Project Athena-INSPIRE: Lessons from the Bleeding Edge of Interoperability

Michael Hogarth, MD
Professor of Medicine
UC Davis Health System

athena
BREAST HEALTH NETWORK

A UNIVERSITY OF
CALIFORNIA PROGRAM

Poor Coordination of Care Is a Real Issue

Percent U.S. adults reported in past two years:

Your specialist did not receive basic medical information from your primary care doctor

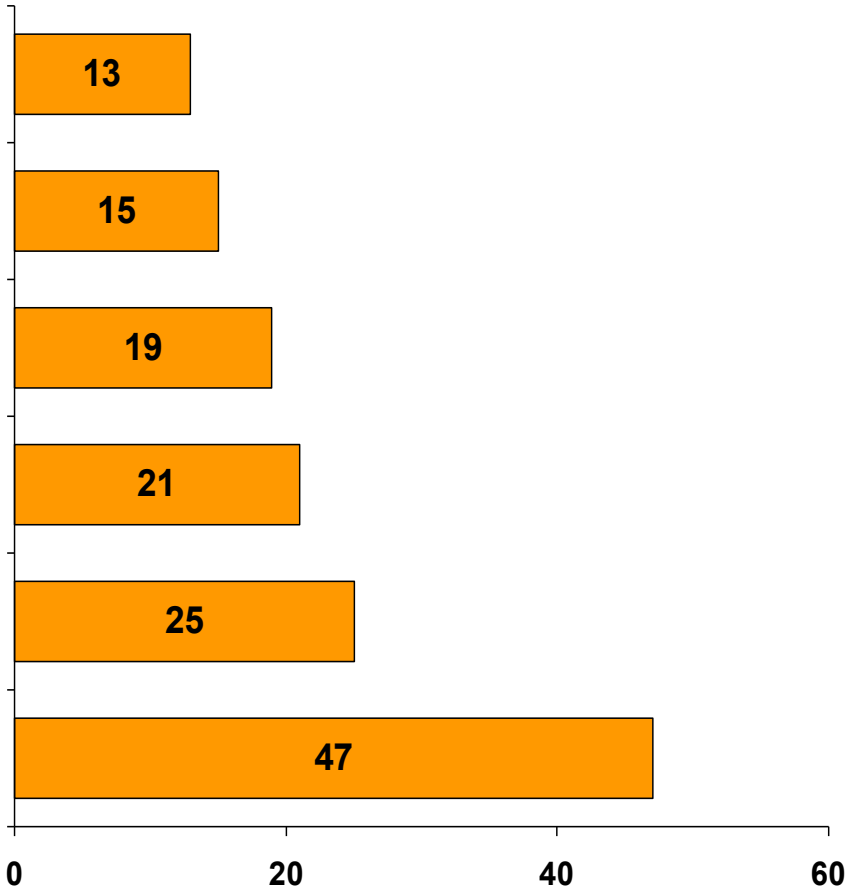
Your primary care doctor did not receive a report back from a specialist

Test results/medical records were not available at the time of appointment

Doctors failed to provide important medical information to other doctors or nurses you think should have it

No one contacted you about test results, or you had to call repeatedly to get results

Any of the above



athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

MacColl Institute for Healthcare Innovation

Commonwealth Fund Survey of Public Views of the U.S. Health Care System, 2008

Some Consequences of poor coordination

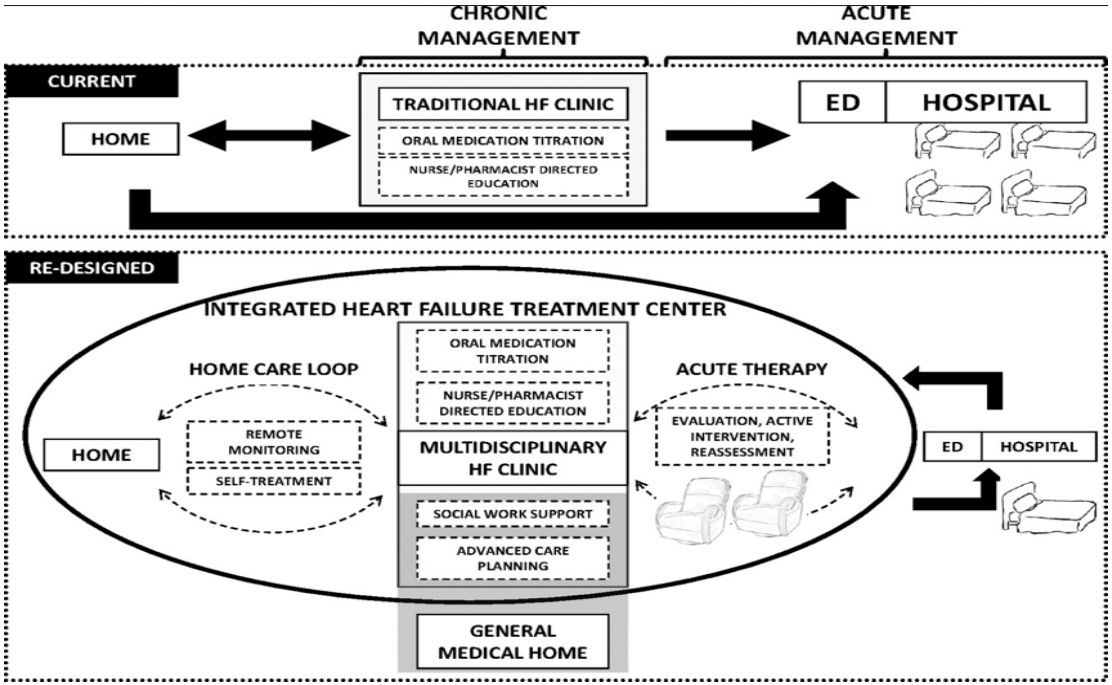
- 2004 Study of 11,855,702 Medicare beneficiaries discharges from hospital
  - 19.6% re-hospitalized within 30 days
  - 34% re-hospitalized within 90 days
  - Estimated only 10% of re-hospitalizations were planned
  - Cost of unplanned re-hospitalizations in the US = **$17.4B**
- "Many hospital readmissions can be avoided with timely follow-up and **care coordination**"

A reason for data exchange in healthcare!!!!

athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

CHF and coordination of care

- 1 million CHF admissions among Medicare beneficiaries
- $17B annual cost
- Discharge followed by re-admission in 24% of cases
- Re-admission rates vary widely across hospitals (10%-50%)
- 75% of early readmissions are preventable



