

Deep Support: Using eHealth Technologies to Foster Healing Relationships

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Break in Infrastructure, Aug. 29, '05



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



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

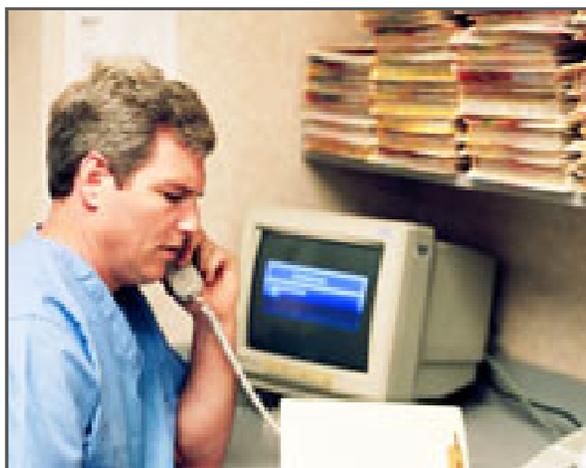
- **318** therapeutic trials were affected
- **7,717** patients participating in CTEP clinical trials were displaced
- CTEP help line 301-496-5725
 - Patients seeking treatment continuation
 - Treatment centers accepting displaced patients





ABC NEWS ORIGINAL REPORT

Digital Medical Records Survive Katrina

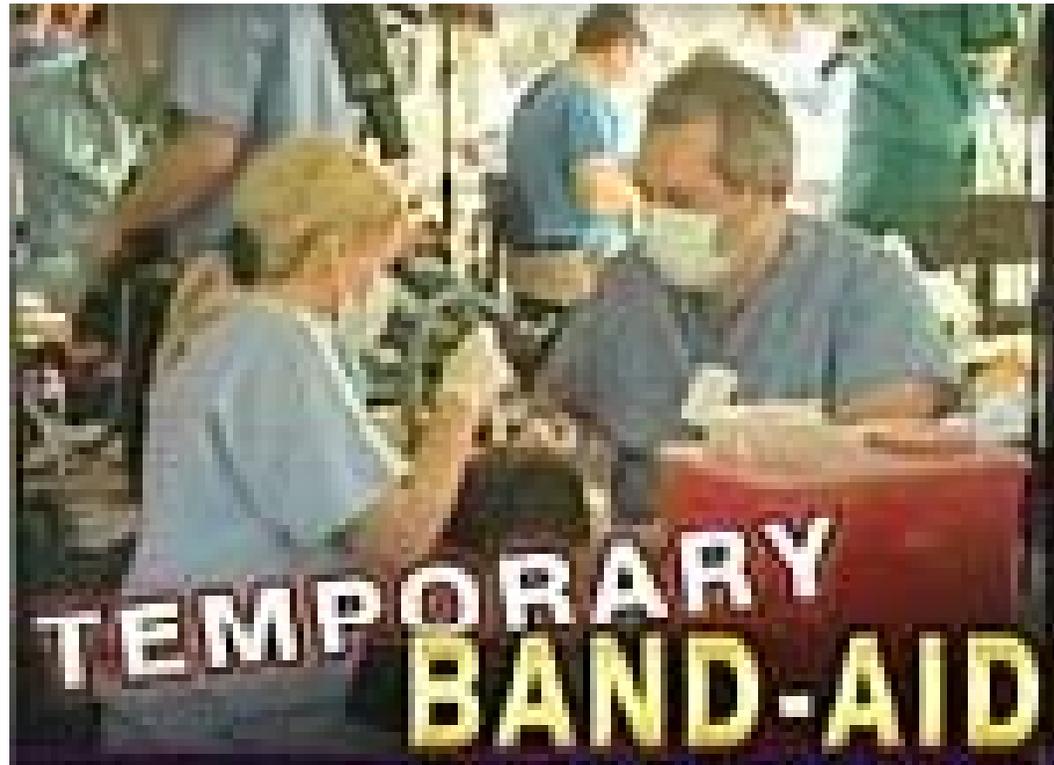


The Department of Veterans Affairs ditched conventional paper-based



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.

