What Nurses Need to Know About Consumer Empowerment and the Personal Health Record

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Webinar Objectives

1. List 3 factors that have led to the rise of health care consumerism in the United States.
2. List 3 events in recent years that reflect momentum among a wide variety of stakeholders for Personal Health Records (PHRs).
3. List 3 barriers to greater use of PHRs among the general population.

NOTE: Please complete the post-webinar evaluation.

CEU credit for nurses will be issued if you provided license information when you registered and complete the evaluation survey at the end of the survey.

This webinar recording and slides will be posted on the TIGER website at: www.tigersummit.com and on the PHR wiki at: http://tigerphr.pbwiki.com

Today's Presenters

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The Rise of Health Care Consumerism in the U.S.

- Natural progression of the consumerist movement
- Consumer frustration with fragmentation of care
- Rising costs of health care and shifting of costs to consumer
- Consumer-directed health plans (CDHP)
  - Forces consumers to take responsibility for health care spending
- Legislation that grants specific rights to consumers for access to their health information (HIPAA)
- Demand from consumers to participate as partners in health care, not objects of it
- Wellness demands by employers
- Mobile population, no single lifelong source of medical record

And, of course, access to the WWW
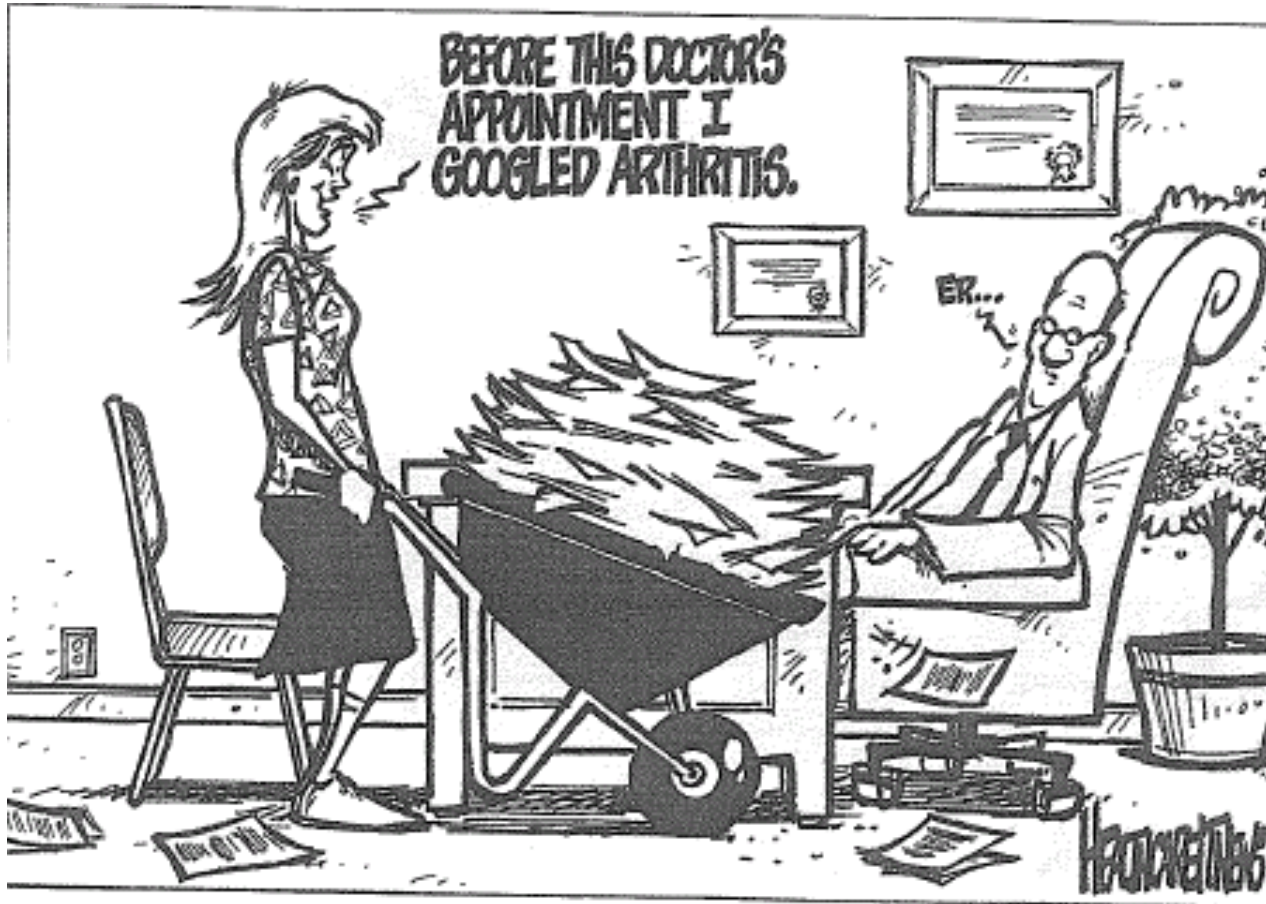
Other Health-Related Technological Resources that Enable the Empowered Consumer

