A Trial Implementation of a "High Density" Health Information Exchange Standard:

Are We Ready for "Coordinated" Care in High Impact Conditions?

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US Medicine Has High Care Fragmentation:

The average Medicare patients sees ~7-8 different doctors a year…

DIAGNOSIS 01.06.13 12:00 AM ET

THE DAILY BEAST

The Best Way to Reform Health Care –and Cut the Deficit

> To explain: the fragmented nature of the U.S. healthcare system is remarkable. Even physicians who practice within the same hospital are typically independent from each other and from the hospital and its nurses. At some hospitals, case managers gamely try to coordinate the physicians working on a given case but have no direct control and little leverage, because the physicians bill separately. Outside of hospitals, the situation is even worse. The average Medicare patient sees 7 to 8 doctors a year, 13 if the patient has a chronic condition, and no one is paid to coordinate them.

http://blogs.law.harvard.edu/billofhealth/2013/01/24/part-i-fragmentation-in-health-care-the-patients-perspective/

IOM 2013: Cancer care is “chaotic”

Modern Healthcare

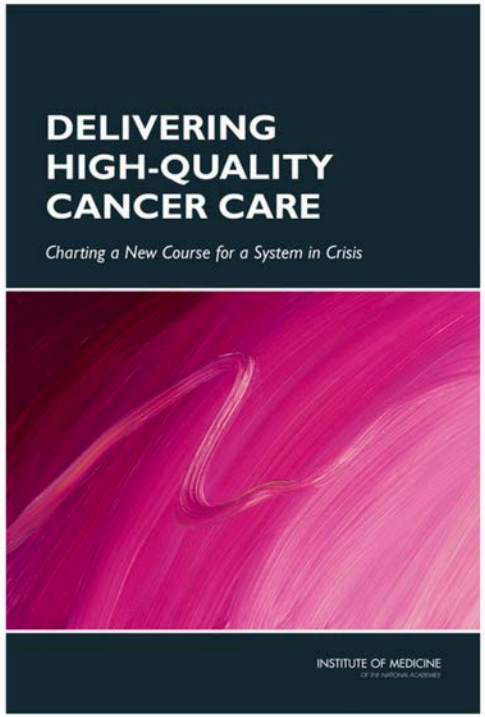
System is 'chaotic, costly,' IOM report says

By **Jaimy Lee** and **Steven Ross Johnson** | September 14, 2013

The cancer-care system in the U.S. is fraught with waste, skewed financial incentives and misinformation about how to provide the best care to the 1.6 million people who are diagnosed with cancer each year.

In a critical report, the Institute of Medicine said the nation's “increasingly chaotic and costly” cancer-care system is in crisis and fails to deliver consistent care that is patient-centered, evidence-based and coordinated.

The report identified issues across the oncology spectrum of care, finding that community oncologists don't always follow or stay up to date with clinical treatment guidelines, genomic advances have made treatment more complex and more expensive, and there has not been enough of an effort to engage patients and provide **palliative care**[1].



2015: Cancer is Fragmented!

Cancer. 2015 Jun 4. doi: 10.1002/cncr.29474. [Epub ahead of print]

Fragmentation in specialist care and stage III colon cancer.

Hussain T[1], Chang HY[2], Veenstra CM[3], Pollack CE[1,2].

Author information

Abstract

BACKGROUND: Patients with cancer frequently transition between different types of specialists and across care settings. This study explored how frequently the surgical and medical oncology care of stage III colon cancer patients occurred across more than 1 hospital and whether this was associated with mortality and costs.

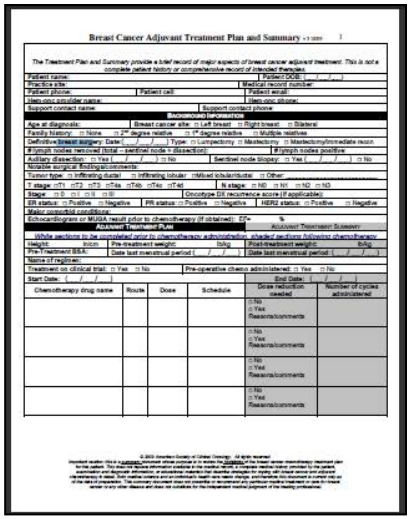
METHODS: This was a retrospective Surveillance, Epidemiology, and End Results-Medicare cohort study of 9075 stage III colon cancer patients diagnosed between 2000 and 2009 who had received both surgical and medical oncology care within 1 year of their diagnosis. Patients were assigned to the hospital at which they had undergone their cancer surgery and to their oncologist's primary hospital, and then they were characterized according to whether these hospitals were the same or different. Outcomes included all-cause mortality, subhazards for colon cancer-specific mortality, and costs of care at 12 months.

RESULTS: Thirty-seven percent of the patients received their surgical and medical oncology care from different hospitals. Rural patients were less likely than urban patients to receive medical oncology care from the same hospital (odds ratio, 0.62; 95% confidence interval, 0.43-0.90). Care from the same hospital was not associated with reduced all-cause or colon cancer-specific mortality but resulted in lower costs (8% of the median cost) at 12 months (dollars saved, $5493; 95% confidence interval, $1799-$9525).

