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Hurdles in the Information Age on Public Health Practice and Healthcare Delivery...

At issue: Privacy, Security, Quality, and the Digital Divide

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2. Todo esta desconectado

3. Hay que pensar en la complejidad de los sistemas

3 Modelos

- El sistema de Súper-Carreteras Eisenhower
- NASA Monitoreo de los astronautas
 - DoD Telemedicina en zonas de guerra
 - DARPA Internet
- La Industria del entretenimiento
 - Juegos computarizados
 - La producción de películas

AGENDA

- El resto del mundo
- Que es el "Digital Divide"
- Genética: Privacidad y Seguridad de la Información Medica HIPAA -
- Múltiples aplicaciones del EHR y de la NHII
- Publicaciones, y Diseminación de la información, Infraestructura
- CONTENIDO
 - Areas (Past, Current and Future)
- Problemas y Oportunidades
 - Administración del conocimiento
 - Multidisciplinas e Ínter disciplinas
 - Otros campos (i.e., NASA, DoD, etc.) Sociedades y "Journals"

Spread of HIV in Sub-Saharan Africa, 1984-1999



The USA view...just a decade ago

- 42% of all US households have computers [24% in 94, 37% in 97]
- 94% of all US households have telephone
- 98% of all US households have television
- U.S. households with Internet access: 26%
- Public schools in the U.S. connected to the Internet: 95% [35% in 94]
- Instructional classrooms connected to the Internet: 63% [3% in 94]

The USA view...Underserved Americans

- White households with Internet access: 29.8%
- Black households with Internet access: 11.2%
- Hispanic households with Internet access: 12.6%
- College educated individuals with Internet access: 48.9%
- Individuals with some high school education with Internet access: 6.3%
- Two-parent households with Internet access: 39.3%
- Female, single parent households with Internet access: 15%
- Children in urban households earning > \$75 K with Internet access: 50%
- Children in low-income, rural household with Internet access: 2%





Americans in the Information Age Falling Through the Net

esident Clinton's New rkets Tour

Digital Divide Summit

On December 9, 1999, the Secretary of Commerce held a <u>Digital Divide</u> Summit, and announced a new web site, <u>digitaldivide.gov</u>.

<u>marks by President Clinton</u>

<u>marks by Secretary of</u> mmerce William M.Daley

<u>marks by Assistant</u> cretary Larry Irving

<u>IA Press Release</u>

lated Department of mmerce Reports



Falling Through the Net: Defining the Digital Divide

Released July 8, 1999, revised November 1999. Third report in the Falling Through the Net series on the Telecommunications and Information Technology Gap in America.

A <u>PDF version of the report</u> is also available (500KB).





NTIA Press Release

Related Department of Commerce Reports

America's New Deficit -- The Digital Work Force: Building Infotech Skills at the Speed of Innovation (PDF file)

U.S. Government Electronic Commerce Policy



A <u>PDF version of the report</u> is also available (500KB).

Previous Reports in the Falling Through the Net Series

July 1998: Falling Through the Net II: New Data on the Digital Divide

July 1995: Falling Through the Net: A Survey of the "Have Nots" in Rural and Urban America

Fact Sheets on the Digital Divide

- Americans Increasingly Use Internet Outside the Home
- Americans Using Internet for Many Tasks
- Education: Boosting the Odds for Internet Use
- "Digital Divide" Widening at Lower Income Levels
- Government Programs Designed to Close the Divide
- Hispanics Falling Back in Information Age
- In Information Expansion, Blacks Lag Behind
- Native Americans Lacking Information Resources
- Racial Divide Continues to Grow
- Rural Areas Magnify "Digital Divide"
- Single Daropt Households At Information Disadvantage

Broad assessment involved:

- Telephone, Computers, Internet/TV/Web
- Internet Access and Usage
- Challenges: Universal Access, Community Access Centers
- Home and external access
- Income
- Race/Origin
- Education
- Household type
- •Age
- Region
- •Gender



Mar 16 2000: A new study finds that the content and information needs of 50 million Americans are not being catered to online. Content aimed at low-income Americans and those with poor literacy is next to invisible online, according to authors of the study, Children's Partnership. The study looked at the information needs of two disadvantaged social groups and then investigated to what extent their needs were being met on the Internet. The results were shocking.

 44 million US adults have below average reading abilities yet less than 1 percent of websites catered to this group.

•2 percent of sites catered to the 32 million non-English speaking population in the US

•1 percent catered to the 26 million foreigners living in the States.