- Disease-specific support groups
- E-mail communication to family, friends and health care providers
- Healthcare systems site offerings as competitive differentiator
- Health risk appraisal tools
- Disease-specific sites that enable self- monitoring (e.g. diabetes, smoking cessation)
- Broadband infrastructure availability for internet
- Most Community libraries with internet connectivity

And, of course, the Personal Health Record

What is a PHR? No Widely Accepted Definition

American Health Information Management Association (AHIMA) definition:

- The Personal Health Record (PHR) is an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions
- Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual
- The PHR is maintained in a secure and private environment, with the individual determining rights of access
- The PHR is separate from and does not replace the legal record of any provider

Information Most Frequently Stored in PHRs

1) Insurance information, such as policy numbers
2) Physician/specialist contact information
3) Personal information such as contact information, social security number
4) Current prescribed medications
5) History of insurance claims, payments, and health expenses
6) Illnesses and surgeries
7) Immunization records
8) Past lab results

Forrester Research, June 2006

Infrastructure PHR Concepts in 2007

Not about technology – it's about information**

In the face of some 200 PHR offerings – Brailer stresses:

- **Technology provides right infrastructure**

- **PHR strategy is based on good health information**

- **Not dependent upon employer, insurance carrier, or residence**

  - information that is well-structured
  - information that is standardized
  - information that is portable
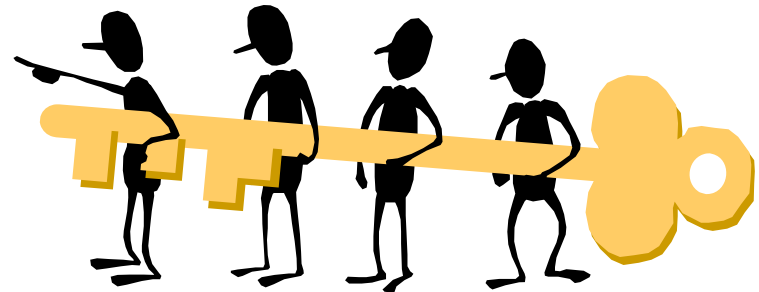
**Milstein A. Health Information Technology is a vehicle, not a destination: a conversation with David J. Brailer. Health Affairs Web Exclusive,'s Heal Feb 15, 2007

Health Issues and the Aging Population

- **The over 65 population will nearly triple – over 70 million**
- **More than 6 of every 10 Boomers will be managing $\geq$1 chronic condition**
  - **80% of Americans 65 and older have at least 1 chronic disease requiring on-going care**
- **More than 1 out of every 3 Boomers will be clinically obese (21 million)**
- **1 of every 4 Boomers will be living with diabetes (14 million)**
- **Nearly 1 out of every 2 Boomers will be living with arthritis**
- **8 times more knee replacements will be performed than in 2007**
- **62% of 50 to 64 year olds report having at least 1 of 6 chronic conditions (hypertension, hi cholesterol, arthritis, diabetes, HD, or cancer)**

American Hospital Association and First Consulting Group. "When I'm 64: How Boomers Will Change Health Care". AHA: Washington DC 2007

"Boomers early participants in era of virtual caregivers"

- Health technology will move into the home
- Remote monitoring, wearable devices and communication links with caregivers
- Technologies will keep people out of hospital, or avoid need to come into clinic
- Less invasive surgical options w/ new technologies
- But service demand exceeds supply of caregivers

