

Communication & Care Plan for Breast Cancer Treatment

Creating a Tool for Patient-Centered Care

Laura Esserman, MD, MBA

Director, UCSF Carol Franc Buck Breast Care Center

Director, Cancer Center Clinical Translational Informatics Unit

Mike Hogarth, MD

UC Davis Associate Professor, Clinical Pathology

UC Davis Associate Professor, Internal Medicine



This work is licensed under a [Creative Commons Attribution 3.0 Unported License](https://creativecommons.org/licenses/by/3.0/).

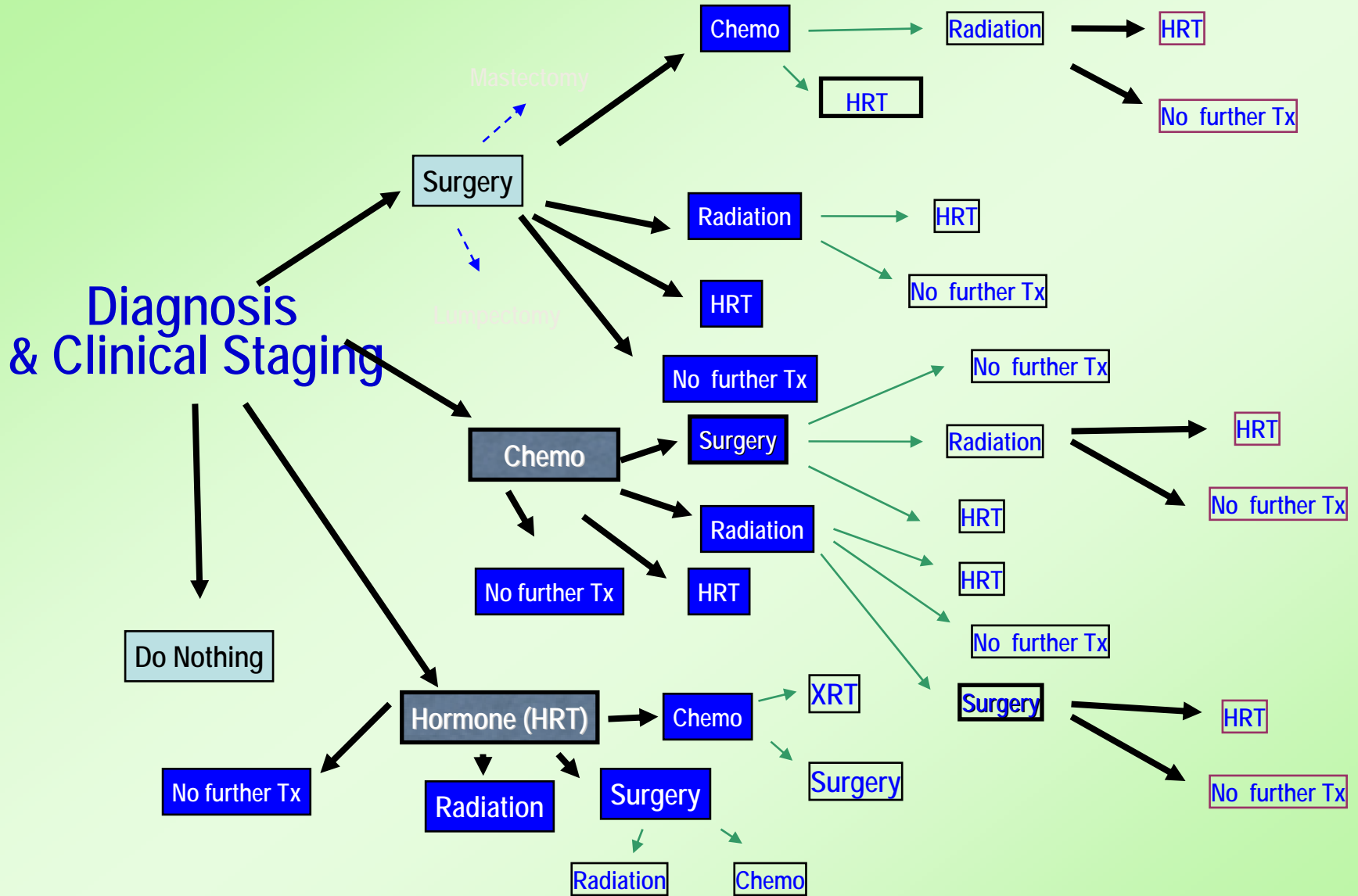
Creating a New Patient-Centered Paradigm

- Harness the power of 21st century information technology to profoundly impact every stage of breast cancer care
- Design a system of care to address the specific needs, experiences, and values of the patient

What Will It Take?