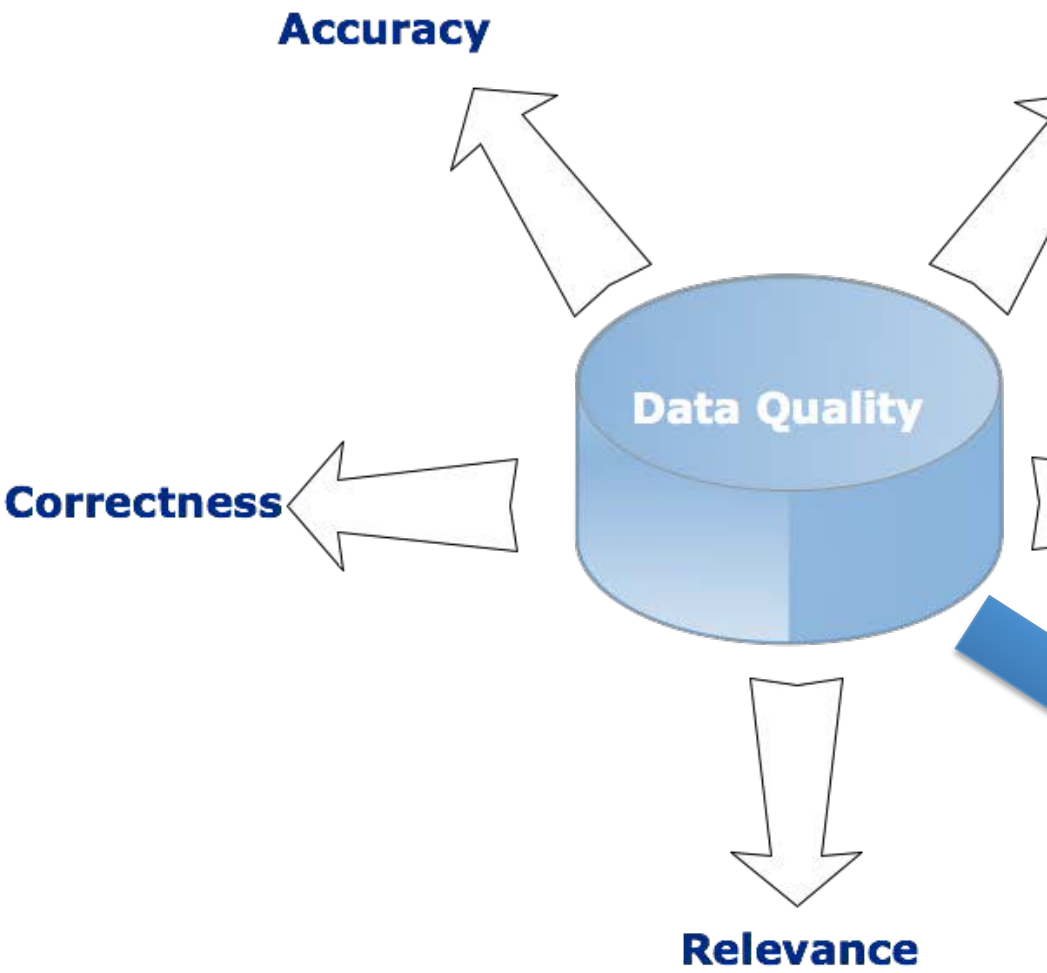
athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

Another Challenge – Data "Quality" and Computable Data

"I am able to exchange data, but how do I know the data is correct and is it computable or re-usable?"

athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

Data Quality -- in Healthcare



Key clinical data is available when it is needed!

Does the data you need even *exists* in the EHR??

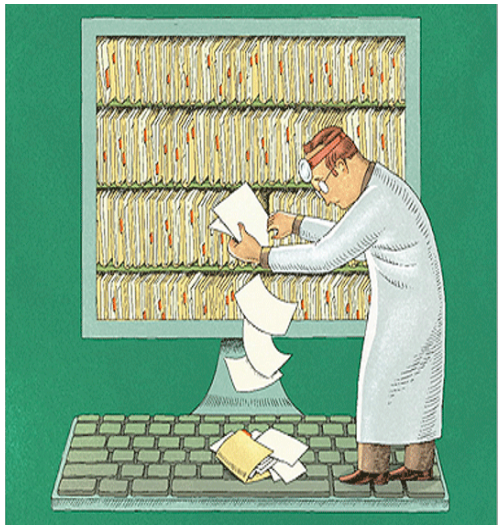
Computability

① Is relevant data structured? (computable)

② Is it semantically "rich" and complete enough to be re-usable for drive CDSS, population analytics, QI, etc..

athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

EHR 1.0 (today) --- we have successfully "computerized" the narrative text paradigm of paper charts...



1907 – ~today

EHR 1.0 (today)

EHR "data quality"…
…. its not all you think it is

- A substantial number of key data elements are buried in narrative text passages
  - NLP performance isn't bad, but it NLP isn't "magical"
  - NLP perpetuates the acceptability of continued "text blob notes"
- EHR clinical notes are often created with 'cut and paste':
  - incorrect information/diagnoses are propagated
  - not clear if the author really is reflecting on the "today events"
  - leads to poor "information findability
    - often auto-inserted data contributes to poor readability for no practical reason…
- FYI -- 90% of EHR using physicians admitted to copying, 80% planned to continue

(1) Thornton, et al. Society of Critical Care Medicine. Feb 2013;41(2):382-388
(2) Hammond, et al. AMIA Proceedings. 2003. pages 269-273

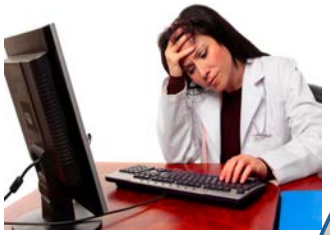
The irony of EHRs and physician productivity

Survey of 9 practices

"**46min** of free time lost per clinic day per physician"

Survey of 410 Internists

"**42min** of free time lost per clinic day per physician"



information finding takes time because notes are bloated and "new" or "key" data is hard to find...

I don't have time, so I will cut & paste...

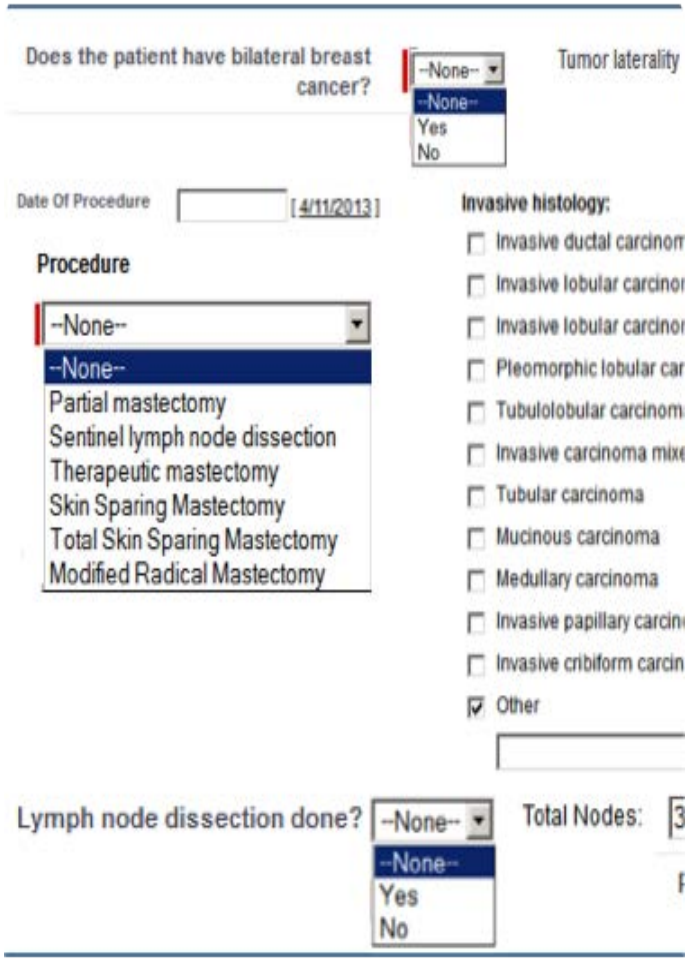
(1) http://www.redwoodmednet.org/projects/events/20130725/rwmn_20130725_mcdonald_v2.pdf
(2) McDonald, McDonald. Arch Intern Med. 2012. Feb 13;172(3):285-7

EHR "Data Quality" – where are we today? (c.2014)

athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

Might we expend effort on capturing high quality data instead of perfecting garbage…

High data quality starts with good data capture



Project INSPIRE (2013)

***IN**teroperability to **S**upport **P**ractice **I**mprovement, Disease **RE**gistries, and Care Coordination (INSPIRE)*

"Improve **acquisition** and **exchange** of patient data in high impact conditions in order to support longitudinal disease registries, care coordination, and practice improvement"

athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

The Athena Network

Athena
- - 5 UC med centers + Sanford
- - 150,000 women over 10 years

Athena Cohorts:
- - Screening and Prevention
- - Diagnosis and Treatment
- - Survivorship

Participants:
- - 150,000 women (50K so far)
- - 200 providers
  - pathologists, radiologists, primary care providers, oncologists, surgeons, radiation oncologists.

