

Sixth Annual National Congress on Health Care Compliance

PRECONFERENCE I: Privacy for Compliance Professionals

Sponsored by the International Association of Privacy Officers

So you want to be a Privacy Professional

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Vice President and Board Member

international association of privacy professionals



Washington, DC - February 5 - 7, 2003





Overview

- Overview
- Making the Case for a CPO
- The Law and Cost
- Warped Mind of a CPO
- ABC's of a Strong CPO
- “Whole View” Approach
- Getting Started
- Privacy Incident Cost Containment
- Enlightenment
- Training
- CPO Top 10 Tasks
- Conclusions
- Contacts

Ripped from the Headlines



Healthcare will be the next big privacy story

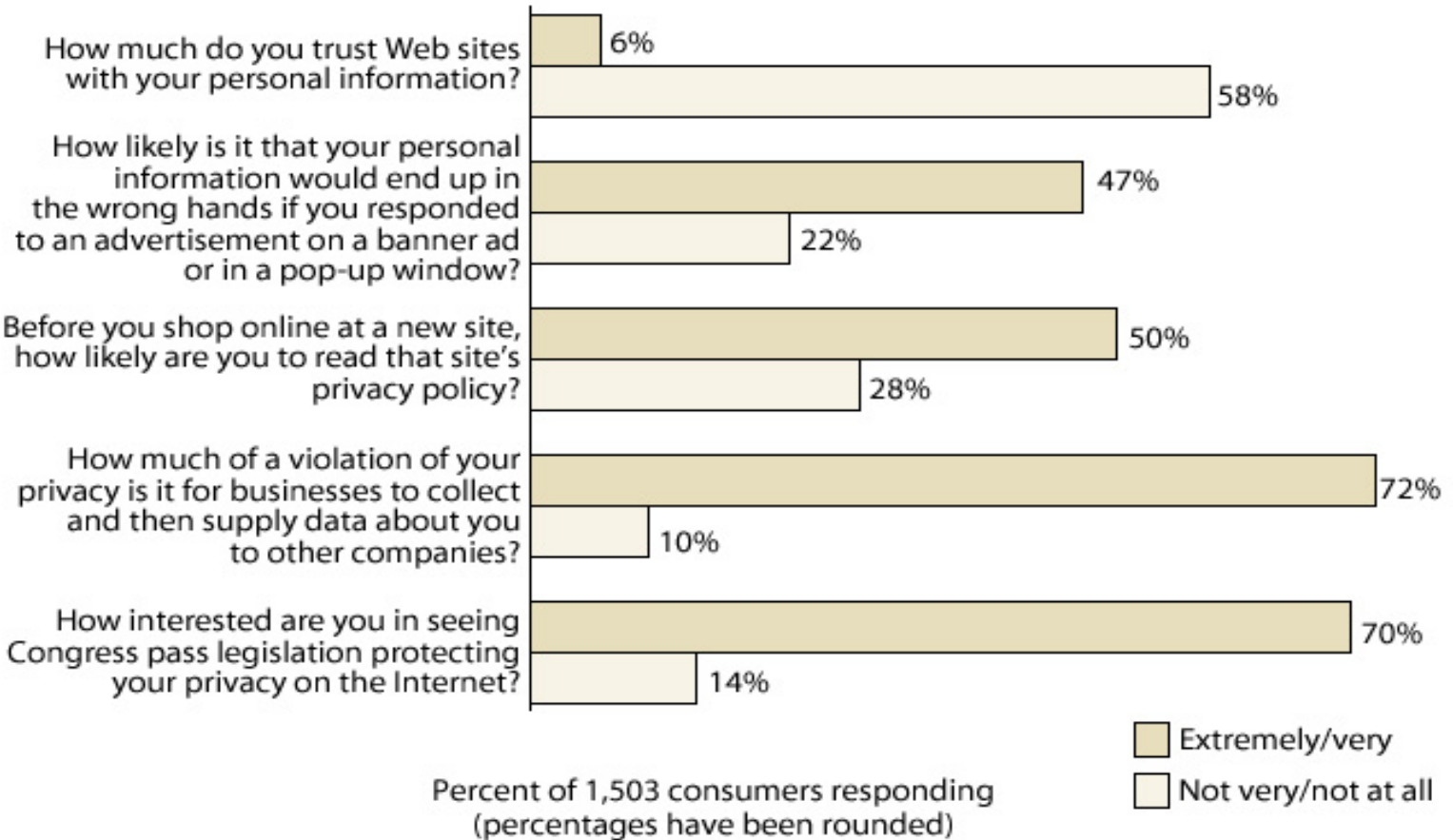


