thyroid lobectomy FOR papillary thyroid cancer INVOLVING a 6mm tumor on a date specified elsewhere in the document.
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Complicated interactions ...

text/plain

The patient has confirmed adenocarcinoma of the left breast.

- Suppose what we need to do is identify the diagnosis, tumor location, and histologic type for a statement like the one above.

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text/plain

The patient has confirmed **adenocarcinoma** of the **left breast**.

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- There are two aspects to get at the meaning, **adenocarcinoma** and **left breast**.

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text/plain

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- Suppose what we need to do is identify the diagnosis, tumor location, and histologic type for a statement like the one above.
- There are two aspects to get at the meaning, **adenocarcinoma** and **left breast**.
- Now suppose, we have a value set of cancer diagnoses that are abstracted to a higher level to capture, say the diagnoses discussed in NCCN guidelines.

Complicated interactions ...

text/plain

The patient has confirmed **adenocarcinoma** of the **left breast**.

- What we might wind up with is:
- Condition - **254837009 |Malignant neoplasm of breast (disorder)|**
- Observation (primary tumor site) - **80248007 |Left breast structure (body structure)|**
- Observation (histologic type) - **35917007 |Adenocarcinoma, no subtype (morphologic abnormality)|**

Complicated interactions ...

text/plain

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- What we might wind up with is:
- Condition - **254837009 |Malignant neoplasm of breast (disorder)|**
- Observation (primary tumor site) - **80248007 |Left breast structure (body structure)|**
- Observation (histologic type) - **35917007 |Adenocarcinoma, no subtype (morphologic abnormality)|**
- NOTE: the finding site and morphology of the condition are less specific than the observations about primary tumor site and histologic type.

Complicated interactions... solve with postcoordination

We could use post-coordination to express this

```
<<< 254837009 |Malignant neoplasm of breast (disorder)| :  
    { 363698007 |Finding site (attribute)| =  
        80248007 |Left breast structure (body structure)|,  
    116676008 |Associated morphology (attribute)| =  
        35917007 |Adenocarcinoma, no subtype (morphologic abnormality)| }
```

Complicated interactions... solve with postcoordination

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<<< 254837009 |Malignant neoplasm of breast (disorder)| :  
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```

But... post-coordination is complicated, and requires use of classification in a deployment. This can be challenging for a lot of reasons.

Complicated interactions... solve with data model

Another approach is to use a data model to capture the individual aspects in a data model:

```
{ "resourceType": "Condition",  
  "code": {"coding": [ {"code": "254837009", "name": "Malignant neoplasm of breast"..} ]},  
  "bodySite": {"coding": [ {"code": "80248007", "name": "Left breast structure"..} ]}...}  
{ "resourceType": "Observation",  
  "code": {"coding": [ {"code": "371441004", "name": "Histologic type"..} ]},  
  "valueCodeableConcept": {"coding": [ {"code": "35917007",  
"name": "Adenocarcinoma"..} ]}...}
```

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```
{ "resourceType": "Condition",  
  "code": {"coding": [ {"code": "254837009", "name": "Malignant neoplasm of breast"..} ]},  
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{ "resourceType": "Observation",  
  "code": {"coding": [ {"code": "371441004", "name": "Histologic type"..} ]},  
  "valueCodeableConcept": {"coding": [ {"code": "35917007",  
"name": "Adenocarcinoma"..} ]}...}
```

Here it is easy to say and share what you want to.

And still support post-coordination when it is possible to do so.

Other things to consider

- SNOMED extensions - there are legitimate gaps in SNOMED (e.g. genomics)
- SNOMED post-coordinated expressions to combine or properly specify
- Inferencing
 - e.g. Understanding that a statement like “underwent a right thyroid lobectomy for a 6 mm papillary thyroid cancer” implies a prior diagnosis of “papillary thyroid cancer”
 - E.g. Taking an observation result and turning it into a clinical finding (e.g. elevated TSH)
- SNOMED context model
 - Subject relationship context (for personal vs family history)
 - Temporal context (for past, present, future)
 - Finding context (for assertion status)
 - Action context (for refused, performed, scheduled, etc)
- Recognizing info models that are a lot like others: an “allergy” is kind of like a “condition” and kind of like a “medication”

Still other things to consider

- When gathering data from variety of sources, the same “treatment” should be given to all of it
 - Including structured data (e.g. possibly rewriting FHIR resources to clean up semantics)
 - Including unstructured data (e.g. saying what you can where you can)
- When sharing data to a variety of different sources (and for different use cases)
 - Important to take a strong stand on where the responsibility for “semantics” lies
 - May actually be favorable to keep a tightly-bound internal model that can be “transformed” to FHIR, OHDSI, or other information models.
- Favoring precision vs. recall is use-case driven
 - Best approach is to capture everything, but understand overall quality of that capture to drive different use cases
- Quality vs. Confidence

Conclusions and Questions

?