Athena's Goals

① Drive the rapid translation of new discoveries and methods into the clinical care process -- accelerate the "knowledge turns" in medicine (currently ~15-20yrs)

② Establish a learning healthcare network to develop new methods and improve outcomes

athena
BREAST HEALTH NETWORK
A UNIVERSITY OF CALIFORNIA PROG

Why is Athena interested in data quality and interoperability?

Ideal Data Source	
Patient Reported data	**Provider verified data** (checklist)
Intake symptoms: *Risk factors, lifestyle, QOL*	Clinical stage
Acute Treatment-related symptoms: *toxicity triggered by interventions, QOL*	Treatment Plan Surgical stage
Chronic phase/ Follow-up: *recurrence symptoms, toxicity, QOL*	Systemic Treatment Treatment Summary

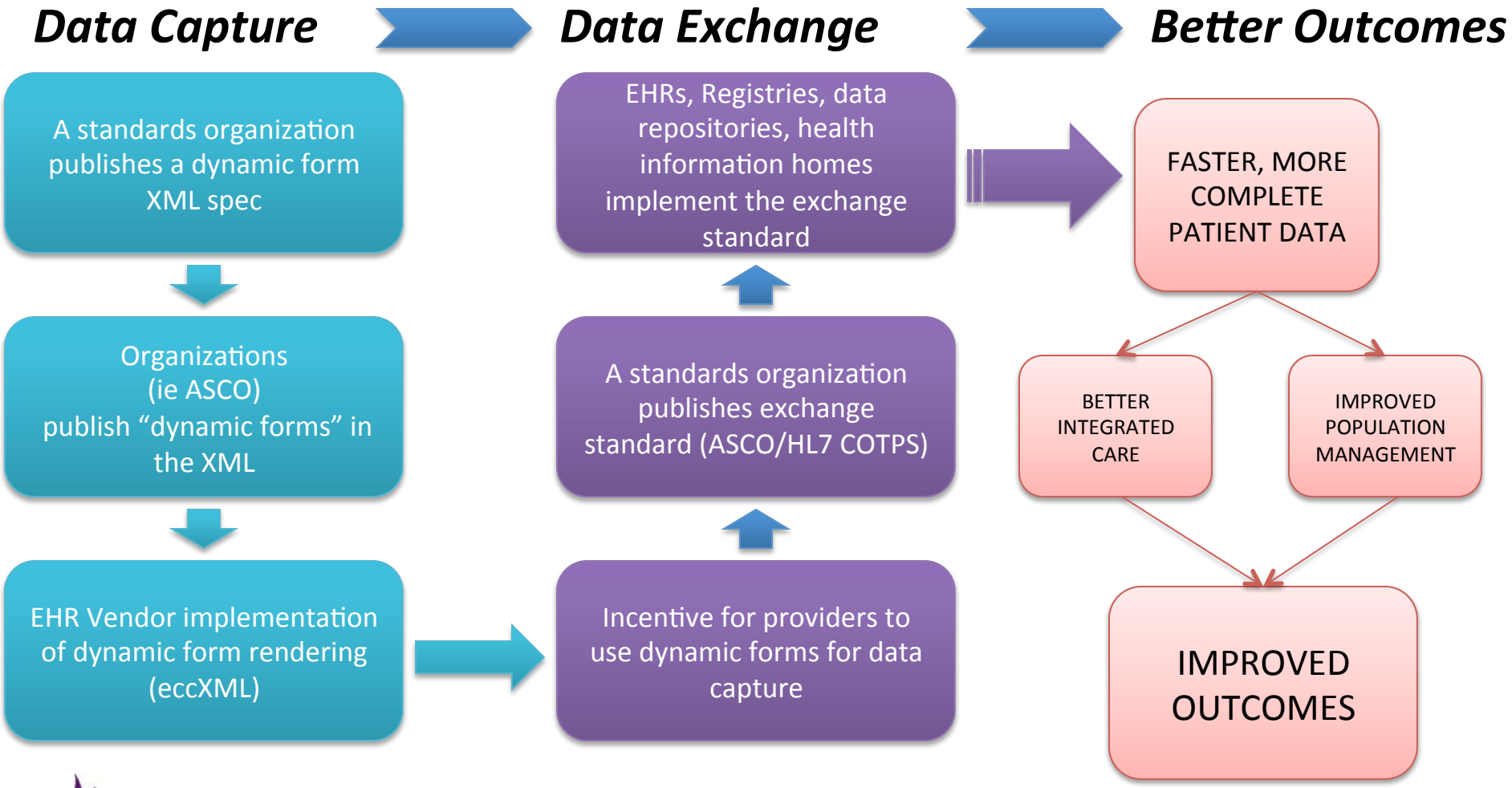
Athena ePRO

Services/Processes

① Automated risk assessment
② Quality Improvement
③ Registry reporting
④ Clinical Research
⑤ Trial Matching and
⑥ registration
⑦ Internal Registries
⑧ Outcomes Tracking
⑨ Automated services
⑩ Patient engagement with social networks

- *Genetic counseling*
- *Peer support*
- *Smoking cessation*
- *Social work*
- *Psycho-Oncology*
- *Life training*

Athena-INSPIRE



athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

Our Approach

①*Start from the clinical process*

- map the workflow (process mapping)
- data element selection is primarily governed by its role in care coordination and clinical registries for quality improvement

②*Be "pragmatic" – use prevailing specifications, be vendor agnostic, leverage professional societies, be vendor-friendly in implementation approach*

- Leverage modern, broadly used, technology (ie, XML)
- Leverage existing "in-use" standards (ie, CCD)
- Leverage work by professional societies (ie, ASCO, CAP)

Work To Date and Observations

Project INSPIRE
The Cancer Data Workflow Study

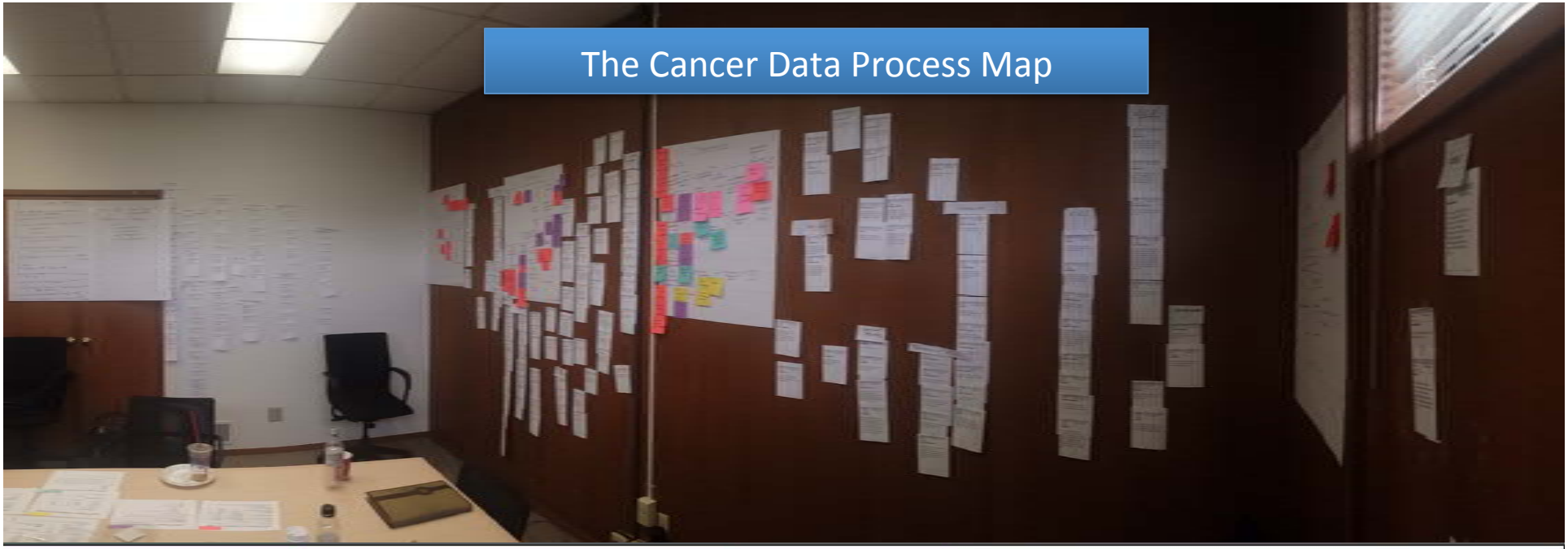
- Studied four UC medical centers with EHRs
  - Data
    - 40 interviews
    - 12 unique roles/ perspectives
    - 120hrs+ observation
  - 4 sites - Irvine, San Diego, Davis, San Francisco