- Convenient data input & access to critical information
- Tools for planning and organizing the care process
- Communication Tools and Patient Resources

Breast Cancer Treatment Options Are Complex



The Communication & Care Plan Solution

- Enables capture of structured data from patients and providers
- Organizes information and displays treatment options on a calendar
- Integrates information about care and streamlines the delivery of services
- Supports the decision making process

Communication & Care Plan Progress

- Conducted patient, provider, and staff focus groups
 - Solicited input on information needs
 - Incorporated feedback on prototype design
 - Flash tool used for rapid prototype development
- Prototype designed and built on Tolven platform
 - Reflects requirements for timeline functionality
 - Not “vaporware”

“How” We Learned: Patient and Provider Input

- Focus Groups:
 - 20 breast cancer patients
 - Received treatment at different facilities
 - Cross ethnic and socioeconomic backgrounds
 - 3 separate focus groups
 - 10 providers
 - 2 separate groups
- Written survey
- 3 prototypes:
 - White board
 - Power point
 - Flash demo
- Built Working Tool on Tolven Platform
 - Security
 - HL7-V3 RIM infrastructure

“What” We Learned: Patient Focus Group Feedback

- Security and confidentiality important
- Useful if practitioners use it as well
- Need for and use of information will vary
 - women should be able to tailor the views to meet their needs
- Outcomes such as Recurrence/mortality data is very emotional and should be shown only when ready
 - Decision support tools should be a nested, but separate component
- Solutions needed for women without internet access or with language barriers

Patient-Requested Functionality

- Document original diagnosis, progression, post-treatment care, and second opinions
- Include test and lab schedules, chemo flow sheet, other drug information, radiation and other treatments
- Include pathology and MRI images
- Show continuum of care so patient can see where they are in treatment, normal findings, treatment side effects, symptom management, etc.
- Provide summary page of all pertinent information
- Offer research protocols for clinical trials, glossary, address book, contact information, links to recommended web sites and resources
- Incorporate reminder system to push out messages or alerts that patients can create

“What we Learned”

