Empowering, Embracing, Energizing Customers: A Mandate for Change

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Empowering, Embracing, Energizing Consumers: A Mandate for Change

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Support for the development of this presentation came from the Moehlman Bascom Fund, the NIH, and numerous conversations with colleagues and students.
Somewhere, not too far away...

John, a 41 year old man, presents at an annual physical two major complaints: right lower quadrant tenderness and a slight change in bowel habits

Shortly, however, the diagnosis is confirmed:

*Familial Adenomotosis Polyposis (FAP)*
DNA tests identify that the mutation is on Codon 1251.

Fear, and hope, lead John to consult all of the experts he can find.

John’s doctor, believing in collaboration, sends John all of the reports, makes a recommendation of surgery and solicits John’s preferences.

John searches the Web, opts for surgery.
John’s chance of success depends in part upon the ability of John and his clinicians to engage in a care partnership characterized by empowerment.
Empowerment

“... a social process of recognizing, promoting, and enhancing peoples’ abilities to meet their own needs, solve their own problems and mobilize the necessary resources in order to feel in control of their lives”

Gibson, 1991
Empowerment: does it work?

Coaching patients using empowerment strategies leads to improved self management but...

empowerment approaches which lack a concomitant response from providers are wasteful and may even have harmful effects
Empowerment emerges within care partnerships

**Demand-side**
*(What the patient needs)*
- Adequate knowledge
- Realistic Goals
- Systematic problem solving
- Coping & Stress management
- Social support
- Self Motivation

**Supply-side**
*(Clinicians & care system)*
- Commitment to collaborate
- Content
- Communication
- Comprehensive
- Confidentiality
- Continuity
Empowerment:
Where does information technology fit?
Empowerment: IT requirements

• Comprehensible, relevant information
• Communication with peers and professionals
• Personal Case Management tools
  – Self-monitoring Modules
  – Decision support systems
• Ubiquitous, complete records access
Empowerment:
IT requirements

• Comprehensible, relevant information
Health Information on the ‘Net: How accurate is it??

89-95%

51%
Empowerment: IT requirements

- Comprehensible, relevant information
- Communication with peers and professionals
- Personal Case Management tools
  - Self-monitoring Modules
  - Decision support systems
Baby Link
Comprehensive Health Enhancement and Social Support (CHESS)
HeartCare

Welcome to HeartCare

username: 

Enter HeartCare

Wednesday, July 28, 1999

Have you seen the AHA’s new section on the latest heart research?
Empowerment = positive health outcomes

• Baby CareLink (Grey, Safran et al, 2000)
  – Greater satisfaction with care, trend towards shorter stay for VLBW

• CHESS (Gustafson et al, 2000)
  – Greater participation, greater control, greater functional well-being

• HeartCare (Brennan, Moore et al, 2001)
  – Patients get better, faster, with fewer symptoms
Empowerment: IT requirements

- Comprehensible, relevant information
- Communication with peers and professionals
- Personal Case Management tools
  - Self-monitoring Modules
  - Decision support systems
- Ubiquitous, complete records access
An IT Architecture that supports empowerment
Empowerment: Directions for the Decade

1. Insure that content is correct, relevant, & accessible
2. Re-engineer clinical practice to capitalize on IT innovations supportive of empowerment
3. Extend the accomplishments of community-based empowerment approaches into institutional care settings
Empowering Consumers:

No longer an option, a necessity!
Beyond Empowerment

• Embracing Consumers
  – Key part of the care team
  – Cultural considerations

• Energizing Consumers
  – The ‘greatest unused resource in health care—and UNPAID!'
IT Recommendations to support Patient Empowerment

IMIA WG 10 Health Information Systems
Charles Safran, Patti Brennan (co-chairs)
Christos Bountis, Hans Ulrich Prokosch, Ursula Veltmann, Frank Ückert, Zoë Stavri, Paul Clayton, Lise Marin, Peter Pietrzyk, Dorothee Dengler, Gunther Eysenbach
Overview of Recommendations

• HIS should employ health professional/patient collaboration as a design philosophy
• Promote Collaborative HIS
  – Consultation/communication tools
  – Information management tools
• Operational Recommendations
• Research Recommendations
Stakeholders

The rights and responsibilities of each stakeholder must be respected

- Healthcare institutions
- Clinicians and other providers
- National health systems
- Payers / Insurance companies
- Individuals, families & communities
Components for the Proposed Collaborative HIS

*Within a secure environment*

- Electronic patient record(s)
  - Belongs to institution(s)
- Personal Health Record
  - Belongs to the person, not the institution
  - Two manifestations
    - Part replica of the institutional record
    - Personally-created and maintained by the individual
- Electronic communication
- Supported by knowledge resources
- Process Utilities
Consultation/Communication Tools

- E-mail
- Conferencing
- Messaging services
- Threaded discussions
- Annotated bibliographies and dynamic references
- Community expert systems
Information management tools

- Data display
- Data acquisition
- Access management, rights and responsibilities
- Identification and definition of data elements
- Links between clinical record, personal health record, human genome, literature and clinical knowledge-bases
- Quality control
- Knowledge navigation
Operational Recommendations for a Collaborative HIS

1. Characterize the personal health record and clarify the relationship between electronic patient record and the personal health record
2. Document best practices
3. Define and promote delivery systems changes and computer tools needed to permit collaboration in achieving healthcare goals
4. Bring clinicians’ attitudes in alignment with a philosophy of collaboration
5. Deploy the set of information, information management and computer tools is needed to complement the health record.
Research

- Examine the impact of collaborative HIS on patient and care team and clinical outcomes
  - Time management impacts
  - Alterations in care processes
- Evaluate patients’ and clinicians’ responses to the transparency of health service delivery
- Host a working group conference linking WG 10 and WG2 efforts on a collaborative health record