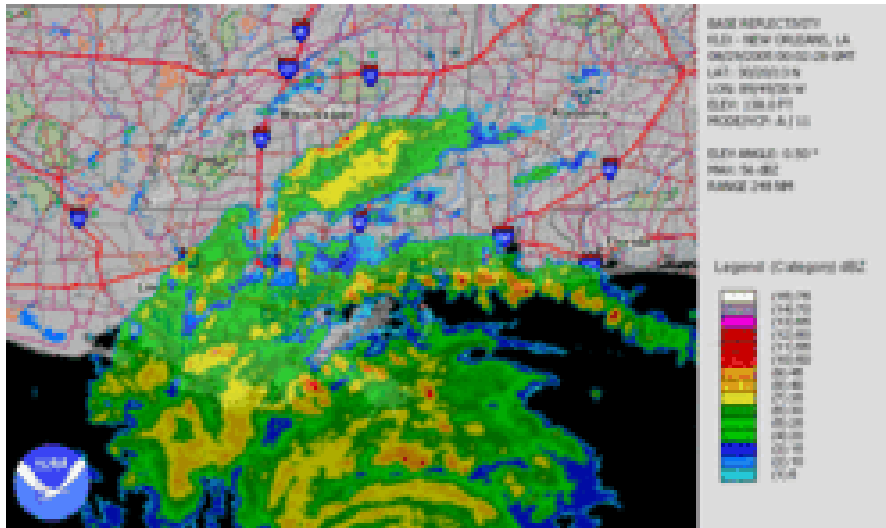# Deep Support: Using eHealth Technologies to Foster Healing Relationships

October 5, 2006

Bradford W. Hesse, PhD
Chief, Health Communication and Informatics
Research Branch, NCI

National Cancer Institute

Radar Image of Hurricane Katrina; Aug. 28-29, 2005

Vertical cross-section of New Orleans showing maximum levee height of 23 ft.

Source: Wikipedia (http://en.wikipedia.org/wiki/Hurricane_Katrina)

2

National Cancer Institute

Flooded I-10/I-610/West End Blvd. and surrounding area of northwest New Orleans and Metairie, Louisiana

Source: Wikipedia (http://en.wikipedia.org/wiki/Hurricane_Katrina)

NATIONAL CANCER INSTITUTE

A U.S. Coast Guardsman searches for survivors in New Orleans in the aftermath of Katrina.

Source: Wikipedia (http://en.wikipedia.org/wiki/Hurricane_Katrina)

Cancer Therapy Evaluation Program (CTEP), National Cancer Institute

- **318** therapeutic trials were affected
- **7,717** patients participating in CTEP clinical trials were displaced
- CTEP help line 301-496-5725
  - Patients seeking treatment continuation
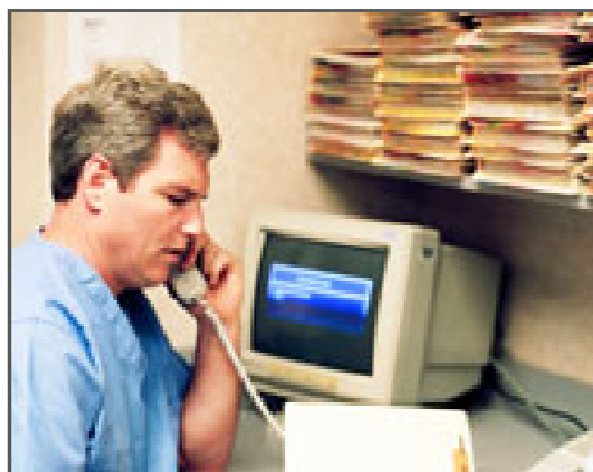 - Treatment centers accepting displaced patients

ABC NEWS ORIGINAL REPORT

Digital Medical Records Survive Katrina

abcNEWS

Sept. 16, 2005 — In this week's "Cybershake," we take a look at how Hurricane Katrina didn't beat war veterans — or, at least not their medical records.

The Department of Veterans Affairs ditched conventional paper-based

*A NewsHour
with Jim Lehrer,
Feb. 8, 2006*


Restoring health records

SUSAN DENTZER:
Part of the health fair was designed to solve a problem that cropped up in Katrina, when most paper health records were destroyed and evacuees who fled often could not remember the drugs or doses they were taking.