CONCLUSIONS: The delivery of surgical and medical oncology care at the same hospital was associated with lower costs; however, reforms seeking to improve outcomes and lower costs through the integration of complex care will need to address the significant proportion of patients receiving care at more than 1 hospital. Cancer 2015. © 2015 American Cancer Society.

The ASCO "Clinical Oncology Treatment Plan & Summary"

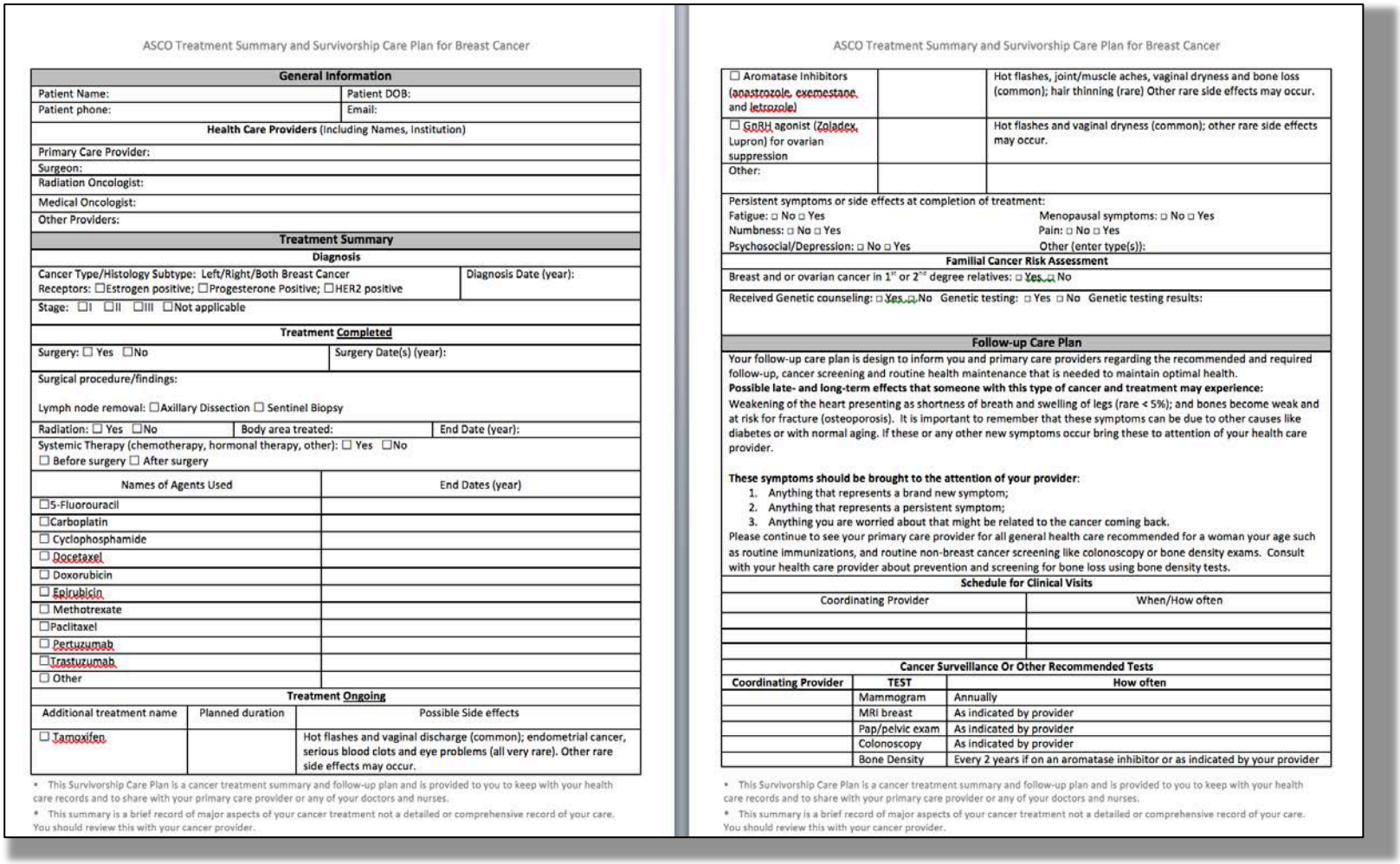
- Paper forms designed to document a patient's treatment plan and then actual treatment
- Developed after Katrina to provide basic information, care coordination, and survivorship information
- Multiple versions – one generic, and six diagnosis-specific
- **Not originally envisioned for electronic transmission; need a standardized exchange standard**


Breast Cancer Adjuvant Treatment Plan and Summary

Included Clinical Information

- Goals of therapy
- Diagnosis (site, histology, and stage)
- Patient health and comorbidities
- Surgical history and pathology
- Chemotherapy regimen and dosage
- Duration of treatment and number of cycles
- Major chemotherapy side effects

ASCO Breast Cancer Treatment Summary and Survivorship Care Plan (c.2000) -- High Information Density!