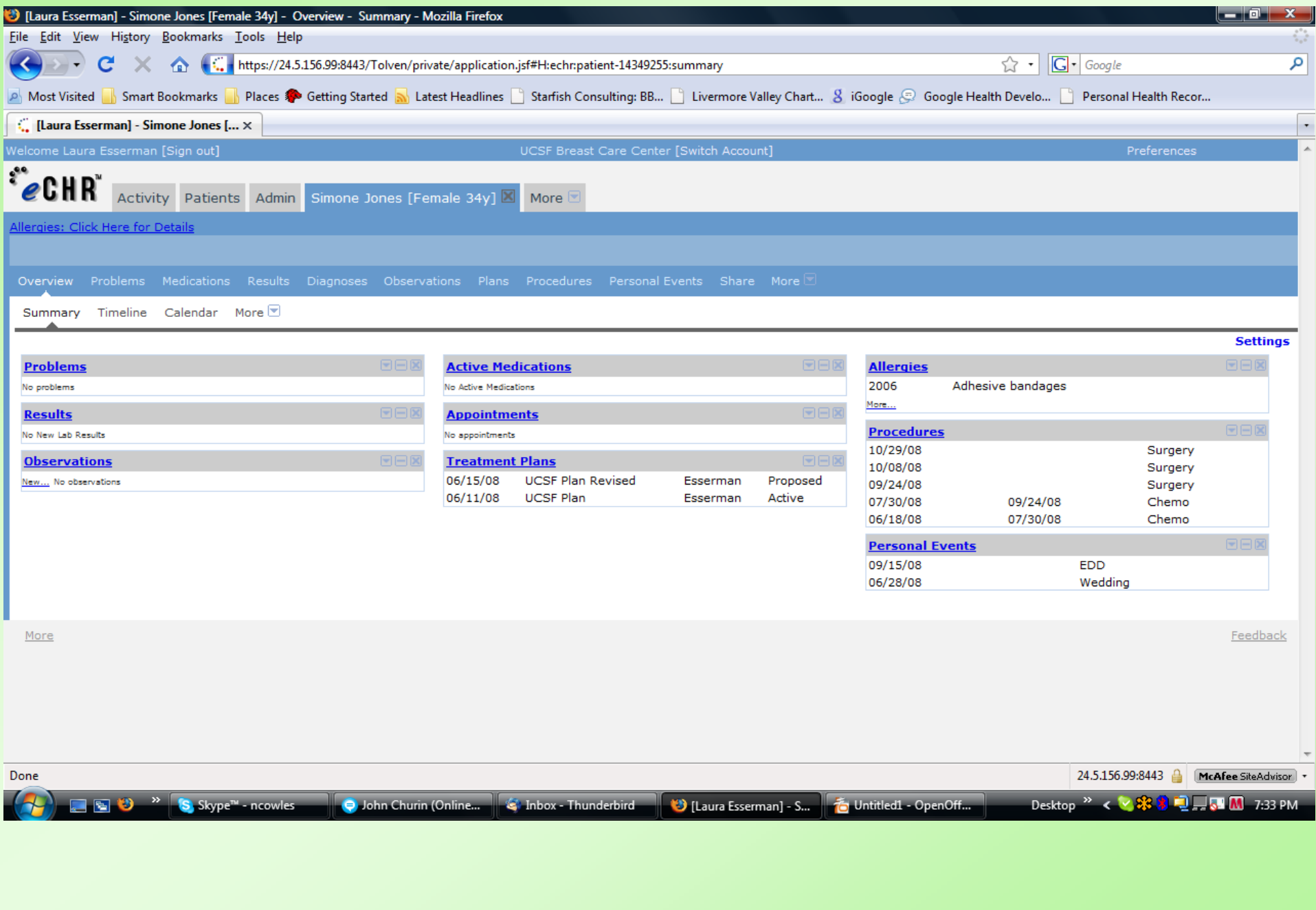
Provider Focus Group Feedback

- Physicians unwilling to enter patient data or use an on-line tool not already integrated into the existing practice management systems
- Initial patient information gathering most time consuming
- Data currently not easily accessible or in one format/place-frustrating
- Great to have visual to show overview of care plan
- Almost all providers would prefer electronic care plan connected to existing EMR
- Care coordination between providers critical

Provider-Requested Functionality

- Information on pathology, tumor size and characteristics, receptor status, etc.
- Way to know if patient is following “Plan A” vs. “Plan B” after initial consult
- Repository of general information about decisions made
- Template to manage order of treatment
- Standard set of orders linked to electronic timeline
- Electronic flow sheet populated with labs, connected to EMR
- Connection to relevant patient educational materials
- Set of rules for all users for entry of information in CCP

COMMUNICATION & CARE PLAN PROTOTYPE



Allergies: [Click Here for Details](#)

Problems [icon] [icon] [icon]
No problems

Results [icon] [icon] [icon]
No New Lab Results

Observations [icon] [icon] [icon]
[New...](#) No observations

Active Medications [icon] [icon] [icon]
No Active Medications

Appointments [icon] [icon] [icon]
No appointments

Treatment Plans [icon] [icon] [icon]

06/15/08	UCSF Plan Revised	Esserman	Proposed
06/11/08	UCSF Plan	Esserman	Active

Allergies [icon] [icon] [icon]
2006 Adhesive bandages
[More...](#)

Procedures [icon] [icon] [icon]

10/29/08		Surgery
10/08/08		Surgery
09/24/08		Surgery
07/30/08	09/24/08	Chemo
06/18/08	07/30/08	Chemo

Personal Events [icon] [icon] [icon]