DOCTOR: The nurse would have to enter the data on the computer.

SUSAN DENTZER: The solution introduced at the fair was a new personal electronic health record, loaded onto a computer disk or memory stick for each attendee.

# Lost in Transition: The Challenge for Cancer Survivors
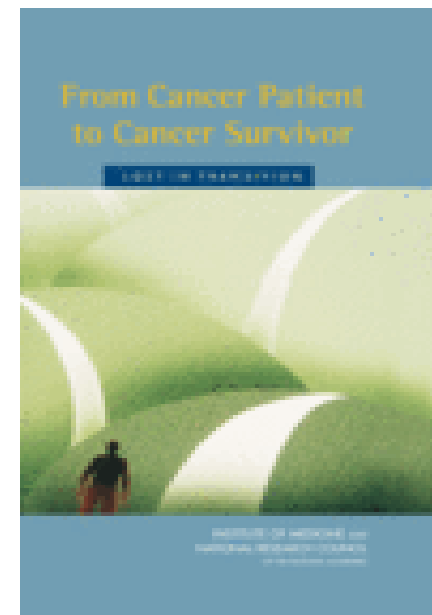
- Cancer patients must be partners in their care with seamless access to health care information

- Cancer is a shifting target with complex, multi-factorial etiologies, symptomologies

- Cancer research is undergoing a revolution (completion of genome, "Big Science")

- Individualized, targeted cancer care is an emerging reality

Source: NCI Center for Bioinformatics Web site (http://ncicb.nci.nih.gov/NCICB/about/bioinformatics/trends)
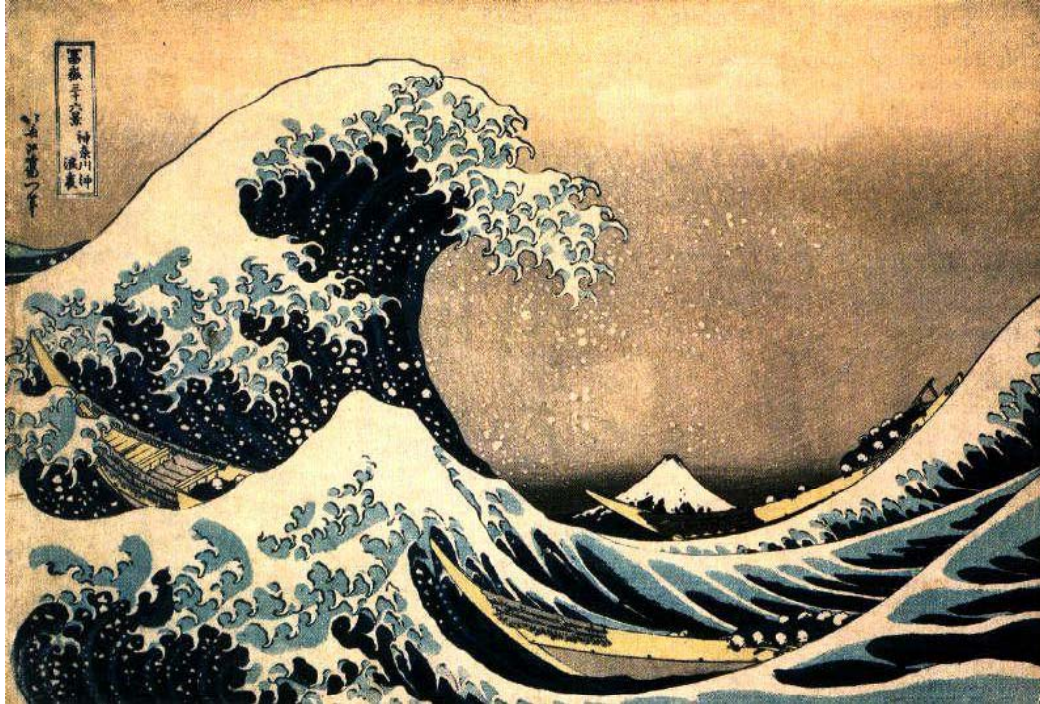
- Overwhelming volume of information
- Multitude of sources
- New channels
- Fragmented communications

Source: NCI Center for Bioinformatics Web site (https://cabig.nci.nih.gov/overview/Presentations_About_caBIG/document_view)

The New York Times
ON THE WEB

Awash in Information, Patients Face a Lonely, Uncertain Road

By JAN HOFFMAN
Published: August 14, 2005

Nothing Meg Gaines endured had prepared her for this moment. Not the six rounds of chemotherapy for ovarian cancer that had metastasized to her liver. Not the doctor who told her, after Ms. Gaines was prepped for surgery, that he could not operate: a last-minute scan revealed too many tumors. "Go home and think about the quality, not the quantity, of your days," he said.