ASCO Treatment Summary and Survivorship Care Plan for Breast Cancer

General Information	
Patient Name:	Patient DOB:
Patient phone:	Email:
Health Care Providers (Including Names, Institution)	
Primary Care Provider:	
Surgeon:	
Radiation Oncologist:	
Medical Oncologist:	
Other Providers:	

Treatment Summary

Diagnosis

Cancer Type/Histology Subtype: Left/Right/Both Breast Cancer Receptors: ☐Estrogen positive; ☐Progesterone Positive; ☐HER2 positive	Diagnosis Date (year):
Stage: ☐I ☐II ☐III ☐Not applicable	

Treatment Completed

Surgery: ☐ Yes ☐No	Surgery Date(s) (year):
Surgical procedure/findings: Lymph node removal: ☐Axillary Dissection ☐ Sentinel Biopsy	

Radiation: ☐ Yes ☐No	Body area treated:	End Date (year):
Systemic Therapy (chemotherapy, hormonal therapy, other): ☐ Yes ☐No ☐ Before surgery ☐ After surgery		

Names of Agents Used	End Dates (year)
☐5-Fluorouracil	
☐Carboplatin	
☐ Cyclophosphamide	
☐ Docetaxel	
☐ Doxorubicin	
☐ Epirubicin	
☐ Methotrexate	
☐Paclitaxel	
☐ Pertuzumab	
☐Trastuzumab	
☐ Other	

Treatment Ongoing

Additional treatment name	Planned duration	Possible Side effects
☐ Tamoxifen		Hot flashes and vaginal discharge (common); endometrial cancer, serious blood clots and eye problems (all very rare). Other rare side effects may occur.
☐ Aromatase Inhibitors (anastrozole, exemestane, and letrozole)		Hot flashes, joint/muscle aches, vaginal dryness and bone loss (common); hair thinning (rare) Other rare side effects may occur.
☐ GnRH agonist (Zoladex, Lupron) for ovarian suppression		Hot flashes and vaginal dryness (common); other rare side effects may occur.
Other:		

Persistent symptoms or side effects at completion of treatment:

Fatigue: ☐ No ☐ Yes — Menopausal symptoms: ☐ No ☐ Yes

Numbness: ☐ No ☐ Yes — Pain: ☐ No ☐ Yes

Psychosocial/Depression: ☐ No ☐ Yes — Other (enter type(s)):

Familial Cancer Risk Assessment

Breast and or ovarian cancer in 1st or 2nd degree relatives: ☐ Yes ☐ No

Received Genetic counseling: ☐ Yes ☐ No Genetic testing: ☐ Yes ☐ No Genetic testing results:

Follow-up Care Plan

Your follow-up care plan is design to inform you and primary care providers regarding the recommended and required follow-up, cancer screening and routine health maintenance that is needed to maintain optimal health.

Possible late- and long-term effects that someone with this type of cancer and treatment may experience:

Weakening of the heart presenting as shortness of breath and swelling of legs (rare < 5%); and bones become weak and at risk for fracture (osteoporosis). It is important to remember that these symptoms can be due to other causes like diabetes or with normal aging. If these or any other new symptoms occur bring these to attention of your health care provider.

These symptoms should be brought to the attention of your provider:

1. Anything that represents a brand new symptom;
2. Anything that represents a persistent symptom;
3. Anything you are worried about that might be related to the cancer coming back.

Please continue to see your primary care provider for all general health care recommended for a woman your age such as routine immunizations, and routine non-breast cancer screening like colonoscopy or bone density exams. Consult with your health care provider about prevention and screening for bone loss using bone density tests.

Schedule for Clinical Visits

Coordinating Provider	When/How often

Cancer Surveillance Or Other Recommended Tests

Coordinating Provider	TEST	How often
	Mammogram	Annually
	MRI breast	As indicated by provider
	Pap/pelvic exam	As indicated by provider
	Colonoscopy	As indicated by provider
	Bone Density	Every 2 years if on an aromatase inhibitor or as indicated by your provider

* This Survivorship Care Plan is a cancer treatment summary and follow-up plan and is provided to you to keep with your health care records and to share with your primary care provider or any of your doctors and nurses.
* This summary is a brief record of major aspects of your cancer treatment not a detailed or comprehensive record of your care. You should review this with your cancer provider.