From NASA's monitoring of astronauts, DARPA's "Internet" and DoD's telemedicine

to

Homecare of the elderly & management of diabetes through the Internet

Decision Support Systems for Health Providers and Consumers



Electronic Health Information: Uses & Concerns

The HIPAA Compliance Puzzle





Privacy of Medical InformationSecurity

Electronic Medical Records

Vulnerable⊰ Data <Patient Name>

Patient Identifier

Input Query Elements <TNSURANCE CARD> <SSN> < Genetic map/coding> <Mother's Maiden Name> <Drivers License#> <ADDRESS > <CREDIT CARD> <CARD NAME="eCard"> <Demographic Information> <0000-123-456-7890-XXXX> <MEDICAL RECORD #> Enter name: <INPUT KEY="N"/> Choose Department: <SELECT /ALLOWED KEY> <VULNERABLE FIELDS> <COMBINATIONS FROM OTHER SOURCES> <SELECT> <DIAGNOSIS>

Patient Card

Patient Chart

Decision Support Systems for Health Providers and Consumers



GLOBAL GENETIC INFORMATION INFRASTRUCTURE

National Patient Identifier

Family's Record •Grandparents •Parents •Siblings

Demographics History Genetics

2.-Digital Libraries (of genetic diseases):
•Genome maps, sequences, gene expressions, etc.
•Diagnostic, therapeutic and prevention guidelines
•Best practices



GLOBAL GENETIC INFORMATION INFRASTRUCTURE

High Performance Computers and Communications and Disease Prevention



Intelligent Agents bring "quality pre-approved" information into the patient's record / or care giver or to the attention of the public...

- •Computer Based Pt. Record [CPR] •Standards for Data Representation
- •Standard Terminology / Vocabulary •National Patient Identifier
- •New diagnostic testing at birth
- Integration of distributed and heterogeneous Data Bases
- •Integration to Query Systems.
- •Integration between CPR and Intelligent Systems.
- Integration to Computer based decision support systems [CDSS]
- •Creation, Support, Maintenance of CDSS
- •Standardization of genetic related prevention guidelines
- •Development of best practices
- •Quality of Information
- **•**Dissemination Practices
- •Development of Digital Libraries for genomic related diseases, maps, sequences, gene expressions, etc.
- •Development and integration of tools [I.e.visualization] for automatic pattern recognition utilization

FUNCTIONAL REQUIREMENTS

GLOBAL GENETIC INFORMATION INFRASTRUCTURE

Development of medications for individualized treatment of multiple or singular conditions.
Development of vaccines curing and/or disease prevention
Gene manipulation for curing and/or disease prevention

Representative Projects

- ✓ Shared Data Bases
- PRIVACY and Security
- ✓ Dissemination
- ✓ Digital Libraries
- ✓ Advanced Laboratory Workstations
- ✓ Testing Techniques
- ✓ ETHICS



- IEEE-USA position statement February 2001 against the use of universal identifiers <u>http://www.ieeeusa.org/policy/POSITIONS/universalidentifiers.html</u>
- Change in heart June 17 2004 -Voluntary Healthcare Identifier http://www.ieeeusa.org/policy/POSITIONS/healthcareidentifier.html

Definitions and Concepts

Computer-Based Patient Record (CPR)



The Dimension of Time in the CPR



Application Examples

•Home

-Communicate behavioral/health issues



Use of Store and Forward Telemedicine for Healthcare of Children with Autism, Oberleitner, Harrington et al, American Telemedicine Conference, April, 2005

Mychildshealthrecord.com



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Works with other Record Systems



Personal Health record - AGRE Data Bank

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The Dimension of Time in the CPR

Provides a single OUTCOMES Measurements Repository for information recorded by multiple organizations throughout the patient's lifetime – Example:

From Civilian, to Military (DoD), to VA, to Civilian.

* Ways & Means Committee, Testimony on June 17, 2004



Improving Content & Multiple use of the "highway"



THE FUTURE OF EMERGENCY CARE IN THE UNITED STATES HEALTH SYSTEM – June 14, 2006

Radio Frequency Identification (RFID) Tags



ID: Juan López Address: Av. Danubio 28 City: Paysandú Contact: Maria López [daughter] 123-5678 Notes: Patient suffers from Alzheimers and Hypertension.

Alergies: lodine, fish Medications: Lisopril 20 mg/day

> Size: 32 Price: \$45

Computer

Data Mining

- Process of discovering new correlations, patterns, anomalies and trends by sifting through large amounts of data
- Pattern recognition technologies and statistical and mathematical techniques
- Bottom-up discovery data analysis, also known as "knowledge discovery"
- Applications
 - Credit Scoring
 - Fraud Detection
 - Churn Analysis
 - Marketing
 - Sales
- Public Health
 - Epidemiology
 - Surveillance
- Disease Prevention wellness
- Environmental Health

Privacidad vs. Seguridad

Creating Meaning— Linking Digital Data to Geography



- Street addresses (my address)
 Streets/Rivers/Land features
 Hospitals/Medical centers/Clinics
 ZIP Codes/Counties
- [•] Spatial analysis (i.e., travel times)
- Service demand/Provider density

Creating Meaning— Linking Digital Data to Space



- **Bed location (my bed)**
- Fluids/Air lines
- **Dedicated electric circuits**
- Fire and smoke sensors
- **Occupancy zones**
- Negative pressure zones