⊞ Enlarge This Image

Not the innumerable specialists whom Ms. Gaines, then 39 and the mother of two toddlers, had already mowed through in her terrified but unswerving effort to save her own life. Not the Internet research and clinical trial reports, all citing the grimmest of statistics. Not the fierce, frantic journey she made, leaving home in Wisconsin to visit cancer centers in Texas and California.

Now, just about out of options, Ms. Gaines faced an excruciating decision. Her last-ditch chemotherapy regimen did seem to be working. Three medical oncologists thought she should stick with it. But two surgical oncologists thought she should first try cryosurgery, injecting liquid nitrogen into the tumors to shrink as many as possible, and then following up with chemotherapy.

Nicole Bengiveno/ New York Times

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Search Term	% Using Term
Depression	19%
Allergies/sinus	16%
Cancer	15%
Bipolar disorder	14%
Arthritis/rheumatism	10%
High blood pressure	10%
Migraine	9%
Anxiety disorder	9%
Heart disease	8%
Sleep disorders	8%

*Rice RE. The Internet and health communication: A framework of experiences. In: Rice RE, Katz JE, editors. *The Internet and Health Communication: Experiences and Expectations*. Thousand Oaks, CA: Sage; 2001. p. 5-46.
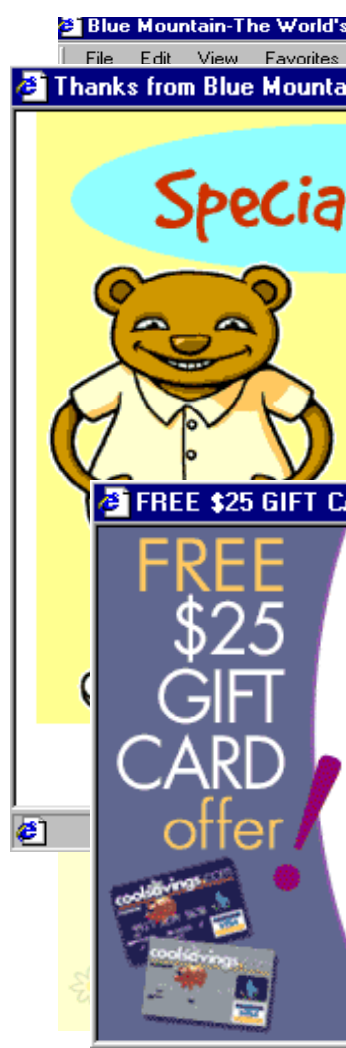
"Exploit value from each transaction"

"People no longer want to bend to antiquated rules of business. They do not want to be the objects of commerce, treated like anonymous pawns in the exploitative games of market segmentation, penetration, and manipulative psuedo-intimacy."

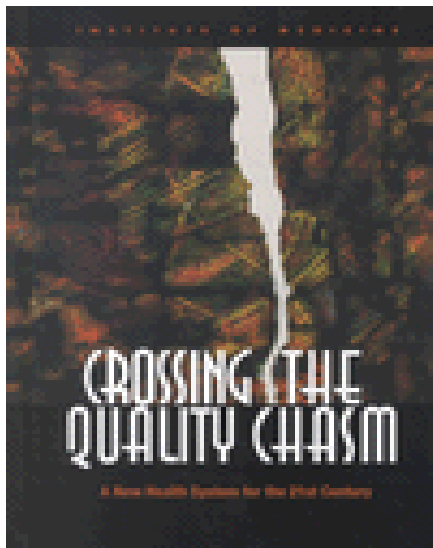*"Individuals want honest assistance in meeting the challenges of their intricate lives."*