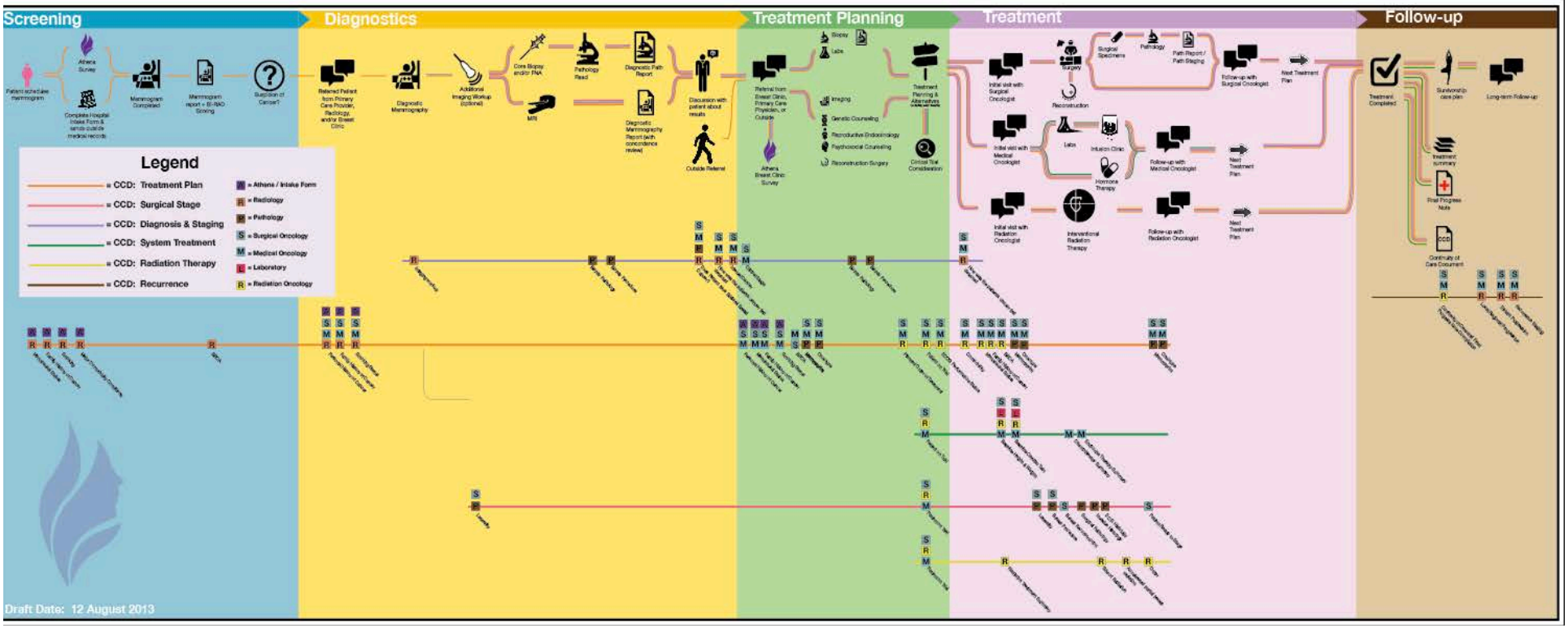
Site	Athena Coordinator	California Cancer Registry	Information Services	Infusion Clinic	Medical Oncology	MOSC	Pathology	Primary Care Provider	Radiation Oncology	Radiology	Registry	Surgical Oncology
CA Cancer Registry		1										
UC Davis	1				2	1	1		1	1	1	
UC Irvine			2		1		1	1	1	1	1	1
UCSD					5		1			3	2	2
UCSF				1	3		1		1	1	2	2

- Output
  - Compilation of “data pain points”
  - Creation of high-level process map

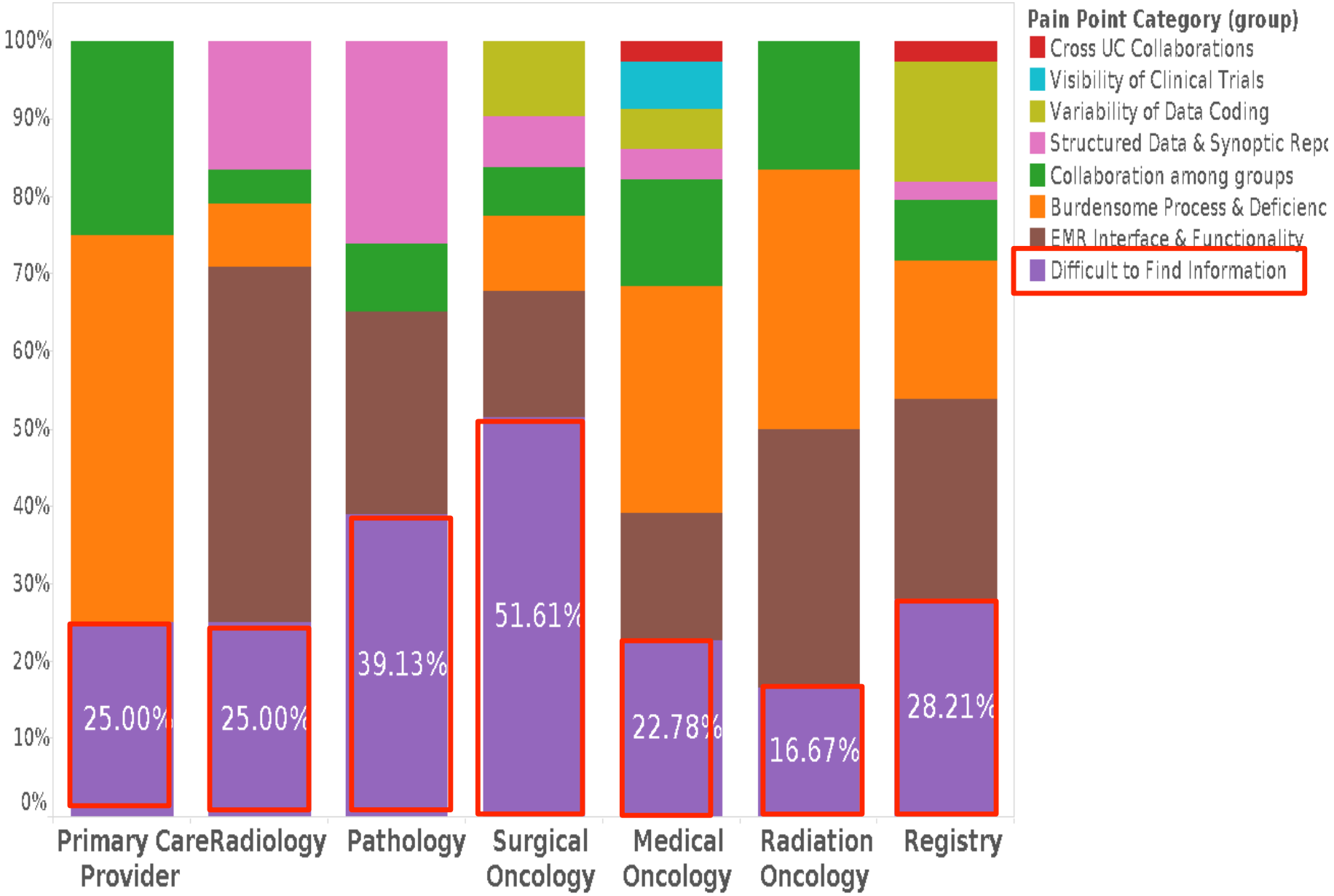
athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