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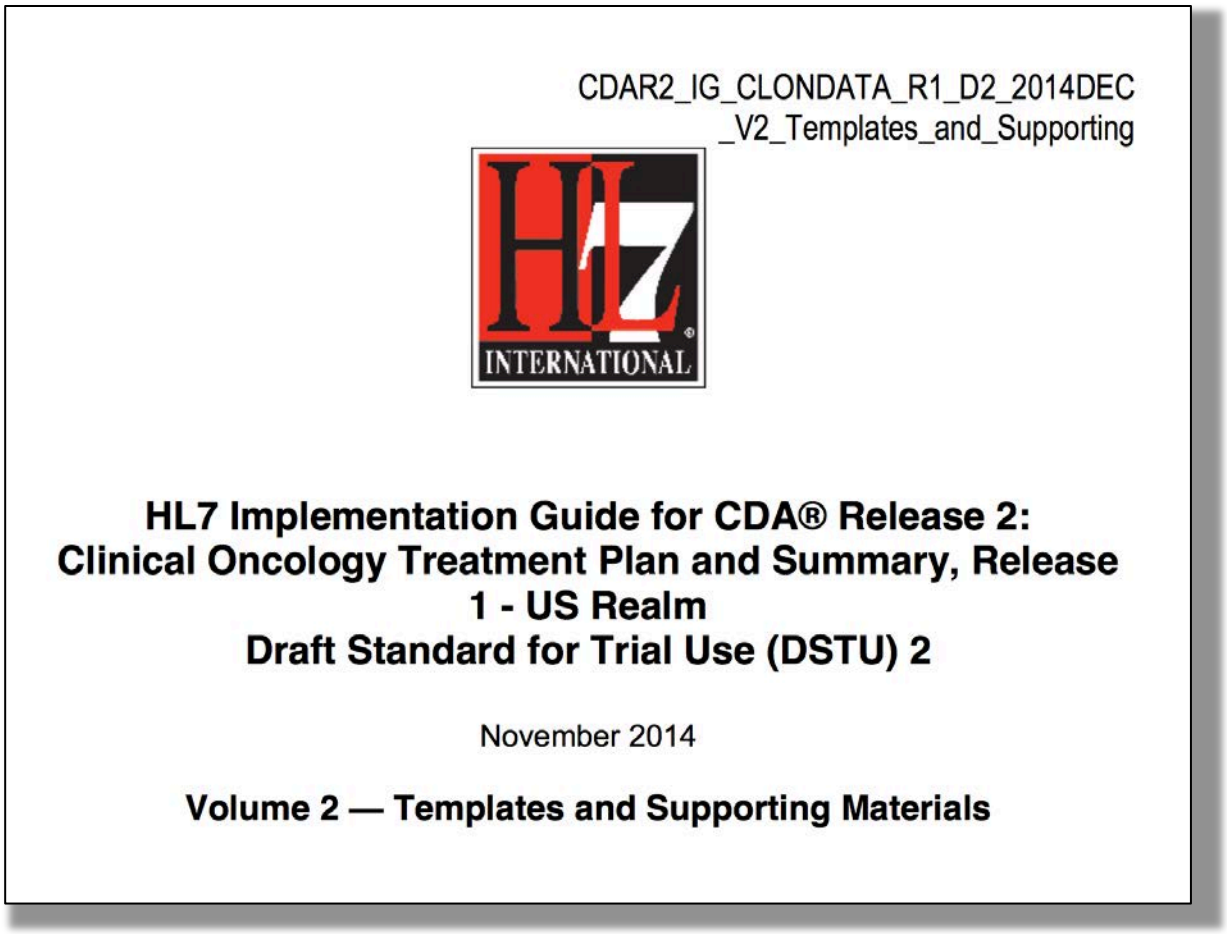
2014 – Draft Standard for Trial Use (DTSU)



CDAR2_IG_CLONDATA_R1_D2_2014DEC
_V2_Templates_and_Supporting

**HL7 Implementation Guide for CDA® Release 2:
Clinical Oncology Treatment Plan and Summary, Release 1 - US Realm
Draft Standard for Trial Use (DSTU) 2**

November 2014

Volume 2 — Templates and Supporting Materials

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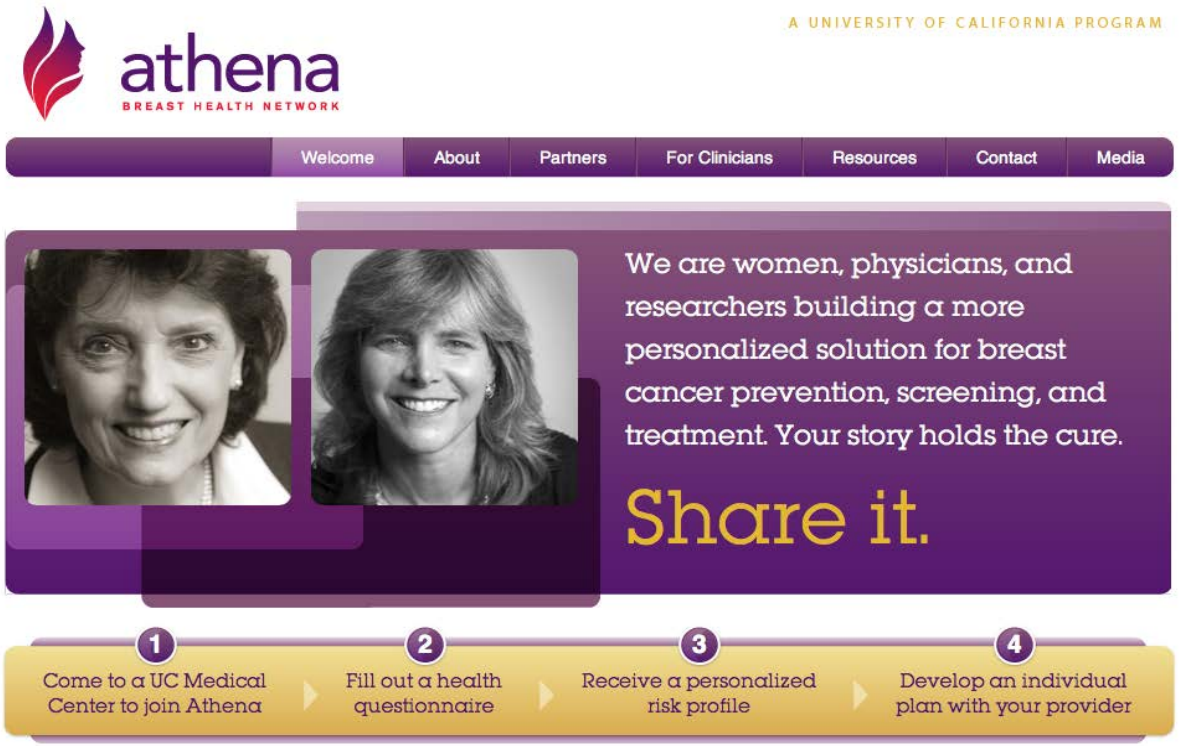
The Athena Breast Health Network



