

# Next Generation Registries: Project INSPIRE

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# Blue Sky and Registries



We were asked to speak about “blue sky” ideas...

## **Next Generation Registries**

- ▶ when EHR adoption is broad based (>70%)
- ▶ how should/could we provision data for registries?

# Registries Today

...anything but a blue sky...



- ▶ case ascertainment can take 24-36 months
- ▶ data is manually abstracted even from 'EHRs' today
- ▶ data is often incomplete
- ▶ assembling data includes identification of duplicates and linking same patient across multiple institutions that have 'reported'
- ▶ cost is substantial -- hundreds of millions across institutions, public health registries, providers, etc..

# Are Registries Of Value?



## Surveillance

- ▶ monitoring population health

## Measuring Quality of Care

- ▶ monitoring delivery of care

## Clinical Research

- ▶ understanding disease
- ▶ improving dx/rx

# Can registries help improve care?



- ▶ Significant amount of care in is ‘fragmented’ across multiple providers -- this is particularly true for complex conditions (ie, cancer)
- ▶ A complete ‘view’ of the patient’s record requires assembling all the ‘slices’ from the providers
- ▶ If “registry” data is high quality, complete, and timely, it should improve care coordination

# Project INSPIRE



*INteroperability to Support Practice Improvement, Disease **RE**gistries, and Care Coordination (INSPIRE)*

“Improve the acquisition and exchange of patient data in high impact conditions to support longitudinal disease registries, care coordination, and practice improvement”

# INSPIRE Initiatives

## Data Capture and Exchange for Next Generation Registries

- develop and demonstrate point-of-care data structured data process that supports clinical care and next generation registries
- develop and demonstrate the use of disease-focused data exchange (“cancer focused CCD = caCCD”) to support care and registries

## Health Information Home

- **“pre-registry”** -- common repository for longitudinal information on the patient
- a **patient-centered view** (360 degree view of their record)
- contributed and consumed by community **providers**

# Our Overall Approach

- ▶ Whatever you do, make it simple, has to work today, make it repeatable across diseases/vendors/organizations
- ▶ Invent little, borrow (leverage) as much as you can...
- ▶ Have an immediate 'starting' point that is clinically relevant and have a 'roadmap' to the future
- ▶ Start by focusing on a single "high impact" disease
- ▶ Partner with a community that is focused on that disease \*and\* willing to undertake 'culture change'
- ▶ Partner with standards organizations \*and\* policy makers to broaden what we develop
- ▶ **\*\*Share,share,share\*\*** --> Show vendors and others what we are doing



# It all starts with good data capture...



Does the patient have bilateral breast cancer?  Tumor laterality

Date Of Procedure  [ 4/11/2013 ]


**Procedure**

- Invasive ductal carcinoma
- Invasive lobular carcinoma
- Invasive lobular carcinoma
- Pleomorphic lobular carcinoma
- Tubulolobular carcinoma
- Invasive carcinoma mixed
- Tubular carcinoma
- Mucinous carcinoma
- Medullary carcinoma
- Invasive papillary carcinoma
- Invasive cribriform carcinoma
- Other


Lymph node dissection done?  Total Nodes:

# Our approach to data capture

Ask providers to enter structured data  
for key data elements only



Providers fill out “electronic  
forms” (templates) at key points of care



Data is is used for structured sharing/  
exchange  
(caCCD, CAP eCC, CDC-CDA)

# Borrow good ideas...



Informatics Solutions for  
Rapidly-Changing Data Sets -  
Patient Care & Cancer Registries



IHE IT Infrastructure  
Technical Framework Supplement

Retrieve Form for Data Capture  
(RFD)

Trial Implementation

## DEF QAS XML - Structured

```
<Q? text="Primary Tumor Site" item-ckey="1.1000043">  
  <A text="Skull" item-ckey="2.1000043"/>  
  <A text="Brain" item-ckey="4.1000043">  
    <Q? text="Specify Location" item-ckey="10.1000043">  
      <A text="Frontal lobe" item-ckey="11.1000043"/>  
      <A text="Temporal lobe" item-ckey="12.1000043"/>  
      <A text="Parietal lobe" item-ckey="13.1000043"/>  
      <A? text="Other (specify)" item-ckey="14.1000043"/>  
    </Q?>  
  </A>  
</Q?>  
<A text="Ours" item-ckey="15.1000043"/>  
</Q?>
```

