Americans expect privacy and control, but....
What does ‘privacy’ mean?

The NCVHS defined health information privacy as “an individual’s right to control the acquisition, uses, or disclosures of his or her identifiable health data”.

(June 2006, NCVHS Report to Sec. Leavitt, definition originally from the IOM)
Congress passed HIPAA, but did not pass a federal medical privacy statute, so the Dept. of Health and Human Services (HHS) was required to develop regulations that specified patients’ rights to health privacy. **Public Law 104-191**

President Bush implemented the HIPAA “Privacy Rule” which recognized the “right of consent”. HHS wrote these regulations. **65 Fed. Reg. 82,462**

HHS amended the HIPAA “Privacy Rule”, eliminating the right of consent. **67 Fed. Reg. 53,183**

“... the Secretary of Health and Human Services shall submit to [Congress]... *detailed recommendations on standards with respect to the privacy of individually identifiable health information.*”

“....a covered health care provider must obtain the individual’s consent, in accordance with this section, prior to using or disclosing protected health information to carry out treatment, payment, or health care operations.”

“The consent provisions...are replaced with a new provision...that provides regulatory permission for covered entities to use and disclose protected health information for treatment, payment, healthcare operations.”
July 8, 2010 **New** federal privacy policy:

Sec. Sebelius: "Administration-wide commitment to make sure no one has access to your personal information unless you want them to”.

Dr. Blumenthal: "we want to make sure it is possible for patients to have maximal control over PHI."

Brave new world of online actuarial research

online data used to predict: Health & Longevity

• life insurer scrutinizes applicant who visits online cancer-research group
• people are significantly increasing their personal transparency," he says. "It's all public, and it's electronically mineable."
Deloitte Consulting uses a hypothetical ‘Sarah’ and ‘Beth’ to promote technology for life insurers that promises to help size up people’s health risk using offline and online dossiers rather than blood tests.

**Some data collected**

**SARAH**
- Second child born last year
- High investment risk tolerance
- Lived in home – two years
- Owns home
- Commuting distance – one mile
- Reads design and travel magazines
- Urban single cluster
- Premium bank card
- Good financial indicators
- Active lifestyle: run, bike, tennis, aerobics
- Healthy food choices
- Little to no television consumption

**BETH**
- Current residence – four years
- Lived in same hometown – 15 years
- Currently renting
- Commuting distance – 45 miles
- Works as administrative assistant
- Divorced with no children
- Foreclosure/bankruptcy indicators
- Avid book reader
- Fast-food purchaser
- Purchases diet, weight loss equipment
- Walks for health
- High television consumption
- Low regional economic growth

**Some risk-assessment factors**

**Good financial indicators**
- Strong ties to community/location
- High activity indicators
- Foreign traveler
- Healthy food choices
- Avid outdoor enthusiast
- Avid golfer
- Little television consumption
- Occasional tobacco user

**Potential actions by insurers**

**SARAH**
- Actively pursue for new business and retention efforts
- Quickly issue a preferred policy and avoid further medical tests

**BETH**
- Do not send offers
- Do not pursue aggressive retention efforts
- Collect more information; send to senior staffer for review
2010 PPR Zogby poll:
2000 adults’ views on privacy, access to health information, and health information technology

Zogby Interactive Survey of Adults 08/24/10 - 08/26/10 MOE +/- 2.2 Percentage Points

http://patientprivacyrights.org/patient-privacy-poll/
Should doctors, hospitals, labs and health technology systems be allowed to share or sell your sensitive health information without your consent?

97% No

2% Not Sure

1% Yes
Should insurance companies be allowed to share or sell your health information without your consent?

98% No
1% Yes
1% Not sure
If you have electronic health records, do you want to decide what companies and government agencies can access them?

- Yes: 93%
- Not Sure: 5%
- No: 2%
When your medical records are kept in electronic systems, would you want to decide which individual people can see and use them?

91% Yes
5% Not sure
4% No
How likely are you to use a website that allowed you to decide who can see and use all your health information?

- Very Likely: 50%
- Somewhat Likely: 28%
- Somewhat Unlikely: 7%
- Very Unlikely: 8%
- Not Sure: 7%
Who should make the decision on whether corporations and researchers can see and use the information in your health records without your permission?

- The government through laws and regulations: 5%
- You personally: 87%
- Your physician or other medical personnel: 5%
- Other: 1%
- Not Sure: 2%

See more at http://patientprivacyrights.org/patient-privacy-poll/