Participation of 150,000 women over 10 years

- Screening and Prevention
- Diagnosis and Treatment
- Survivorship

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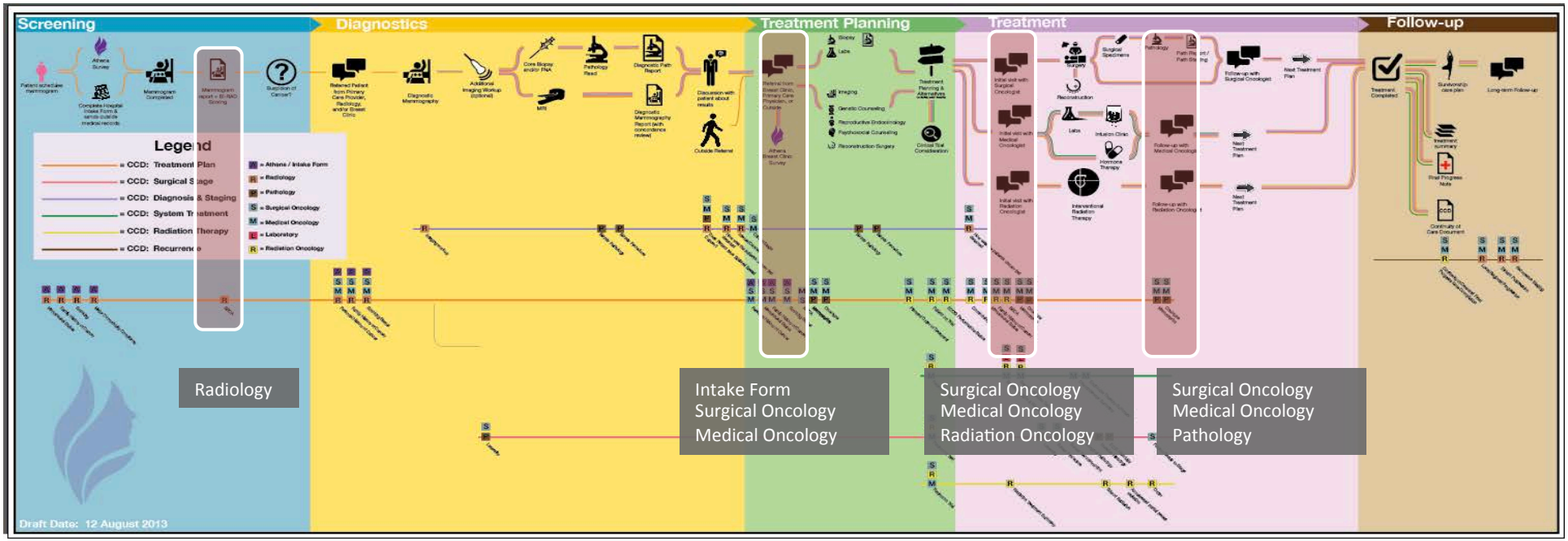
- **An Established "network" with a large community referral** percentage
  - 10 UC hospitals, 13 Midwest hospitals
- **Providers all using EHRs**
  - Two HIMSS Stage 7
- **>200 providers committed to modernization and improvement**
  - Pathologists, radiologists, primary care providers, oncologists, surgeons, radiation oncologists.