American Hospital Association and First Consulting Group. "When I'm 64: How Boomers Will Change Health Care". AHA: Washington DC 2007

PHR "System" May Offer Tools for Education, Health Management and Communication

- Education and decision support

- Communication and support

- e-Commerce

- Personalized services

- EHR/EMR integration

- Journaling and home monitoring tools

HIT- Enabled Innovations in Care Delivery

- **Telehealth and virtual health care teams**
    - Remote monitoring with integrated medical devices
    - Primary care delivered virtually
    - Multidisciplinary teams

- **Senior care and the medical home**
    - Baby Boomers will explode demand on healthcare system
    - Goal to keep seniors in the home
    - Care management & PHRs

- **New roles for nurses**
    - Telehealth – primary care remotely
    - Virtual nurse for health populations

And, of course, the Personal Health Record

![MODERN HEALTHCARE ONLINE]

"Personal health records are probably the hottest thing in healthcare information technology right now, with the potential of becoming a key information-sharing vehicle for hundreds of millions of Americans in the next several years."

J. Conn, Modern Healthcare, July 10, 2006

Several Events Over the Past Few Years Reflect Momentum for PHRs

- Markle Foundation Connecting for Health
- Veterans Administration "MyHealth-e-Vet" PHR pilot
- President Bush: Personal Health Record for Every American
- CMS – contracts to pilot PHR for beneficiaries
- ONC Commission for Systemic Interoperability – "Ending the Document Game"
- Dossia – Consortium of employers
- Robert Wood Johnson Foundation "Project HealthDesign" Initiative
- AHRQ Grants "Patient participation in PHR design"
- AHIP-Blues joint venture: standards for interoperable PHR's

Robert Wood Johnson Foundation

Project HealthDesign:
Rethinking the Power and Potential of Personal Health Records

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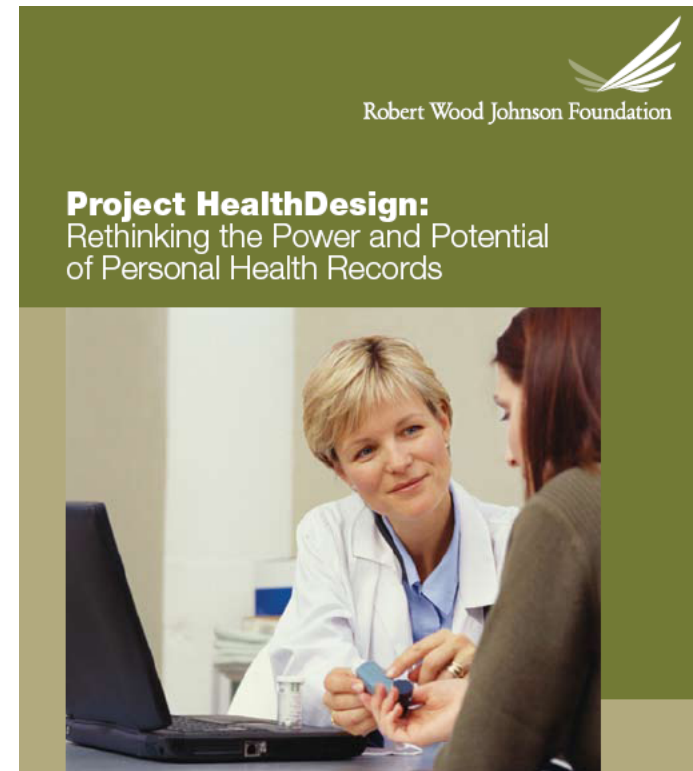
Even Microsoft and Google Are Getting Into the Act!

- Microsoft announces "Healthvault" – personal health information storage service
    - » October, 2007

- Google Health announces pilot with Cleveland Clinic for patient-controlled personal health record with data uploaded from medical record
    - » February, 2008

Let's take a poll!

How Does a Person Get a PHR?

- Offered by their healthcare organization
  - Sometimes populated with data from medical record
- Offered by their insurer
  - Often populated with claims data
- Offered by their employer
  - Often comes with health risk appraisals, lifestyle programs
- Self-purchased
  - Online subscription to web-based portal
  - Purchase of software for personal computer
  - Purchase of application to be run on flash drive
- In fact, an individual may have SEVERAL PHRs!