## QAS Format for Answer Sets

```
<Q? text="Primary Tumor Site" item-ckey="1.1000043">  
  <A text="Brain" item-ckey="4.1000043">  
    <Q? text="Specify Location" item-ckey="10.1000043">  
      <A text="Frontal lobe" item-ckey="11.1000043"/>  
      <A? text="Other (specify)" item-ckey="14.1000043">  
        Cingulate gyrus and corpus callosum</A?>  
    </Q?>  
  </A>  
</Q?>
```

## eCC Data Entry Form

The screenshot shows a complex data entry form with multiple sections. The top section is titled 'SPECIMEN' and contains various fields for specimen identification and collection. Below this is a section for 'TUMOR' with a list of checkboxes for different tumor types. The form is designed for data capture in an EHR system.

'electronic checklist' form XML (eCC XML)

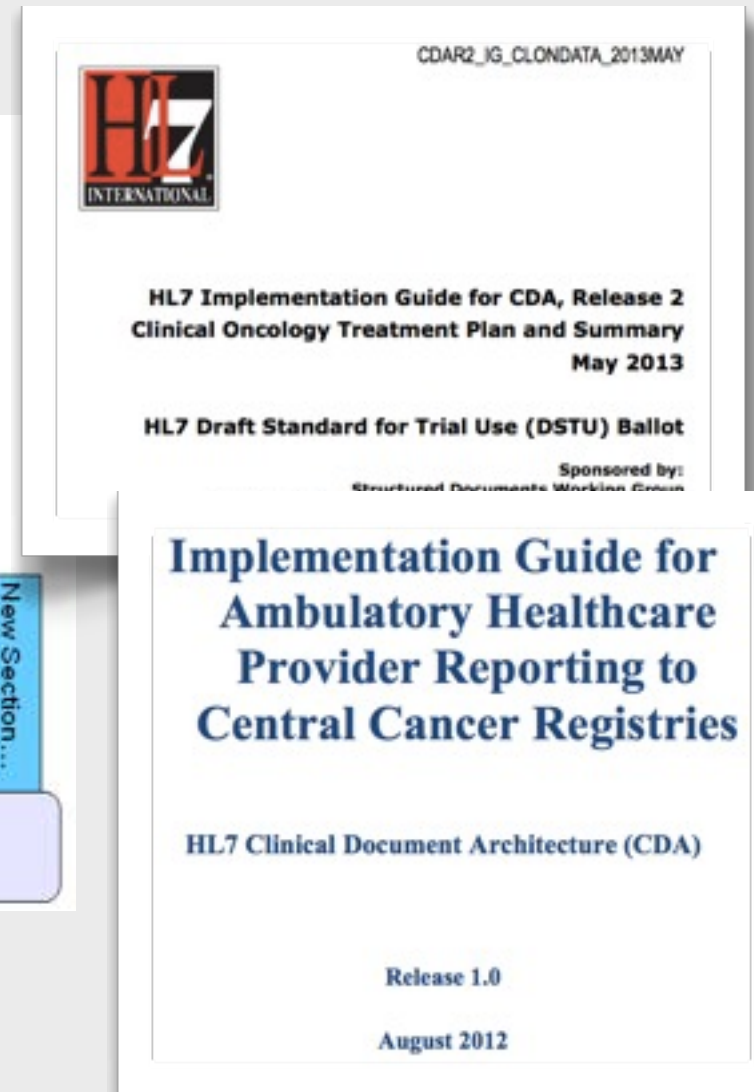
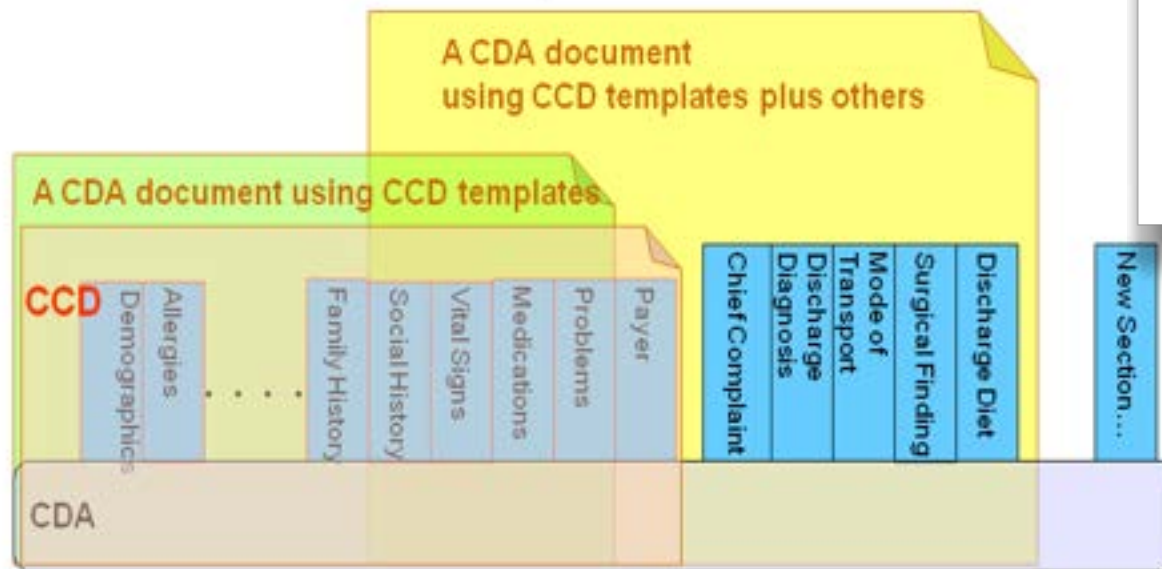
EHR System