- Shoshana Zuboff & James Maxmin "The Support Economy," p. 11-12
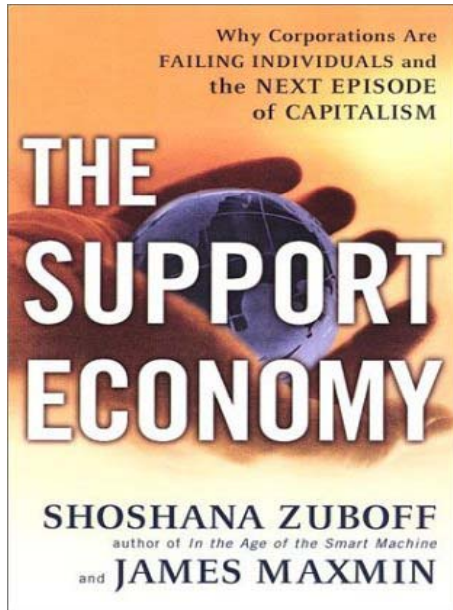
Deep Support

People experience "… an enormous hunger for self-determination in matters of medical care." … They want "tangible support" in leading healthy lives.

- Shoshana Zuboff & James Maxmin
*   "The Support Economy," p. 156-157*

Recommendation: "Care based on continuous healing relationships."

- Institute of Medicine,
"Crossing the Quality Chasm," p. 61

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Avert or Delay its Onset

Detect and Eradicate its Presence

Control its Behavior

Break in Support

Eligible Cases 833
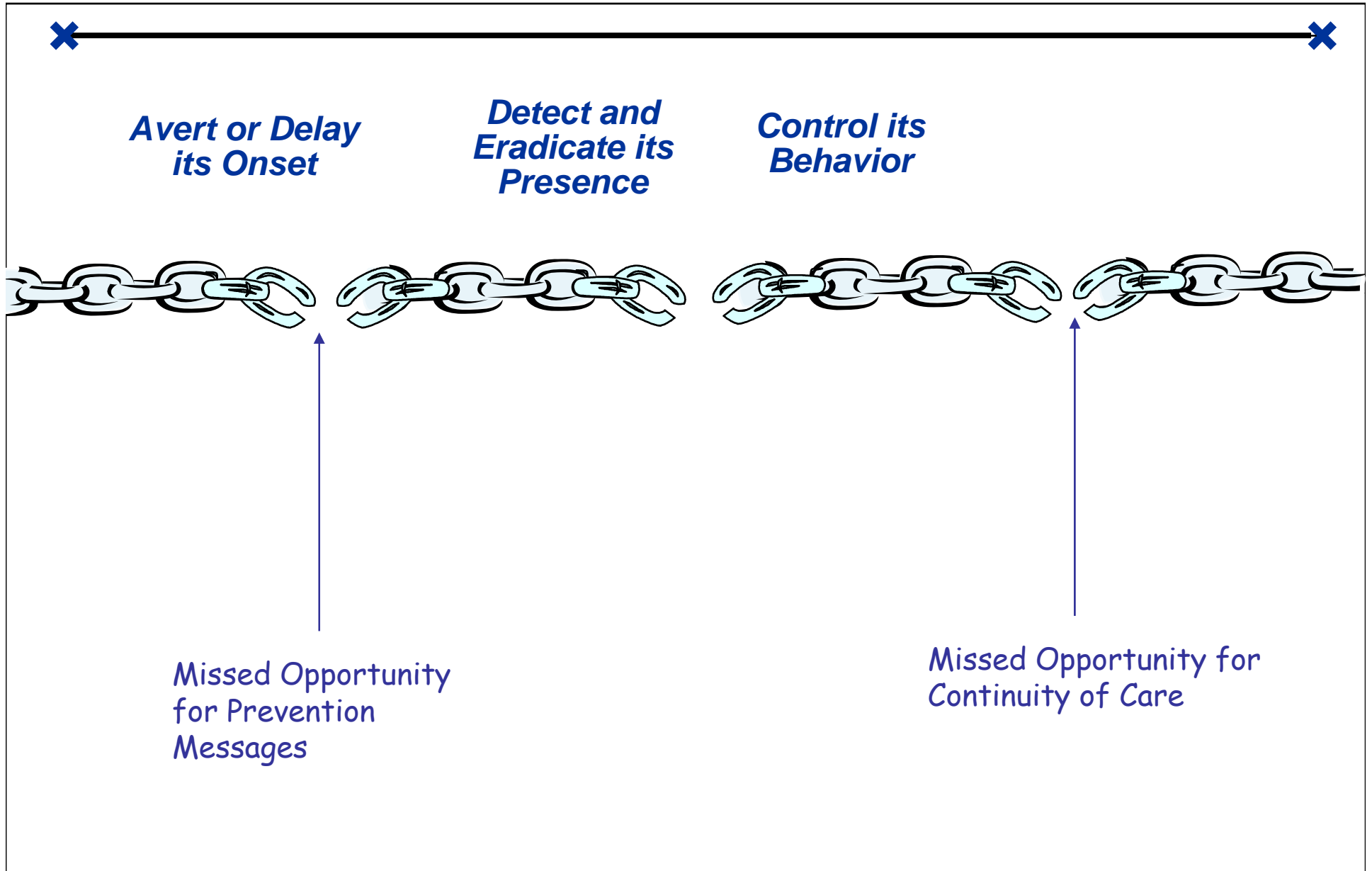
Chart review: Pap results 4-36 mos prior to dx