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



Restoring health records

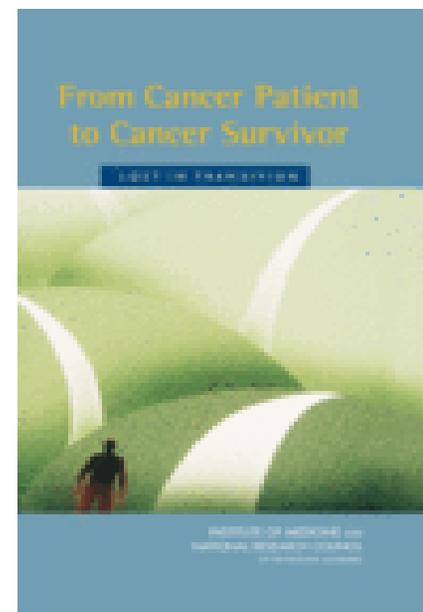
SUSAN DENTZER:

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.

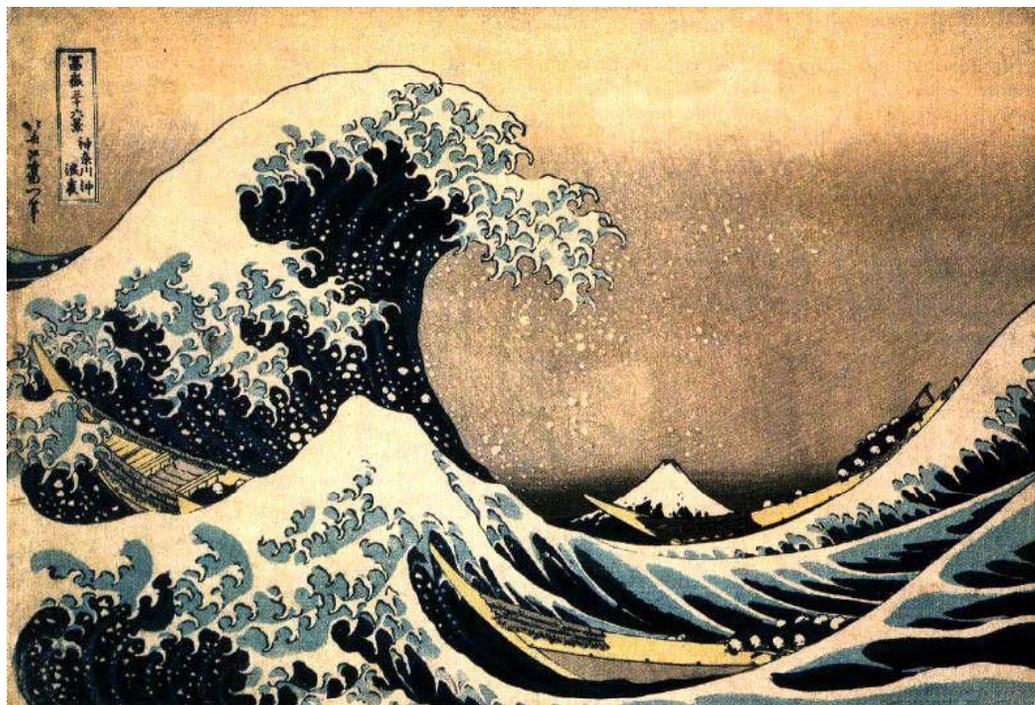
SUSAN DENTZER: The solution introduced at the fair was a new personal electronic health record, loaded onto a computer disk or memory stick for each attendee.

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](#)



Nicole Bengiveno/ New York Times

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.

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Public Turns to Web, Other Sources

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.

Transaction Economics

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Alanis Morissette

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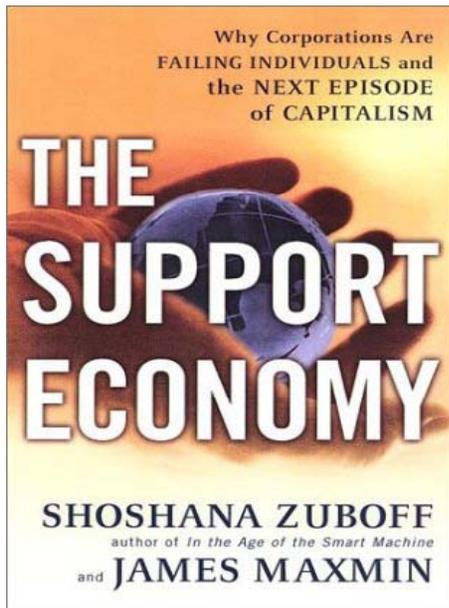
“Exploit value from each transaction”



“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.”