The Cancer Data Process Map





Summary of “Data Pain Point” Analysis



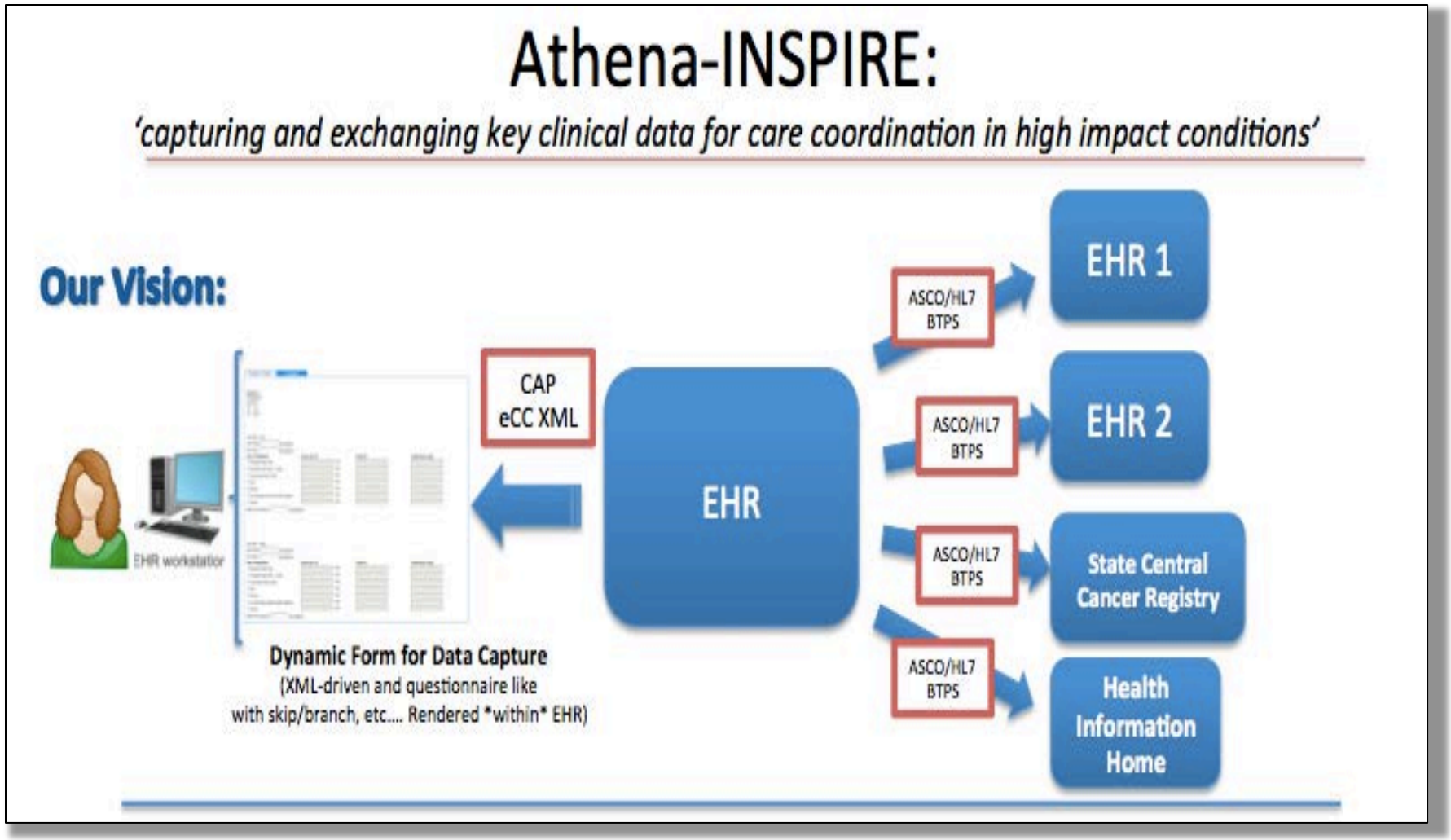
Athena-INSPIRE Data Capture Project

Develop a core list of
key data elements for clinical care of breast cancer patients

Experiment with dynamic data entry forms ("electronic checklists") for capture/assembly of core data elements

Experiment with specifications that possibly can transport a "cancer case summary" (ASCO/HL-7 COTPS CDA)

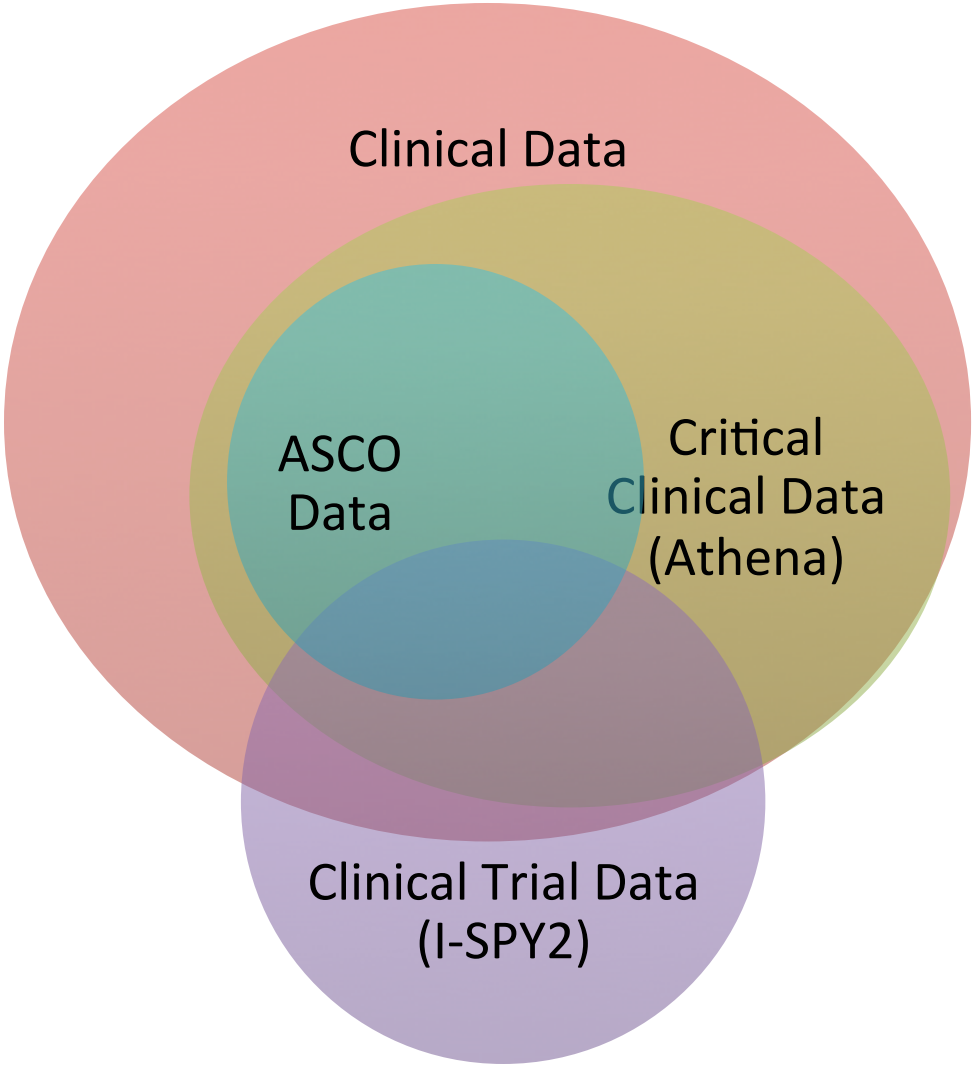
Athena-INSPIRE Data Capture Vision



BTPS = ASCO's Breast Cancer Adjuvant Treatment Plan and Summary (Breast TPS)