FAILURE TO SCREEN
No Pap
464 (56%)

FAILURE TO DETECT
1st Pap Normal
263 (32%)

FAILURE IN FOLLOW-UP
1st Pap abnormal
106 (13%)

Source: Leyden WA, Manos MM, Geiger AM, Weinmann S, Mouchawar J, Bischoff K,Yood JG, Taplin SH (2005). Cervical cancer in women with comprehensive health care access: Attributable factors in the screening process. JNCI, 97(9), 675-683.
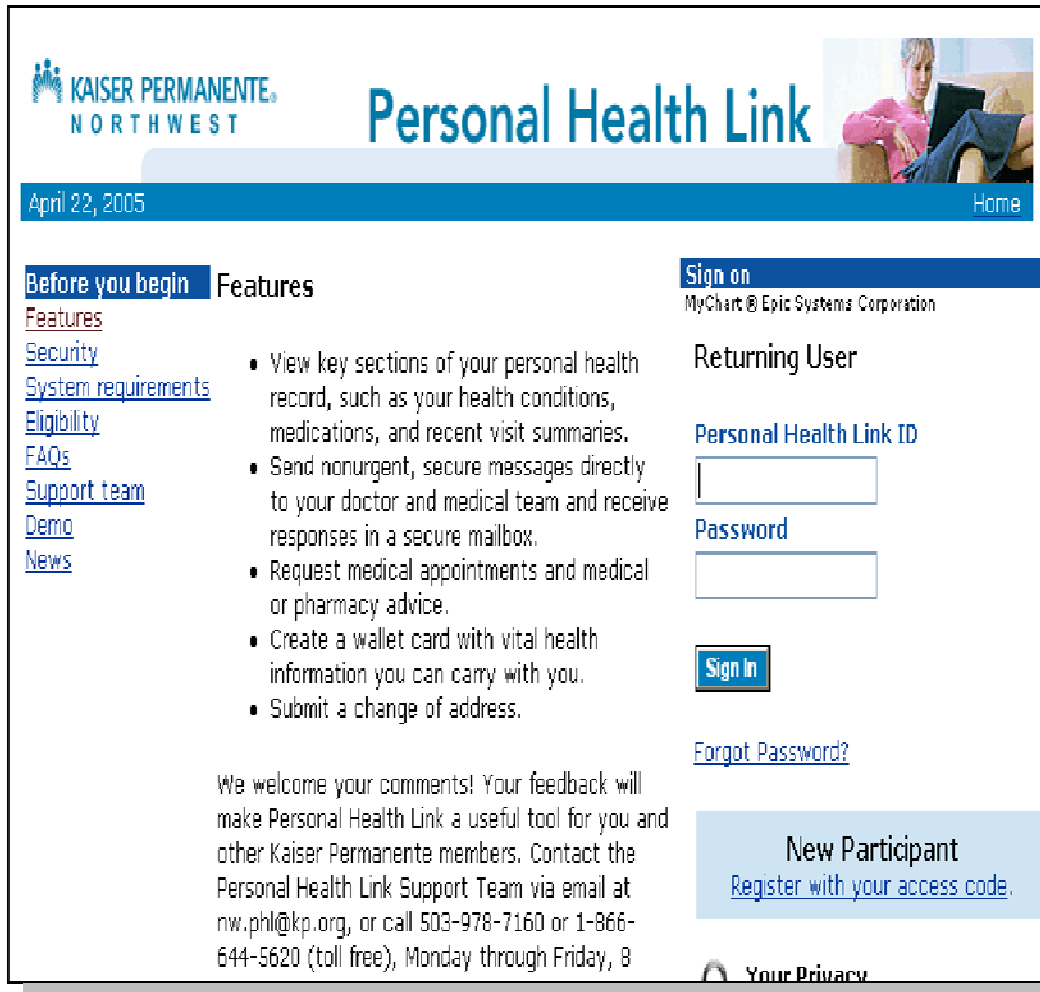
Avert or Delay its Onset