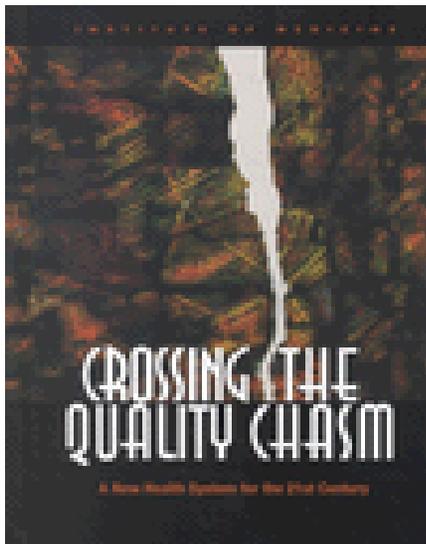
***- Shoshana Zuboff & James Maxmin
“The Support Economy,” p. 11-12***



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*

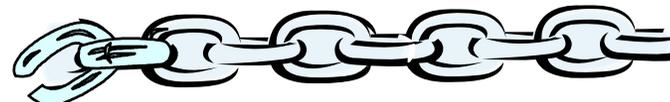
Consequences of Broken Support



*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

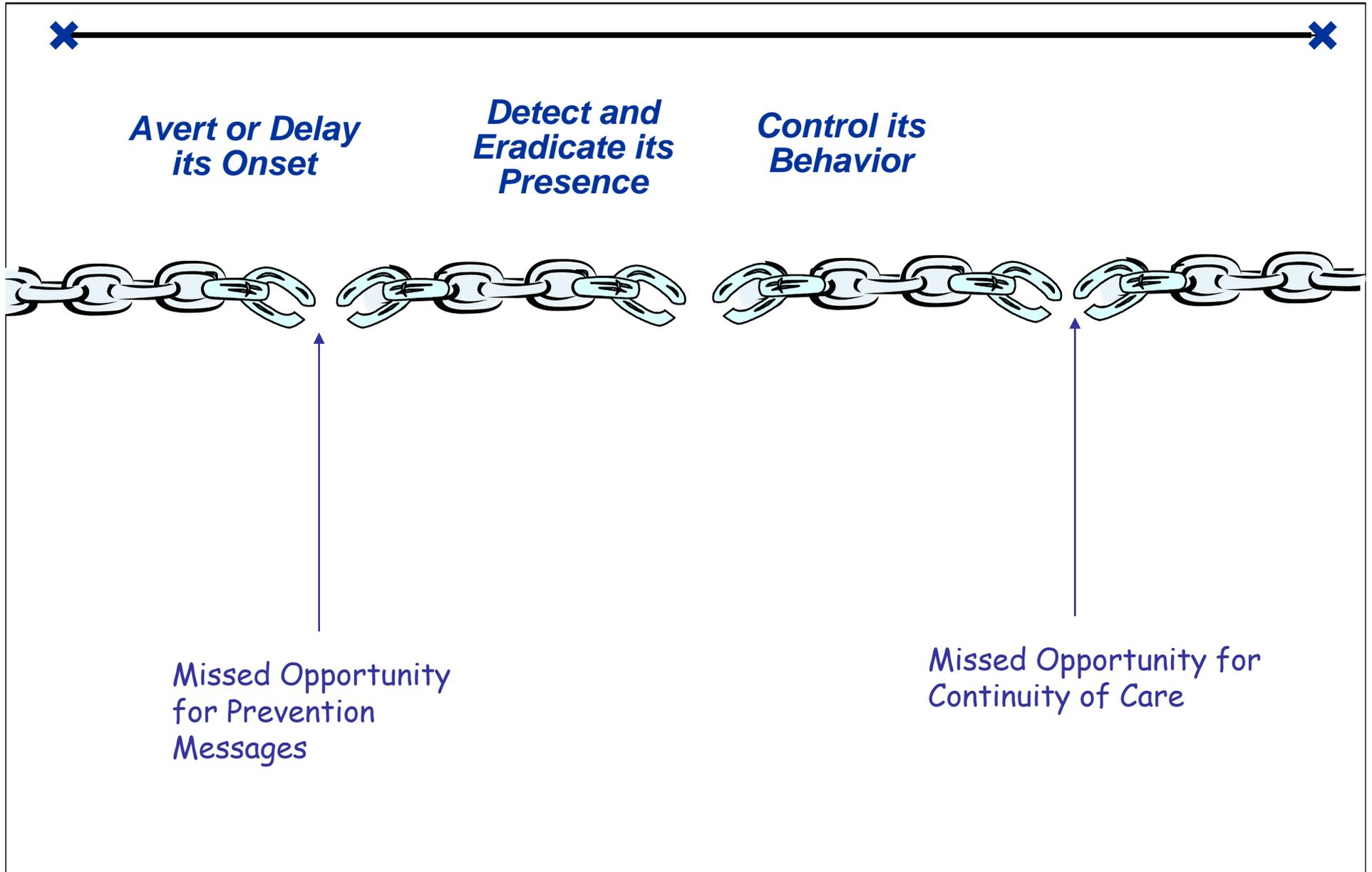
FAILURE TO SCREEN
No Pap
464 (56%)