# Continue Borrowing Good ideas...

ASCO/HL CDA + CDC's Registry CDA + ?

... a path to a "longitudinal record CDA" --> "caCCD"

- Many different kinds of documents.
- A bucket of reusable templates.



# Athena Breast Health Network

**athena**  
BREAST HEALTH NETWORK

A UNIVERSITY OF CALIFORNIA PROGRAM

Welcome About Partners For Clinicians Resources Contact Media

We are women, physicians, and researchers building a more personalized solution for breast cancer prevention, screening, and treatment. Your story holds the cure.

**Share it.**

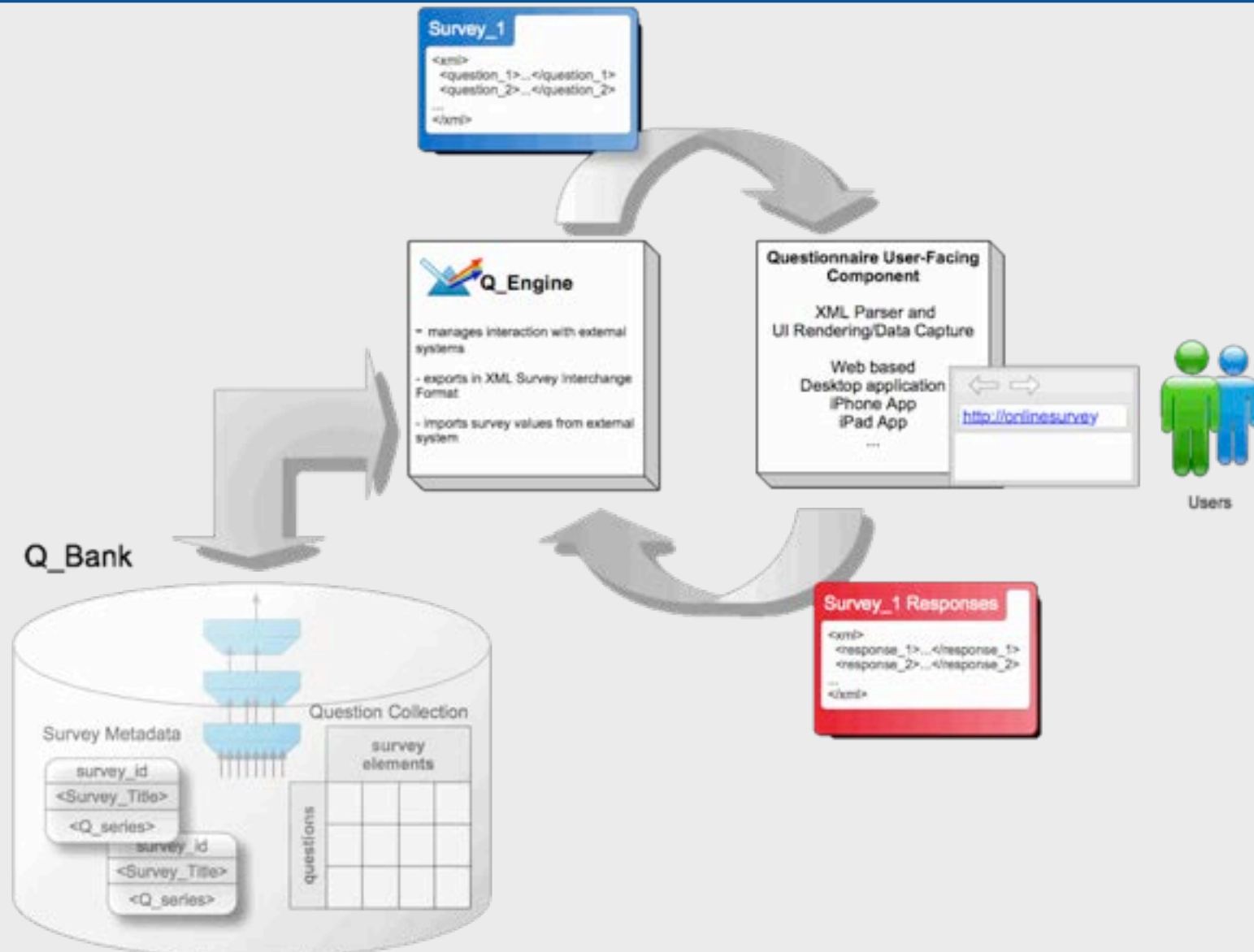
- 1 Come to a UC Medical Center to join Athena
- 2 Fill out a health questionnaire
- 3 Receive a personalized risk profile
- 4 Develop an individual plan with your provider

150,000 women over 10 years

- Screening and Prevention
- Diagnosis and Treatment
- Survivorship

- Improved screening and detection
  - Risk-based screening
  - Biomarkers, predictive models
- Comparative effectiveness
- Patient engagement

# Isn't a 'form' just a simple type of questionnaire?



# Athena XML-based "remote" questionnaire system



**Breast Health Questionnaire for ASU BuildVIII**

Please verify your answers below. To edit, click on the answer you wish to modify.