Breast Cancer Clinical Workflow



- What we saw in an Integrated Delivery Network → **Multiple providers, multiple and varying sources of data**
- What we believe → **Fragmented information = fragmented care**

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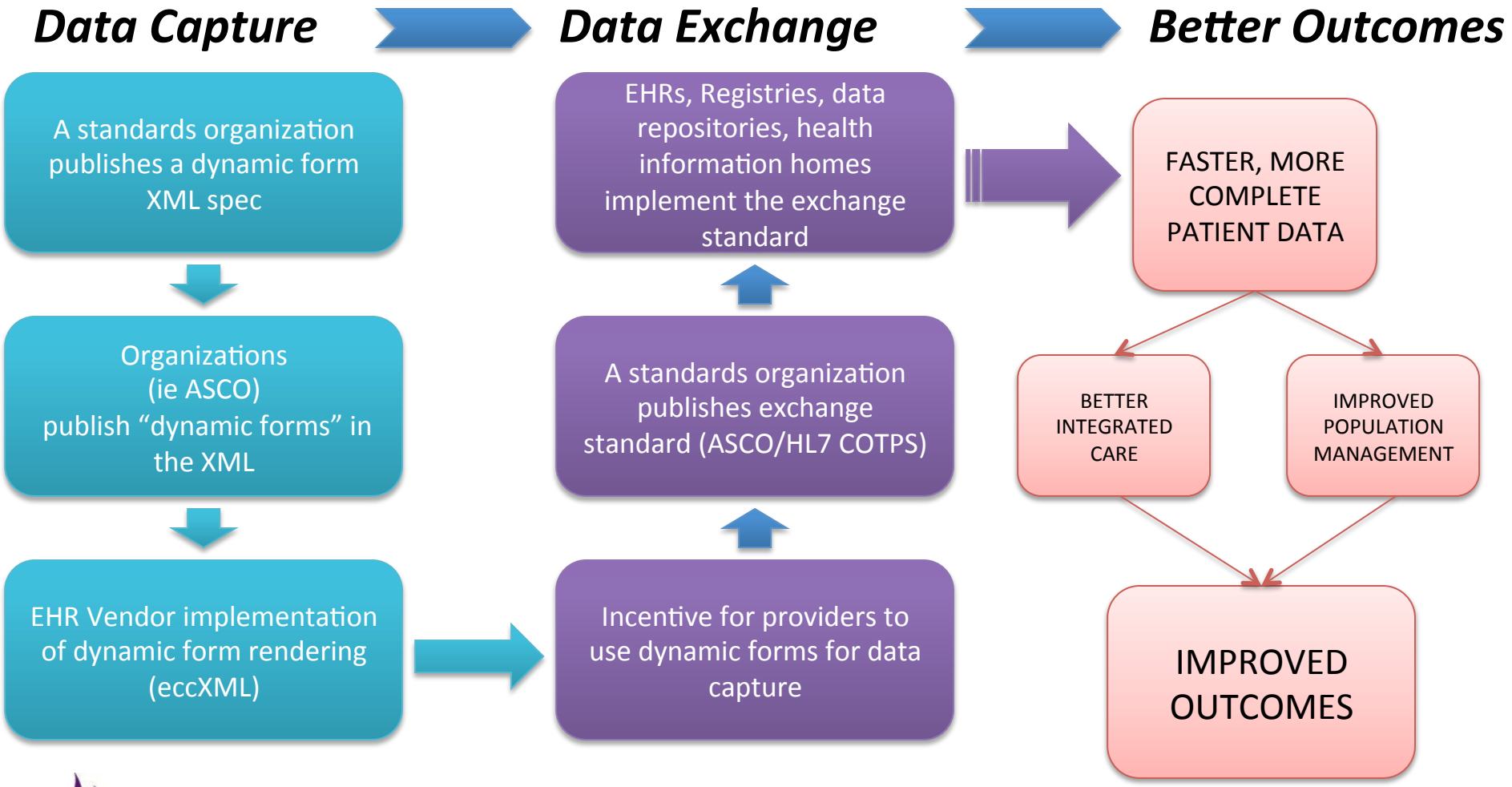
What is Athena's Project INSPIRE?