Detect and Eradicate its Presence

Control its Behavior

Missed Opportunity for Prevention Messages

Missed Opportunity for Continuity of Care

Goal: Unbroken Support

Avert or Delay its Onset

Detect and Eradicate its Presence

Control its Behavior

Coordinated Cancer Care Provides Preemptive Support Across Lifespan
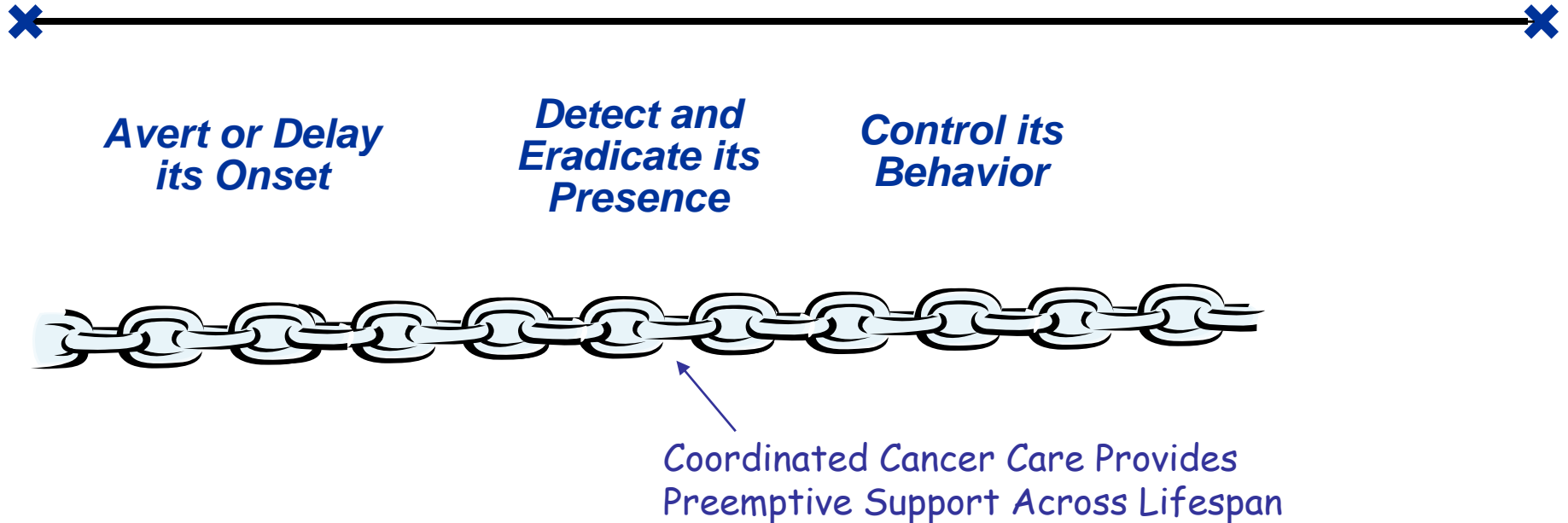
Goals Driving eHealth for Survivors*

1. **Prevention** of recurrent & new cancers and of late effects
2. **Surveillance** for cancer spread, recurrence, or 2nd cancers
3. **Intervention** for consequences of cancer and treatment
4. **Coordination** between specialists & primary care

* IOM, From Cancer Patient to Cancer Survivor: Lost in Transition, p. 3

"Moving toward a streaming, life-sensitive medical record – where data are collected continuously over a life time."

-Dr. David Brailer*

* Brailer D. Action through collaboration: a conversation with David Brailer. The national coordinator of HIT believes that facilitation, not mandates, are the way to move the agenda forward. Interview by Robert Cunningham. Health Aff (Millwood) 2005;24(5):1150-7.