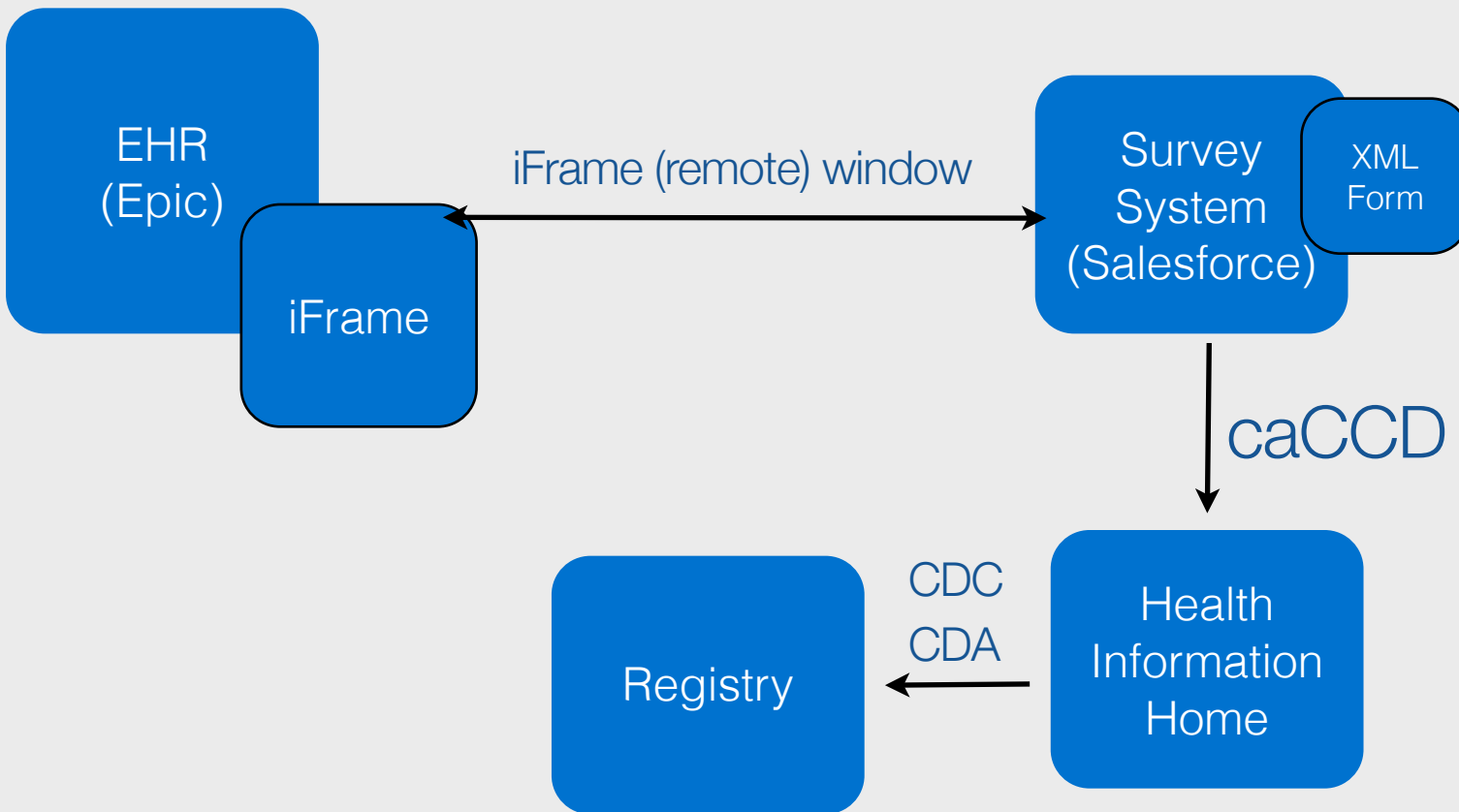
When you are satisfied, please click the "Submit" button to submit your answers to your clinician. NOTE: You will not be able to edit your answers after clicking the "Submit" button.

|  |                   |
|--|-------------------|
| Gender                                 | Female            |
| Ever had a mammogram                   | No                |
| Clinical breast exam in last 3 months  | No                |
| Changes in left breast - Last 3 months | Some of the above |
| Changes in left breast - Last 3 months | Some of the above |
| Breast cancer diagnosis                | No                |
| Diagnosed with other cancers           | Don't know        |
| Adopted                                | No                |
| Number of sisters                      | 0                 |
| Number of daughters                    | 0                 |
| Number of maternal aunts               | 0                 |
| Number of paternal aunts               | 0                 |



# What we are planning to do today...

XML Form delivered to EHR user through iFrame with single-sign-on (SSO)