Project INSPIRE

***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"

Broadly Implementing INSPIRE



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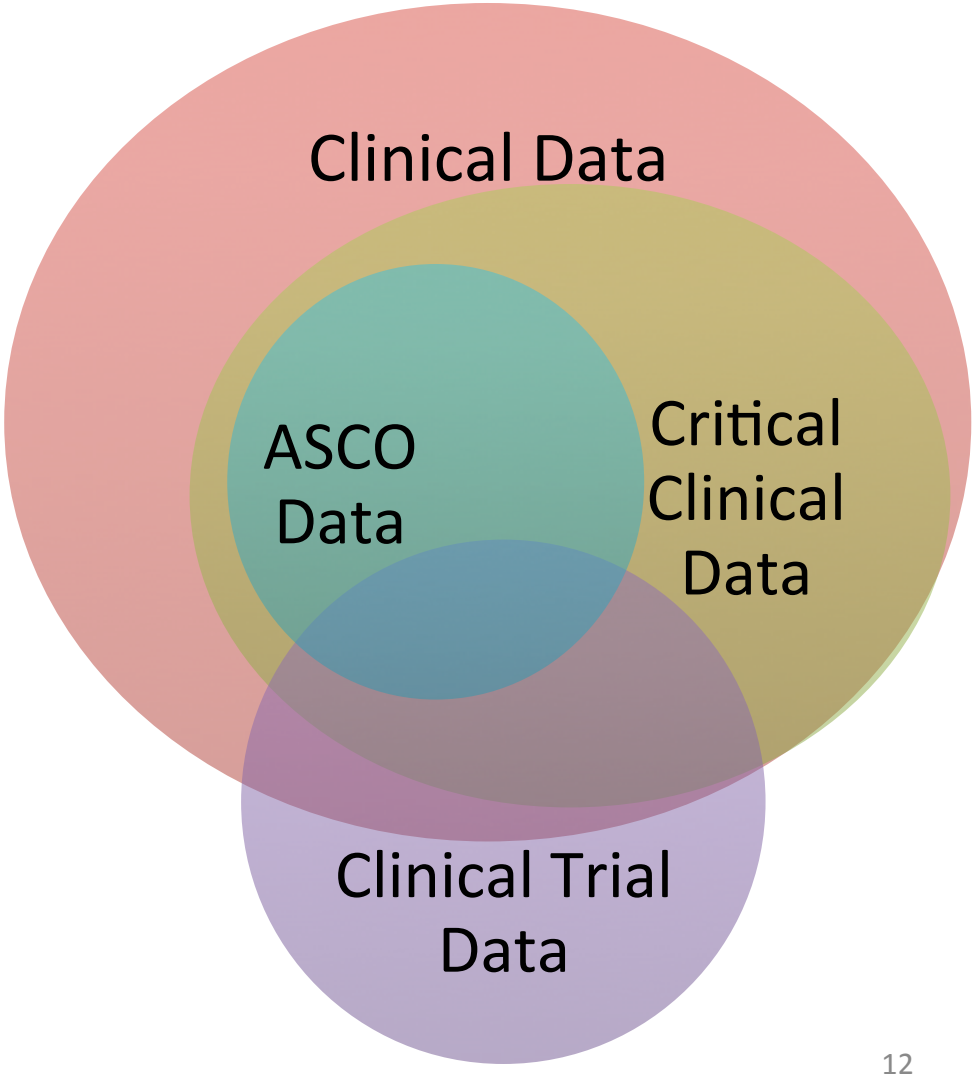
Athena "Checklists" (key data)

- Clinical Dataset captured on all patients
- Identify subset that is critical for decision making, reporting
  - Elements 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
- Compare against Community Data Standards
  - ASCO, CAP, Cancer Registry, NCI CTEP Common Data Elements (for Clinical Trials)



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The COTPS Project

- Goal: Demonstrate exchange of data sourced from Athena checklists using the COTPS CDA