Developing Breast Cancer Core Clinical Data Element List

- Athena – INSPIRE Core Data
  - Assembled from Athena data elements, I-SPY2, UCSF Breast Cancer Center
    - vetted by over 50 clinicians across the UC Medical System for clinical and research importance
  - Re-vetted by 50 clinicians for functionality, adoption and workflow
- Compared against Other Data Element Lists
  - ASCO, CAP, Cancer Registry (NAACR), NCI CTEP Common Data Elements (for Clinical Trials)



athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

The Athena breast cancer "key" data elements

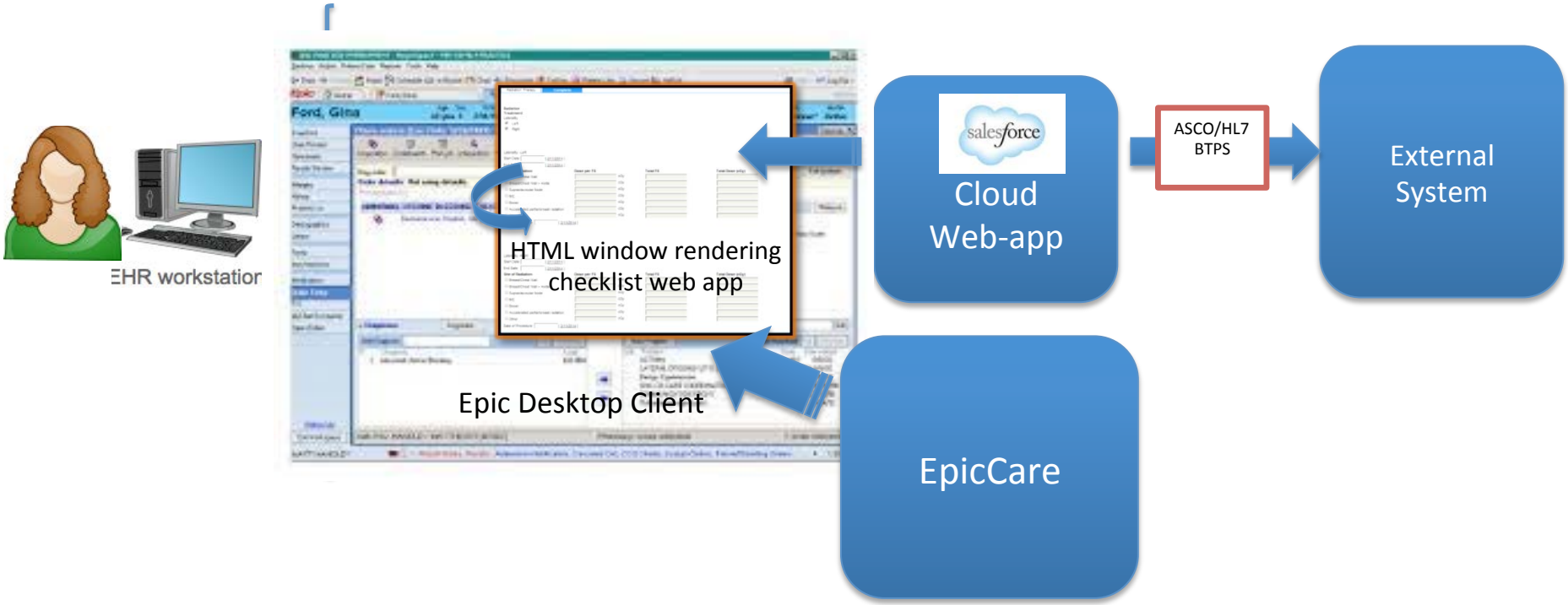
- Group of ~50 Athena participants developed list of key data elements
  - pathologists
  - breast surgeons
  - oncologists
  - radiologists
  - radiation oncologists
  - nurses
  - cancer registrar

- ~ 80 key data elements for care of breast cancer patients

No	Field Name	no sect.	header	social	problem	proc	result	meds	plan	vital	family	encount	function
1	Patient First Name		1										
2	Patient Last Name		1										
3	Patient Middle Name		1										
4	Patient Name's Suffix		1										
5	Patient Date of birth		1										
6	Patient medical record number		1										
7	Institution		1										
8	Date of diagnosis	1											
9	Race		1										
10	Ethnicity		1										
11	Smoking history			1									
12	Primary Type of Tobacco			1									
13	Family history of breast cancer										1		
14	Referred for Genetic Counselling								1				
15	Menopausal status				1								
16	Interested in fertility preservation								1				
17	Last menstrual period				1								
18	Major comorbid conditions				1								
19	ECOG Performance Score												1
20	Method of detection				1								
21	Was cancer detected between screening intervals?				1								
22	Multifocal disease				1								
23	Imaging work-up					1							
24	BIRADS Density						1						
25	Lesion Visible, Mammogram						1						
26	Lesion Index						1						

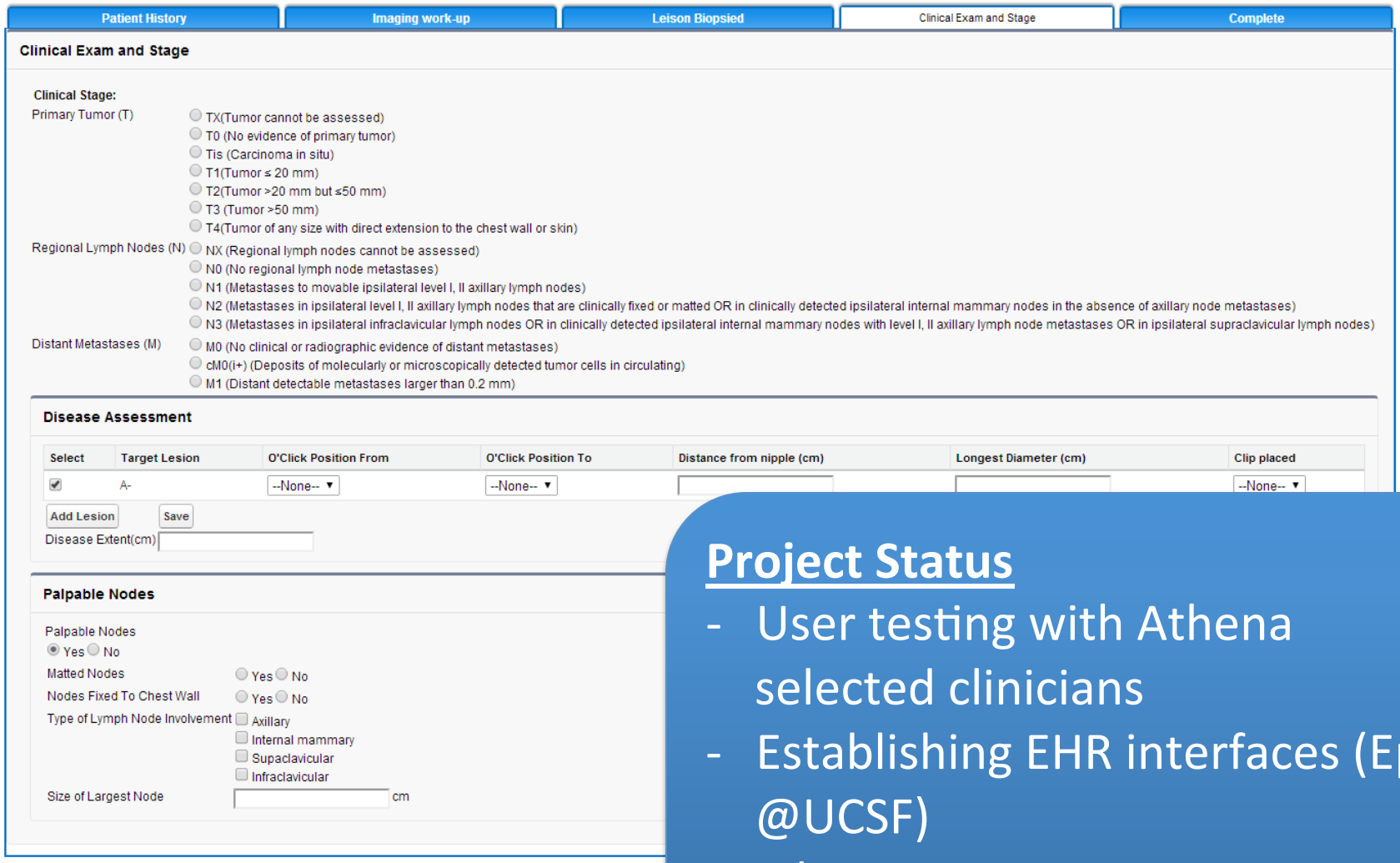
Athena-INSPIRE Pilot (today)