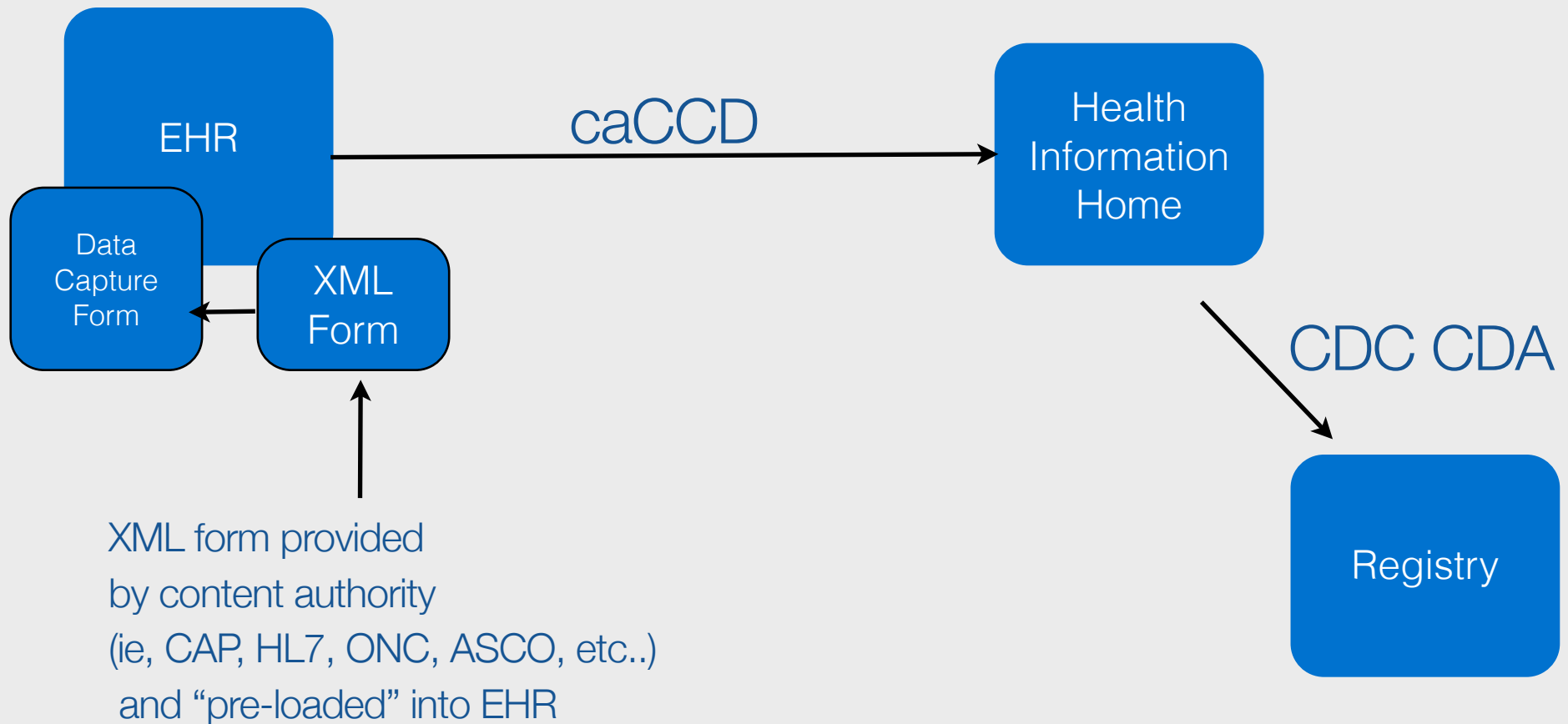




# The road to the future...



- ▶ XML-based structured data capture
- ▶ Disease-focused data exchange



# Health Information Home

## *More uses of a patient-centered repository*

### Problem

- a number of patients receive care from a fragmented assortment of clinicians and health systems