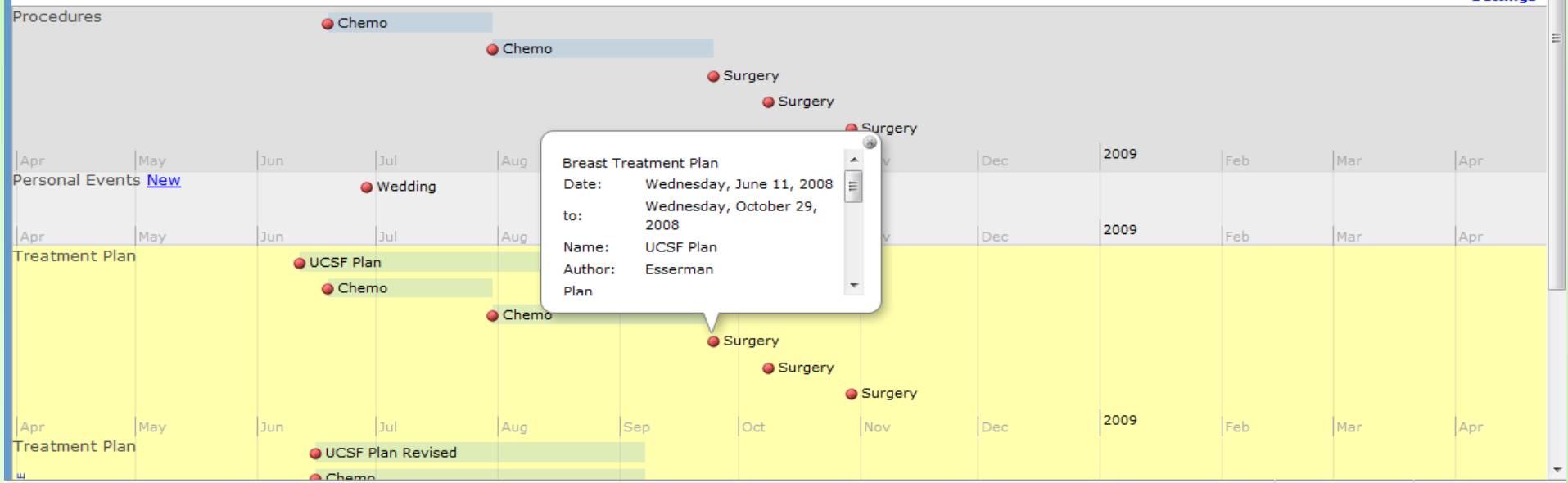
09/15/08		EDD
06/28/08		Wedding

[More](#)

