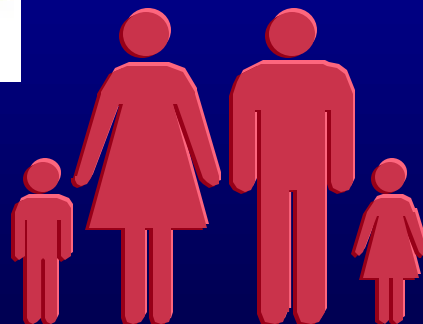




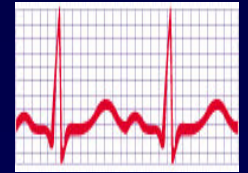
The Challenge Facing Privacy Officers in HIPAA



Presentation of Professor
Alan F. Westin, Columbia
University and Privacy &
American Business

at the Third National HIPAA
Summit, Washington D.C.
October 26, 2001

Privacy Officer's Focus Thus Far



- **PO's focused on compliance**
- **mastering regs, updating information systems, reviewing data sharing, developing training and certification, etc.**
- **quite logical and very necessary**
- **PO the key coordinating staff person**
- **BUT, compliance is not the full HIPAA task**
- **winning health-consumer trust is also vital**
- **and PO's the ones to lead this effort**

Consider the Health Consumer



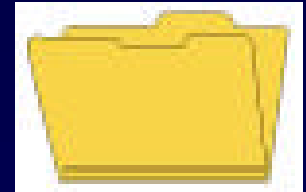
- **PO's must anticipate how health consumers will react to required HIPAA privacy practices**
- **will be different types of consumers with different privacy orientations**
- **If all handled the same, in “letter-of-the-law” compliance, will generate confrontations, health-consumer distrust, complaints to regulators, and potential litigation**
- **FEW IF ANY PO's ADDRESSING THIS YET**

My Health Privacy Background



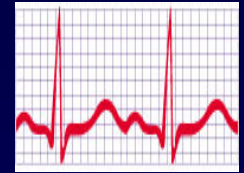
- Privacy and Freedom (1967)
- National Acad'y of Sciences Study (1970-72); Data Banks in a Free Society (1972)
- U.S. National Bureau of Standards study; Computers, Health Records, and Citizen Rights (1976)
- Harris-Westin Health Information Privacy Survey (1993) (advisor in 50 privacy surveys since 1978)
- 1990-2001: privacy consulting for providers, payors, health-data-systems, both government and private
- 2000-2001 Privacy & American Business Corporate Privacy Officers Program

Dynamics of the Health Consumer



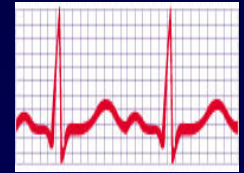
- have some excellent and sophisticated health privacy surveys (also some garbage)
- will draw on three solid ones that reach quite similar results:
 - Harris-Westin, 1993
 - California HealthCare Foundation, 1999
 - Gallup, 2000
- key-factor analysis the most important value
- offers guidance for communications development and privacy-administration by PO's

What Solid Surveys Confirm...1



- protecting privacy of health information “very important” to consumers -- 77%
- shift from paper to computer records seen to weaken confidentiality -- 54%
- 84% concerned their personal health information might be given to others without their consent
- high info.-handling trust in doctors (90%) and hospitals (66%) but not insurers (42%) and managed care companies (35%)

What Solid Surveys Confirm...2



- 18% in 1999 say their medical info. was disclosed “improperly” by a provider, insurer, gov’t agency, or employer. Down from 27% in 1993 survey
- Half say this resulted in harm or embarrassment
- 15% of consumers (and 38% reporting breaches) say they have taken actions to keep their health information confidential
 - go to another provider
 - pay for care themselves
 - give incomplete or false medical history info.
 - ask doctor not to record a condition or use less serious terms

What Solid Surveys Confirm...3



- Majorities not comfortable with many uses of their health info. beyond the care setting
- 60% would not grant access to hospital offering preventive care programs
- 61% would not allow employer for hiring
- 56% would not allow health insurer offering benefits at lower costs
- but, 70% would grant access to drug companies to notify about new drugs or other products
- and majorities would grant for government or academic research studies with privacy safeguards

What Drives These Views?



- **beyond demographics, Harris-Westin surveys find three key factors shaping consumer attitudes here**
- **1. Distrust Index: based on level of trust in institutions and fears of technology abuse**
- **2. Personal medical situation: users of mental health services; persons with adverse physical conditions; persons without health insurance**
- **3. Health-privacy orientation: 45% in 1993 scored High on Medical Privacy Concern Index -- 89M adults then. Compares to 25% of public who are general Privacy Fundamentalists in 2001**

Implications for HIPAA and PO's



- health consumers will differ strongly in their reactions to HIPAA communications and procedures
- predictable adverse reactions to Notices, Consents, and Authorizations by High-Privacy consumers if done in traditional bureaucratic-legal manner
- similar potential in face-to-face explanatory communications, seeking data-sharing, responding to record-access requests, etc.
- bad experiences with GLB (financial services) are a warning -- and bad notices would produce worse reactions in health settings

What Can/Should PO's Do?



- **One**: study the survey data, and assess implications for your type of covered entity, your consumer population; etc.
- **Two**: identify the “consumer-trust pressure points” in the HIPAA requirements
 - I see at least 20 such critical situations, primarily in provider settings but also for managed-care, insurers, pharmaceutical companies, and data-processors
- **Three**: develop a multi-step, multi-media communication process, geared to the different potential reactions of health-consumer segments

Some Resources to Assist PO's



- **Harris Interactive and Privacy & American Business will conduct a new HIPAA-oriented consumer-trust survey in January**
- **will explore how consumers would want the privacy-service “pressure points” to be handled**
- **will test responses to different organizational communications formulations, overall and by consumer segments**
- **will not only help covered entities but could help shape HHS interpretations of HIPAA rules**

Survey Sponsorships Available



- the new survey will be made public in early Spring and widely discussed
- health organizations and foundations that sponsor will participate in choosing key topics and developing questions
- If interested in considering sponsorship, contact:
 - Dr. Alan F. Westin, Privacy & American Business
 - Tel. 201-996-1154 Fax 201-996-1883
 - Email: ctrslr@aol.com

Also P&AB's CPO-2002 Program



- Since 2000, P&AB has had year-long program for corporate privacy officers -- 60 organizations now
- Provides special proprietary materials, workshops, peer case studies, participation in P&AB's annual national privacy conference, and more
- HIPAA issues fully covered, in Industry working Group
- If interested, please contact:
 - Lorrie Sherwood, Privacy & American Business
 - Tel. 201-996-1154 Fax 201-996-1883
 - Email: ctrslr@aol.com