A Few Commercial Suppliers of PHR Systems to Insurers, Health Plans and Healthcare Organizations:

Products Available Direct to Consumers

- AARP produced a report identifying 24 suppliers of PHRs Direct to Consumers
  http://www.aarp.org/research/health/carequality/2006_11_phr.html

- Among the largest:
  - CapMed *Personal HealthKey™*

    www.capmed.com

  - Medem *iHealthRecord™*

    www.medem.com

  - WebMD *Health Manager*

    www.webmd.com

Despite the Availability, Uptake of PHRs Is Low

– Forrester: Only 28% of US households formally track health and medical information

- Of these, 94% keep the data on paper
- 4% keep it in PC-based applications
- Only 1% use a web-based application

– Older persons with serious medical conditions more likely to keep health records, less likely to keep them electronically

Forrester, June 2006

– 40% of California consumers express interest in accessing a personal health record, but only 2% currently do so

California Healthcare Foundation, 2008

Security and Privacy Are the Top Concerns of Consumers

– AHIP survey: Public is "Very" or "Somewhat" concerned that personal information could be leaked

<div align="right">July/August 2005</div>

– Markle Foundation: 91% of respondents "Very concerned" about privacy

<div align="right">September 2005</div>

– HarrisInteractive: Biggest concerns of respondents are privacy (68%) and security (66%)

<div align="right">August 2004</div>

– Virtually all internet-based PHR's offer protected access, provide a link to their privacy/security safeguards

Other Barriers

- Disparate sources of data, lack of interoperability, portability
  - Can't port record when consumer changes provider, payer, employer
- Lack of integration with medical record
- Usability: the people who are most likely to keep PHRs are the least technologically savvy
- Access: High-speed internet not universally available, especially in rural areas
- Lack of perceived value if consumer must do all the work, and if required features are absent or tools are not relevant

Recent Developments

- America's Health Insurance Plans (AHIP): Development of standards for claims data to promote portability
    - Being piloted in Massachusetts and California

- National Health Council: Development of messaging to promote use of PHRs among consumers
    - Pilots in Massachusetts and California, in conjunction with AHIP
    - Focus groups of consumers have resulted in "AHA!" moments

Recent Developments

- HL7: Development of functional model of PHR

- Dossia Network: Consortium of large employers developing secure, life-long PHR for employees

- Health Information Technology Standards Panel (HITSP): Standards for interoperability to allow consumer access to medication, laboratory data

What is nursing's role in promoting use of PHRs among patients and consumers?

"There is no aspect of our profession that will be untouched by the informatics revolution in progress."

Angela McBride, Distinguished Professor and
University Dean Emerita, Indiana University School of Nursing

Nurses in Clinical Practice

- Become familiar with technology resources available to patients
  - Another means for promoting health, dealing with illness
  - Assess appropriateness for individual patient

- Encourage and enable patients to use the technology

Nurse Educators

- Become familiar with technology resources available to nurses as tools for patient care
- Incorporate use of technology into curriculum

Nurse Administrators

- Become familiar with technology resources available to nurses as tools for patient care
- Consider PHRs as part of organizational strategy for community outreach, marketing

Nurse Informaticians

- Become familiar with technology resources available to nurses as tools for patient care

- Participate in groups whose agenda is to forward the use of PHRs (e.g., standards development, surveys, research, design)

- Become familiar with the standards for PHRs that are being developed
  - HL7
  - America's Health Insurance Plans (AHIP)
  - Health Information Technology Standards Panel (HITSP)

Nurse Informaticians

- Become familiar with the special design requirements for applications aimed at consumers

  - Usability

  - Cultural sensitivity

  - Literacy

  - Consumer vocabulary

  - Accessibility: Needs of elderly and disabled

  - Special features for those living with chronic and terminal illness

What Can Nurses Contribute to the Field of Consumer Health Informatics, Including PHRs?

- Our deep expertise in patient education
- Our strong ethic of cultural sensitivity
- Our extensive background in both individual and community-focused assessment, treatment and research
- Our long heritage of patient advocacy and patient empowerment

Thank you!

For additional learning resources, go to

http://tigerphr.pbwiki.com

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