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.

Other Breaks in Support



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

The screenshot shows the Kaiser Permanente Northwest Personal Health Link website. At the top left is the logo for Kaiser Permanente Northwest. The main heading is "Personal Health Link" with a background image of a woman sitting on a couch using a laptop. Below the heading is a blue navigation bar with the date "April 22, 2005" and a "Home" link. On the left side, there is a "Before you begin" section with a "Features" link and a list of features:

- View key sections of your personal health record, such as your health conditions, medications, and recent visit summaries.
- Send nonurgent, secure messages directly to your doctor and medical team and receive responses in a secure mailbox.
- Request medical appointments and medical or pharmacy advice.
- Create a wallet card with vital health information you can carry with you.
- Submit a change of address.

 Below the list is a paragraph: "We welcome your comments! Your feedback will make Personal Health Link a useful tool for you and other Kaiser Permanente members. Contact the Personal Health Link Support Team via email at nw.phl@kp.org, or call 503-978-7160 or 1-866-644-5620 (toll free), Monday through Friday, 8 AM to 5 PM PT." At the bottom left of the screenshot is a "Your Privacy" link. On the right side, there is a "Sign on" section for MyChart® Epic Systems Corporation. It includes a "Returning User" section with fields for "Personal Health Link ID" and "Password", a "Sign In" button, and a "Forgot Password?" link. Below that is a "New Participant" section with the text "Register with your access code."

“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.

The screenshot shows the Henry Ford Health System website. At the top, there are navigation links: HOME, CORPORATE INFORMATION, CAREERS, NEWS CENTER, CONTACT US. Below this is a search bar with the text 'Search Henry Ford' and a 'GO' button. On the left side, there are several menu items: MAKE AN APPOINTMENT, FIND A DOCTOR, SIGN UP FOR HEALTH NEWSLETTER, REFER A PATIENT, HENRY FORD SERVICES, HEALTH ENCYCLOPEDIA, INFORMATION ON YOUR PRE, INT, HEI, ME, RES, MEN, HEA, NEL, ORT, CAN, ORG, PRO. The main content area features a 'Drug Interaction Tool' with a mortar and pestle icon and a 'Living After Breast Cancer Diagnosis' section. The 'Living After Breast Cancer Diagnosis' section includes a sub-header 'CHES - Breast Cancer' and a list of links: Introduction, How to Participate, Member Login, What Women Are Saying about "Living After Breast Cancer Diagnosis", Helpful Publications, Research Happenings, View a Demonstration, What is CHES?, For More Information, and Chess Home Page.

“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