Bed/Care Management



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Notification of an emergency



Example of Aftosa:

- ArgentinaBrazil
- Uruguay

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Surveillance / Medical Control









Integrating Surgical Systems for Autonomy "the staffers"





100,000

Surgeon

Assistant

Scrub Nurse

Circulating nurse

Courtesy: Satava March, 2000

MEMS — intelligent tools for surgery



Courtesy: Michael Miguilio, Xactria, Inc, Pittsburgh, PA

20.04





"Penelope" – robotic scrub nurse

Michael Treat MD, Columbia Univ, NYC. 2003

The future OR



S



Encapsulated camera gastrointestinal endoscopy

Cortesy: Paul Swain, London, England

Intelligent Prosthesis MEMS - Neurosurgery for monitoring spinal fusion

Spinal Instrumentation





Antenna

Pressure

Sensor

Electronics Module

Strain Gauge



Coutresy: E.C. Benzel, L.A. Ferrara, A.J. Fleischman, S.Roy

Accelerating Delivery of New Therapeutics





Knowledge Management

Using the example of Biomedical Engineering And Computer Science

















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Special Issues of the IEEE-EMBS Magazine Dedicated to Bioterrorism and Homeland Security





Biomedical Informatics in Perspective



Biomedical Informatics in Perspective from a multidiscipline perspective: Multiple Stakeholders

Biomedical Informatics Methods, Techniques, and Theories



Bioinformatics Imaging Informatics Clinical Informatics P

Public Health Informatics

Applied Research

Basic Research

Kun, L: Medical Informatics, CRC Press, Handbook of BME, 2006 Biology -Biomathematics-Medicine-Nursing-Computer Science-Engineering Epidemiology-Public Health-Surveillance-Vaccine Registries-GeoSpatial-Emergency Preparedness and Response-Genetics-Statistics

Molecular and Cellular Processes

Tissues and Organs

Individuals (Patients) Populations And Society

Impact of the Information Age

- Information Age
 - Public and professional expectations
- Impact of IT
 - Advances in biomedical, public health (and other fields) research
 - Changes in the way we teach, we learn, we do R&D, the way we do business and the way we publish and disseminate data, information and knowledge.
 - Convergence of (most / many) technologies
 - Has cascading effects, and create new dependencies that require different specialization and therefore bring new stakeholders into the process.
 - Coordination ("Connecting the Dots")
 - Synthesis ("Info-Glut")

Impact of Globalization

- Increased pace of cultural and economic interconnectedness
- The interconnectivity means interdependence
 - Every action has multiple implications for this and for other spheres
 - Difficult to identify the unintended consequences of actions or in-actions (from us to others and from others to us)
- We know about problems sooner, they come to us faster which creates: an increased pressure for resolution and an increased opportunity for collaboration.
- Crisis
 - Local crisis have global implications and global crisis have local implications
 - Not only "population / public health implications" but National Security implications as well (i.e., the economy of a nation can be completely ruined)

Challenge of connecting the "islands of excellence"

- If we look at all the societies that work in the health care arena, and we carefully inspect all their areas of specialty we will find that increasingly all of them find a "potential application" or niche that is (health or biology) related and that we may need to explore.
- In other cases BM engineers may find tools and or applications that require a new defacto partnership with someone (outside the field) that may possess the answer to a particular problem.

Many of these issues of organizations whose knowledge has grown vertically deeper and deeper become defacto stovepipes. "Horizontal" integration with the other segments, becomes then very difficult to accomplish.

Challenges (cont.)

- Getting the benefits of "cross-fertilization"
 - Multi-disciplines and its benefits
 - Inter-disciplines and its benefits
- Getting the bigger picture and a more accurate one allows you (the field) to grow both in depth and in breadth

The applications include clinical information systems, systems such as decision support systems and computer assisted or remotely guided diagnostic and therapeutic procedures based on e.g., virtual reality, applications and technologies for collaboration of healthcare providers (telemedicine), home healthcare (hospital without walls), disease management, eHealth, and health and wellness management.

The integration aspects may range from functional and semantic interoperability, clinical guidelines and pathways, protocol-based care, and evidence-based medicine, architectures and middleware to hardware and software security aspects and privacy of confidential patient data.

In the field of biomedicine covering IT tools and methods (including GRID computing applications) to improve our understanding and knowledge of biological systems, such as bioinformatics, tools for protein sequencing and proteomics, computational biology, biocomplexity and modeling of the physiological system.

Change of attitudes ...

In the use of global resources to resolve local issues / problems. Although they are global issues / problems

- AIDS / HIV): 2 decades ago (~1985) ... no solutions.
- SARS: Spring 2003 working as a group, multiple solutions through the use of the Internet and the WWW.
- CONSIDERATION: What was the reason for this shift?
 - Time?
 - Generational? ...