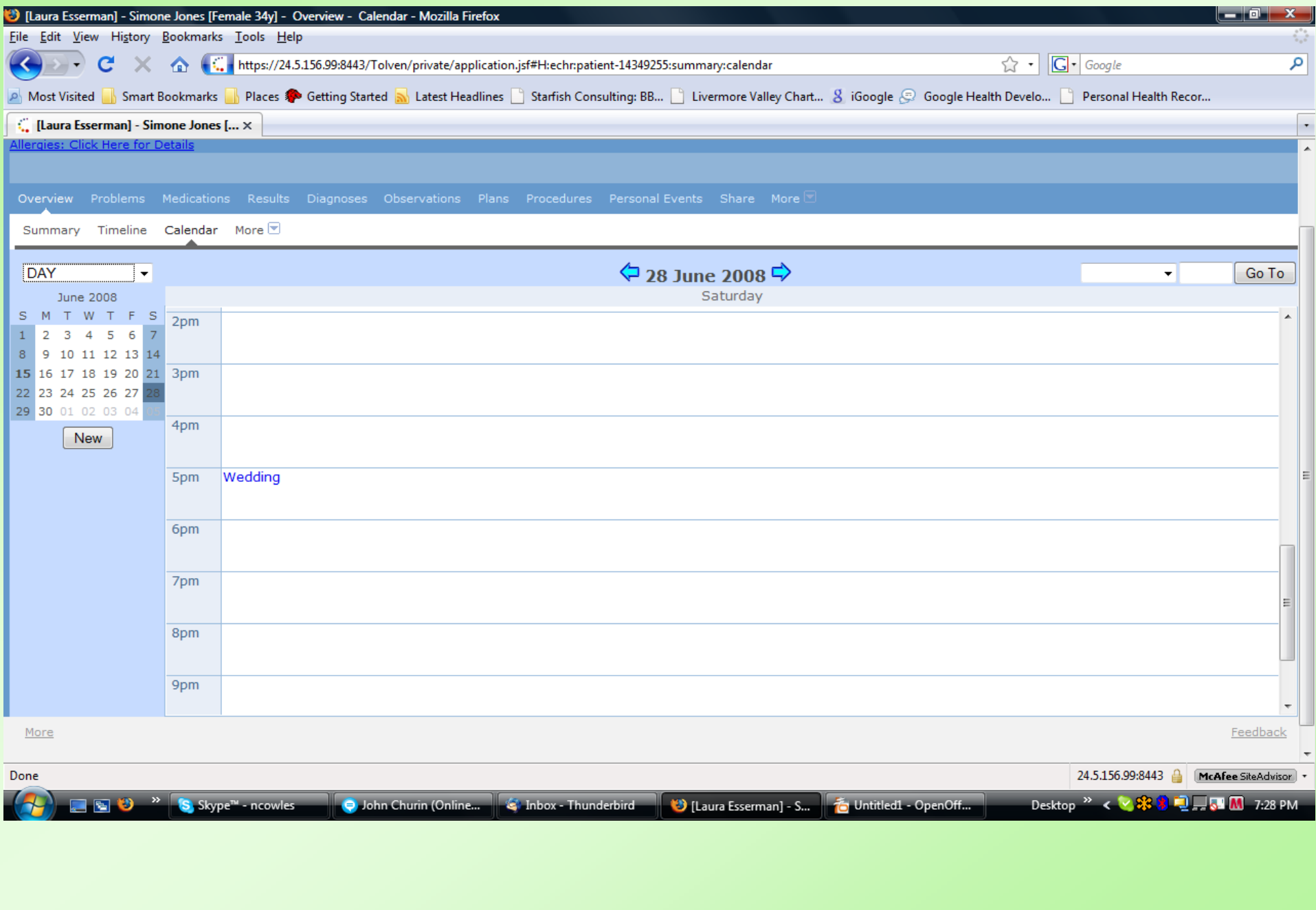
[Feedback](#)

Allergies: [Click Here for Details](#)

Procedures [Settings](#)



Breast Treatment Plan
Date: Wednesday, June 11, 2008
to: Wednesday, October 29, 2008
Name: UCSF Plan
Author: Esserman
Plan



DAY

28 June 2008

Saturday

Go To

June 2008						
S	M	T	W	T	F	S
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	01	02	03	04	05

2pm	
3pm	
4pm	
5pm	Wedding
6pm	
7pm	
8pm	
9pm	

New

More

Feedback

Done

24.5.156.99:8443 McAfee SiteAdvisor

Simone Jones Breast Treatment Plan [Source](#)

Breast Treatment Plan (NEW)

Breast Treatment Plan → Wait → Surgery → Wait → Chemotherapy → Complete

- Surgery
- Chemotherapy
- Radiation
- Hormone Replacement
- Wait

Procedure
Skin Sparing Mastectomy plus reconstruct

Axillary Surgery
Sentinel Lymph Node Right

Surgeon
none

Cancel Previous Next Submit

CCP Core Components

- HL7 used for underlying data structure
- Open Source software platform
- Built in accordance with existing standards
 - Tolven integrated existing security standards and modern software stack
- Developed open source Calendar component
- Ready to integrate with core component functions such as medication list
- Future functionality could incorporate observation with calendar

CCP Implementation Challenges

- Integration with existing EMR systems – most data not currently in standard, structured format
- Integration with scheduling and practice management systems
- Linkages with existing PHRs – most are currently not portable or interoperable

Plans for RWJ Transitional Period

- Participate in PHD meetings in DC and Nashville
- Conduct usability testing:
 - 8-10 breast cancer survivors
 - 5-7 providers
 - Evaluate the ease of use and perceived value of the different views of the data in the CCP calendar and timeline prototype
- Develop a patient-friendly interface by the end of the grant period.
- Allow for structured pathology data to be uploaded into CCP tool in Phase II
- Develop grants to develop a more comprehensive tool that builds on CCP
 - DOD IMPACT grant, NCI I-SPY TRANSCEND