### Opportunity

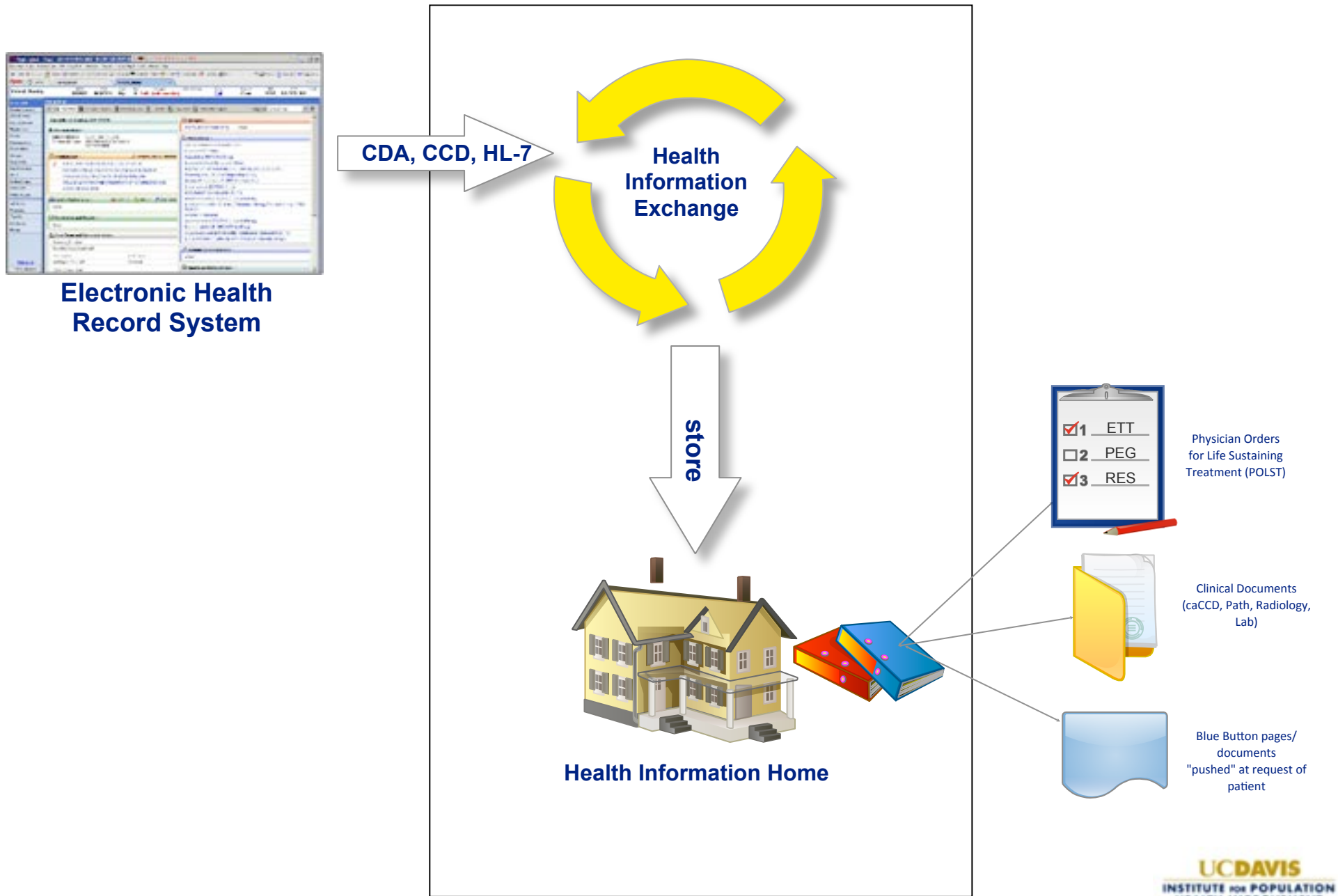
- a 'health information home' will facilitate coordinated care by providing a shared view of the patient for all of their providers
- intersection with public health registries -- data is submitted to health information home, then forwarded to registry (making data available for clinical care)

### Project Specifics

- Implement a health information home for
  - longitudinal health record for foster care children
  - repository to store physician orders for life-sustaining treatment (POLST registry)
  - \*\*\*long-term care facilities (skilled nursing homes, rehab facilities, etc...)



# The Health Information Home



# Questions?