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      </entry>
    </section>
  </component>
  <!--Social History-->
```

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Mapping Athena “Data Elements ” to ASCO/HL7 COTPS CDA elements

INSPIRE caCCD Notes Data Elements as of 11/4/13							full CDA format					
No	Field Name	Validation	Form / Screen Name	COTPS Sections: Implementation guide; ***add cda sections names to final version	additional COTPS or Athena notes, and conformance #s,	COTPS Templates Ids; and/or Consolidated CDA names & template IDs	RW #s	Present/Absent	Multiple/Single	Mandatory/ conditional/ not required	Main note	C
13	Family history of breast cancer	1.1st Degree Relative 2.2nd Degree Relative 3.Multiple Relatives 4.None	Initial Diagnosis	Family history section.							CDA entries may appear or not according to the values of the CDA data elements. I.e. we may also be able to use presence or absence of the ECOG to signify number 5.	
14	Referred for Genetic Counselling	1. Yes 2. No	Initial Diagnosis	Plan of care section for all referrals. 3.6 general; 3.6.1 specific to Breast Cancer.							General plan of care for genetic counselling, needs to be added to CDA XML.	
15	Menopausal status	1.Premenopausal 2.Perimenopausal 3.Postmenopausal	Initial Diagnosis	Not present; section 4.44.1, supporting observation of BCTPS problem... Needs a basic result observation created with these codes.		??					May need to define a new 'observation' for this on the basis of (finding correct snomed or Loinc code and code values if one is not present in the Consolidated CDA) (MJS to check).	
16	Interested in fertility preservation	1.Yes 2.No 3.Referred	Initial Diagnosis	Plan of care section for all referrals. 3.6 general; 3.6.1 specific to Breast Cancer.								
17	Last menstrual period	1.Date 2.Unknown	Initial Diagnosis	Problem section.see 3.7.1, 4.28 (unk is done w/ null indicatotr)		2.16.840.1.113883.10.20.30.2.1 ; 2.16.840.1.113883.10.20.30.3.6 ; 2.16.840.1.113883.10.20.30.3.34	11146 ; ?? Problem; not present...				note: null indicator usage if unknown.	

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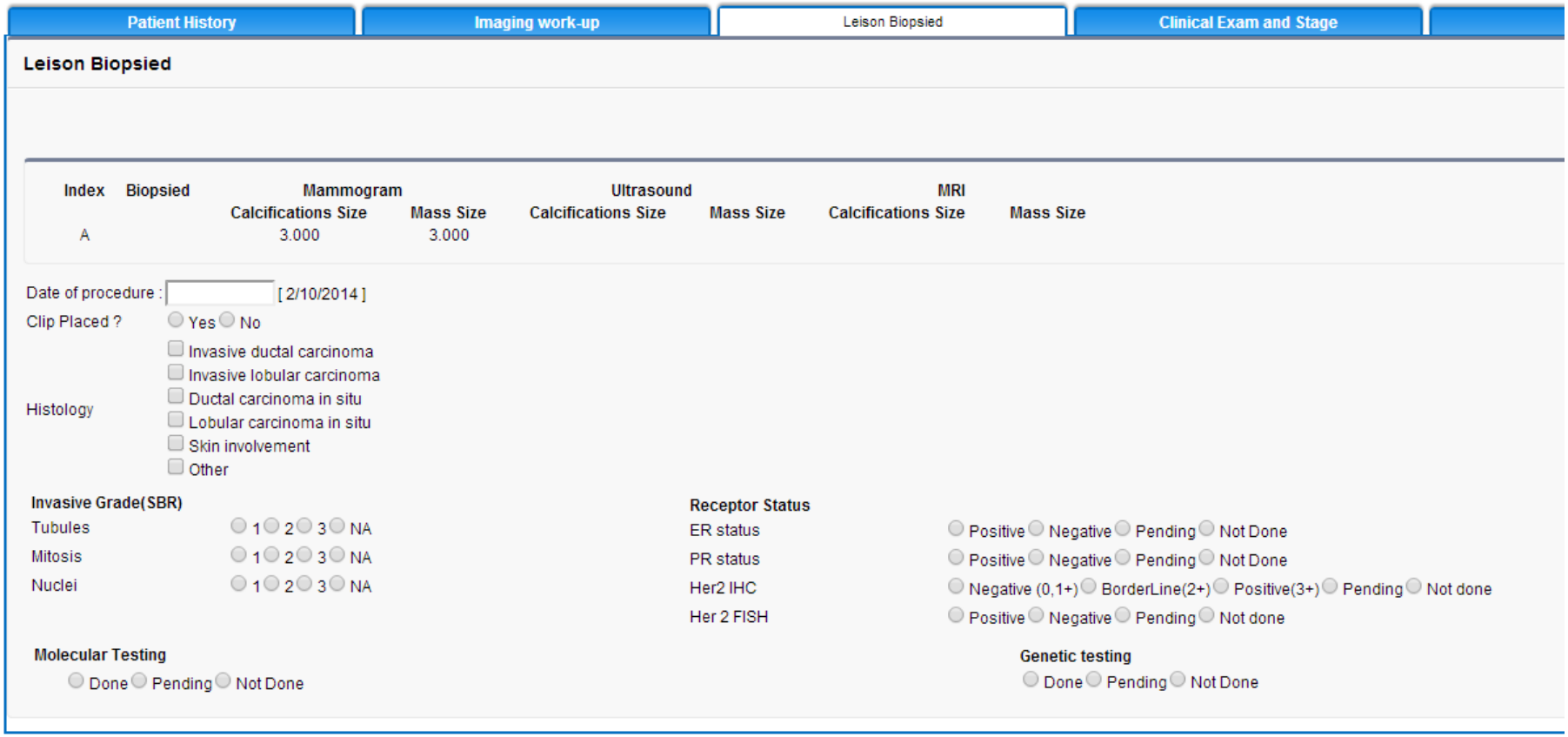
Athena Checklist Application (2014)



Lesion Biopsied – Initial Diagnosis Section

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Lessons Learned

- COTPS and INSPIRE had different intended purposes
  - COTPS is meant to exchange a **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)*
- COTPS CDA shortcomings for our implementation:
  - ① **Lack of "Longitudinality"** -- Athena needed to support multiple points in time (multiple versions of the CDA over time – overwrite? append?
  - ② **Lack of "Granularity"** -- Athena needed to have specialty-specific information such as exact radiation treatment dose, chemo dosing, etc..
  - ③ **Lack of "Relationships" between observations** -- Athena needed to *related* lesions to imaging findings and radiation dosing

More information

Development, implementation, and initial evaluation of a foundational open interoperability standard for oncology treatment planning and summarization

RECEIVED 10 July 2014
REVISED 16 September 2014
ACCEPTED 28 October 2014
PUBLISHED ONLINE FIRST 20 January 2015

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My Final Thoughts

- We are at "EHR Interoperability Stage 1" (version 1.0)
  - We have standards but they are very light on representation of problems "over time"
  - Consolidated CDA (ie, CCD) is "a snap shot in time"

- We have no standard to 'package' a medical record and move it from one system to another in its entirety (at that point) – and remember the point at which that was done in the record!

- Where we need to be (version 2.0 and beyond):
  1. **Exchange standards that are *clinical useful* for *high impact conditions* (Cancer, Parkinson's, Lupus, etc…)**
  2. **The standards need to allow for high density of data**
  3. **The standards need to enable us to achieve a longitudinal accounting of the care**