Athena "Checklist" Data Capture Project (UCSF):



athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

The Athena-INSPIRE "electronic checklist" data capture tool – built as Force.com web application



Project Status

- User testing with Athena selected clinicians
- Establishing EHR interfaces (Epic @UCSF)
- Pilot in UCSF Breast Center Q4 2014

athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

The COTPS Mapping – Critical Issue

- Task: Map Athena checklist data elements to the CDA (ASCO-HL7 COTPS)
- Some Lessons we learned:
  - Athena checklist elements more comprehensive than the COTPS
  - Athena workflow has data captured in real-time to facilitate care coordination – COTPS was for "summary" at end (temporal awareness).
  - The Athena checklist was at a finer level of detail than is specified in the COTPS specification.
  - Related observations were common -- but COTPS (CDA) did not have an unambiguous way of relating them
    - EXAMPLE: Imaging procedure (clip placement and measurement of lesion "A") related to the histology of lesion "A" (two related observations) This additional 'relationship' information needs to be resolved in order to design a 'semantically interoperable' representation to use in the COTPS CDA document.
  - Repetitive elements – multiple lesions, each with these related "observations" – difficult to map in COTPS, which assumed one lesion.
    - "patient centered information model" vs. "lesion centered information model"

Observations and Lessons from the "Bleeding Edge" of Interoperability

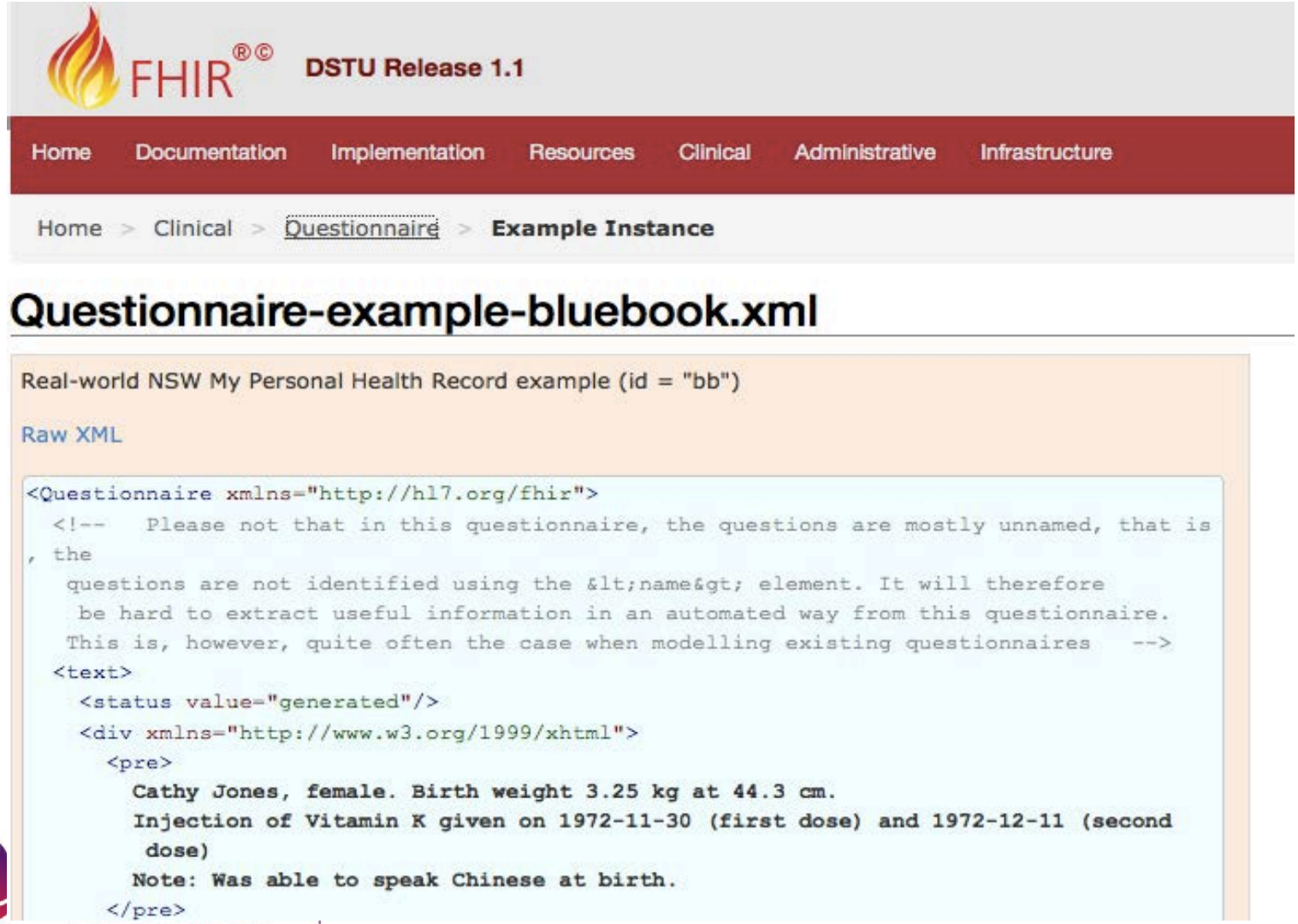
athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

Some “gold nuggets” we discovered RFD, SDC, CAP eCC XML

- IHE Remote Form for Data Capture (RFD)
- College of American Pathologist “electronic checklist XML”
  - XML specification for ‘dynamic forms’ (question driven data capture/ forms... Questionnaires!)
- S&I Framework Structured Data Capture (SDC)

athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

FHIR Questionnaire XML



The Importance of Data Exchange and Interoperability

- Care coordination is a key factor in *quality of* care (reduction in cost, improves outcome)
  - Proven to improve outcome (good care coordination reduced re-admissions and mortality in CHF – 1995!)
- Unless the entire US healthcare system is to become Epic users, data exchange is required for effective care coordination!