Right Information at the Right Time
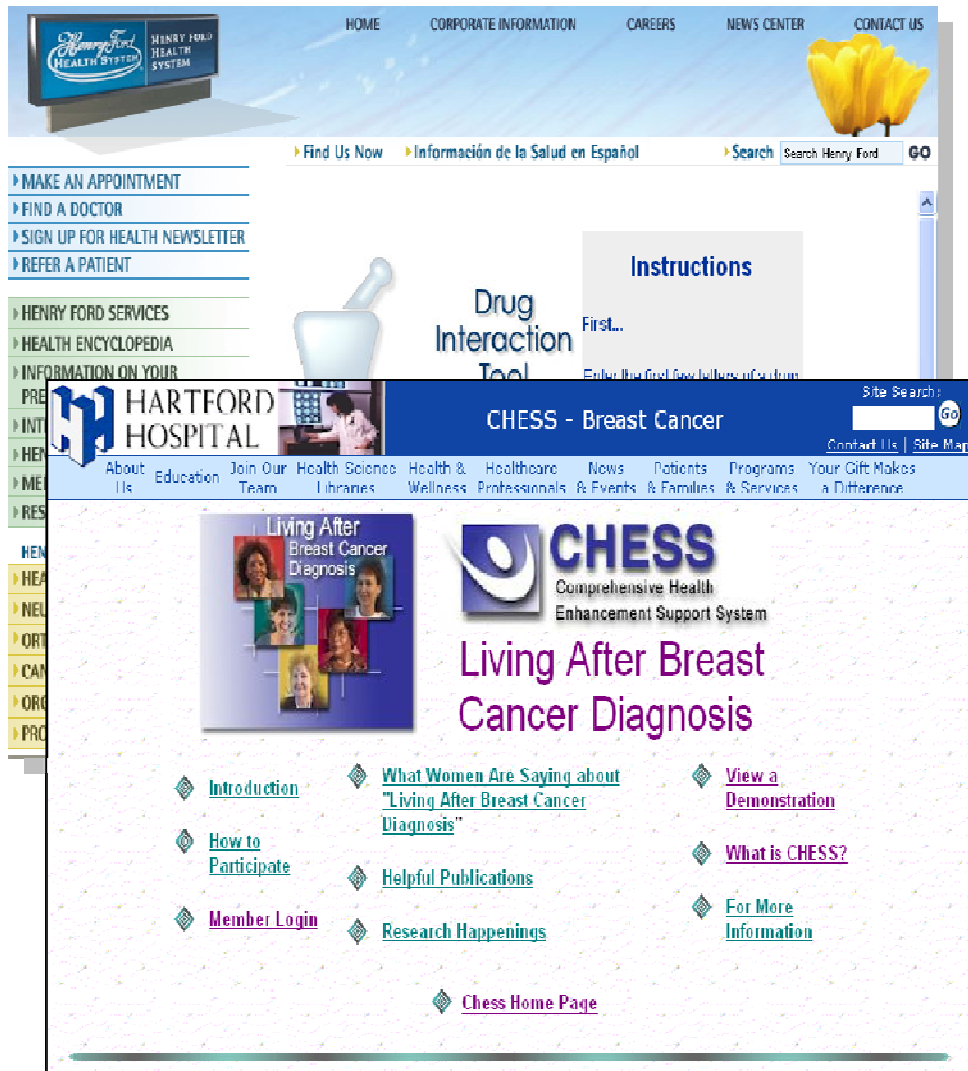
"How do we customize all the {online} textbook information available today and make it relevant to a specific person?"

-Dr. David Brailer

Introduction
- "Deep Support: Using eHealth Technologies to Foster Healing Relationships," B. Hesse

Research on Support Technologies
- "The Passport for Care Program," D.Poplack
- "Cancer Survivors – Successfully Swimming or Struggling to Stay Afloat in a Sea of Cancer-related Information?," N. Arora
- Using a Comprehensive Informatics Support System to Improve Survivor Outcomes

Cancer Survivor Panel Discussion
- Virgil Simons, Founder & President: The Prostate Net"
- Susan Lowell Butler, Executive Director, DC Cancer Consortium
- Gilles Frydman, Founder & President: Association of Online Resources