The Importance of Data Capture

- Data exchange depends on good data to achieve its goals
  - garbage in = garbage out
- Data Capture directly impacts data quality (and re-usability)
- Data Capture is a very complex issue
  - E.g.: how do I improve physician documentation productivity yet also increase the computability (structured nature) of the data?
  - E.g: how do we standardize key *required* clinical data for specialty specific decision making but keep it vendor neutral and **vendor friendly** (simple and cheap to implement)?

The Importance of Specifications – and guidance on use

- CDA (and HL-7 v3 RIM) patient data is largely centered around "observations" -- but how do map checklist "questions" and "answers" (data) to HL-7 "observations" about a patient?
  - Mapping of system data to HL-7 "observations" for exchange is not trivial and can be time-consuming as well as error-prone
- Exchange specifications need to support the workflow
  - Since the breast cancer care process happens over time, the COTPS would be sent multiple times to external systems -- but the specification does not have the notion of a "disease lifecycle state" – was intended to be sent/stored at the "end of treatment" (when is that? – surgery, radiation, chemo, all of it?)

The Importance of Terminology

- Some of the key clinical data elements could not be coded due to lack of content in prevailing, comprehensive, well-maintained terminological systems (ie, SNOMED, LOINC)
  - Content depth/breadth in terminological systems is the result of history, opportune collaborations, and contributor subject matter expertise
  - Ideally, professional societies (ie, ASCO) authoring "key clinical care data element list" would work with terminology authoring entities to make sure the elements are "codeable" – and there is guidance on use (ie, akin to TermInfo)

The Importance of Intent

- COTPS and INSPIRE have different intended purposes:
  - INSPIRE: support care coordination with point of care data capture by clinicians of comprehensive list of mission critical data elements
  - COTPS: basic set of patient oncology-related health status and treatment plan information; it is a summary of plan and treatment received at the time the document was created. It is not intended contain detailed specialty-specific information (e.g., exact radiation treatment dosages) *(adapted from COTPS Introduction section 1.7)*

The Importance of real world implementations of Specifications

- "Release early, release often" – must have real world experiences to make the specification usable
  - A pillar of open source and its success
  - Must know if the specification can support the achievement of the workflow's goal in the real-world!
  - Many IHE profiles have been "demonstrated in connectathons" – good first step, but does not demonstrate/prove specification accomplishes the *goal*

The Importance of Keeping it Simple

- CDA is not simple...
- HL-7 v3 RIM is not simple...
- "Burping" all data onto clinicians is not effective --- key data elements at key points of the care process

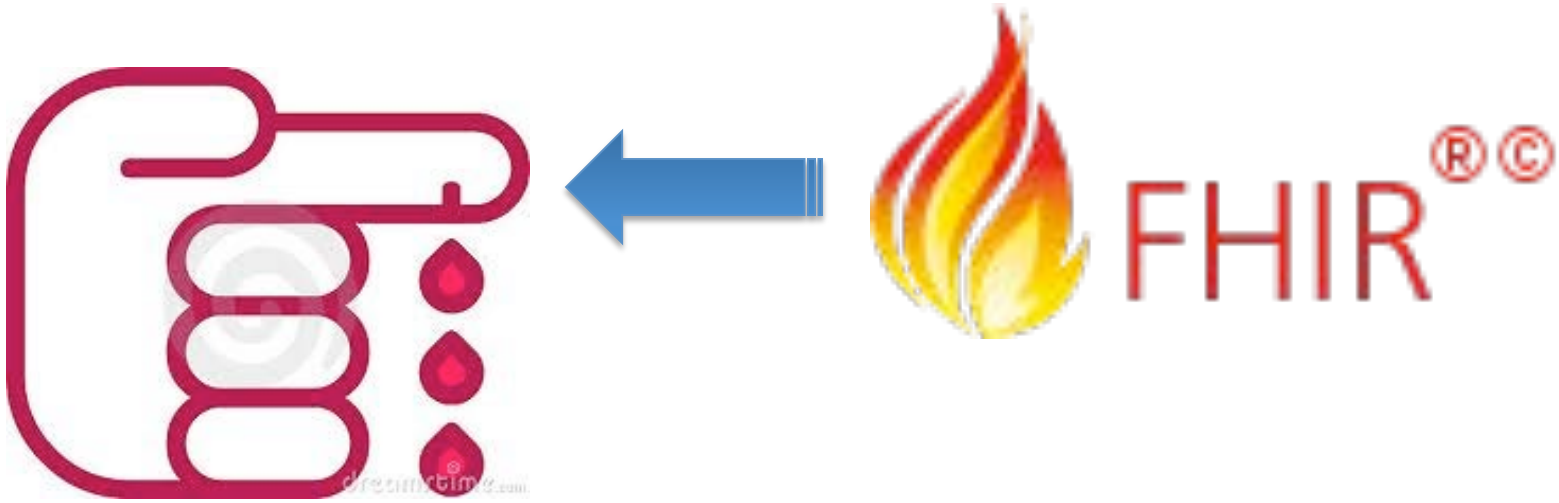
- "effective data delivery" often means "concise context-aware data delivery" (right data at the right time)
  - requires more effort from designers than simply moving large chunks of data...

athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

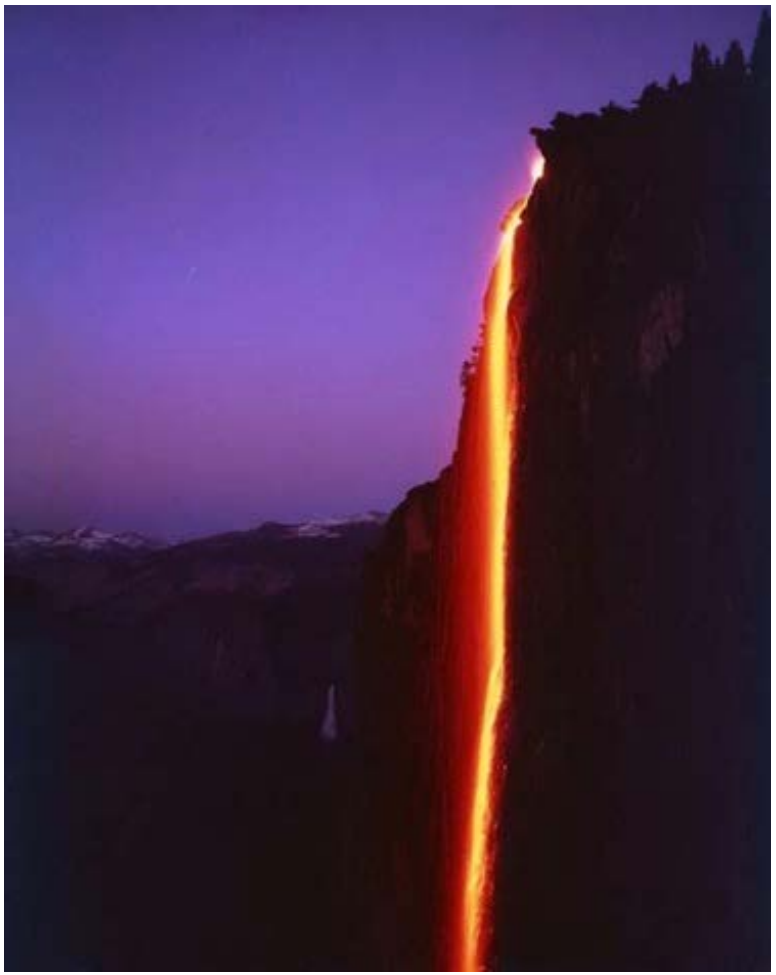
The Road Ahead
- beware of apperances-

athena BREAST HEALTH NETWORK | A UNIVERSITY OF CALIFORNIA PROGRAM

?Will Fire Help the Bleeding?



Questions?



Yosemite Fireball