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Making the Case for a CPO

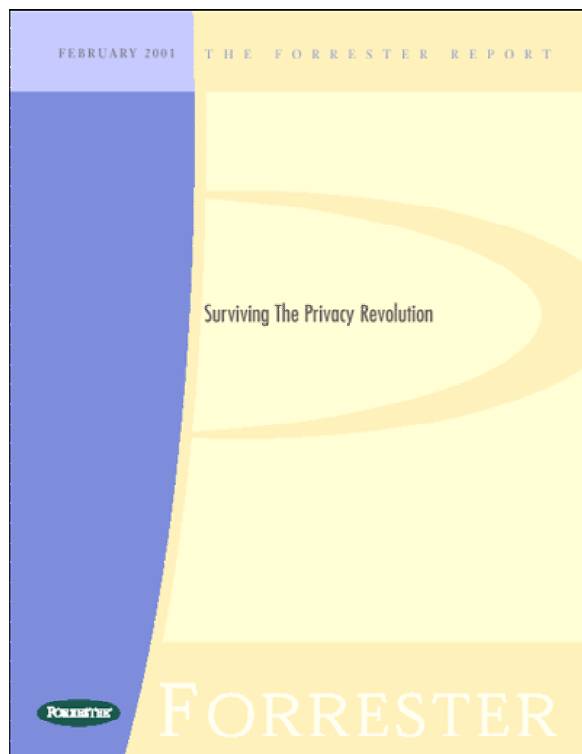
Consumer Perception Of The Privacy Issue



Source: Forrester Research, Inc.



Making the Case for a CPO – It's the LAW!



- **“Privacy sensitivity & visibility are intensifying”**
- **“Existing privacy rules already cover most companies”**
 - Of Fortune 100, 73 must comply with at least one set of recent privacy regulations
- **New technologies will keep privacy “wound” from closing**
- **Regulatory labyrinth will worsen**
- **Conclusion: “Whole View” approach to Privacy is required**



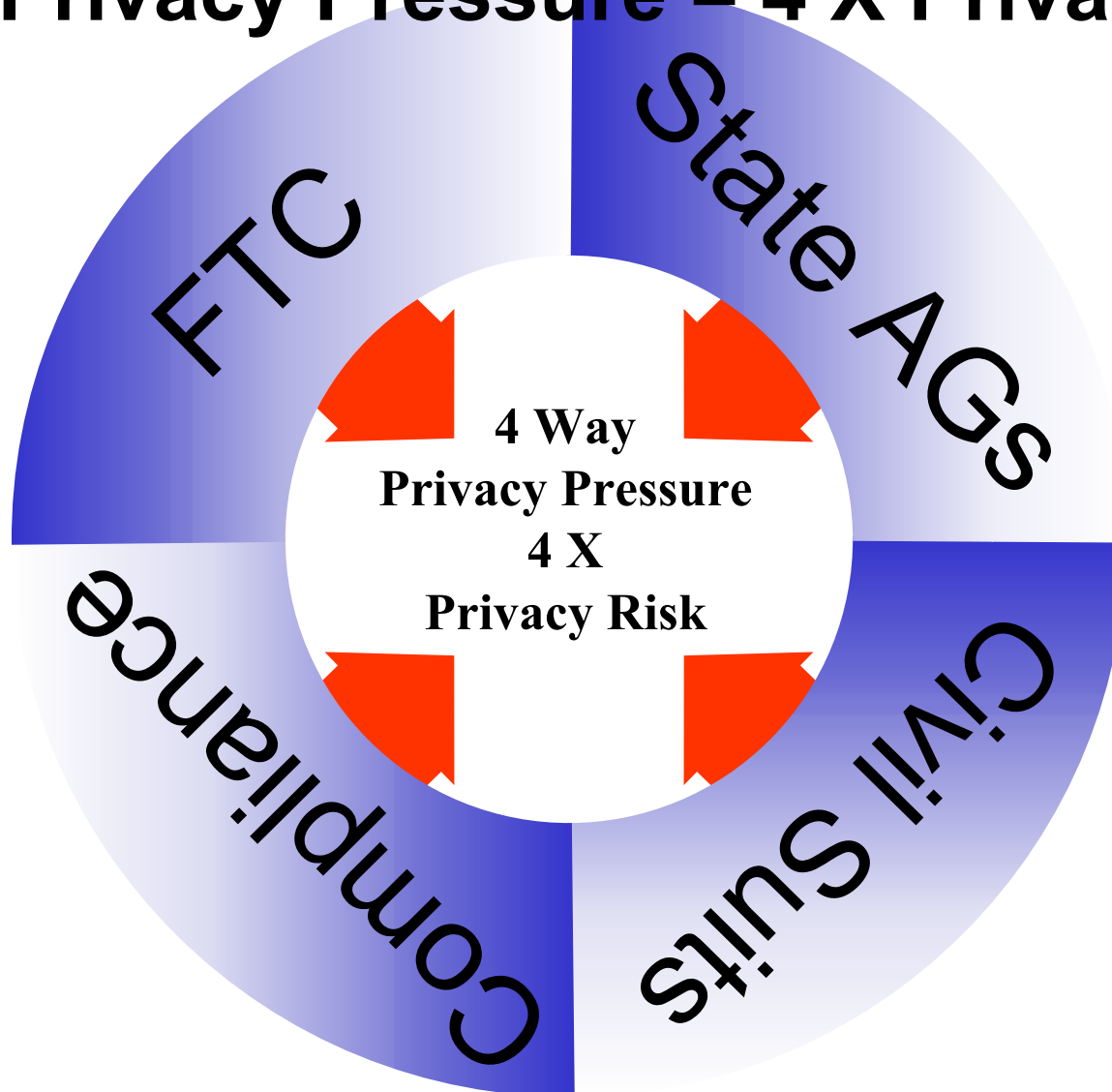
Three “Types” of Laws

- Established Laws
 - Fed, State, International
 - FIPP
 - EUDPD
- Emerging Laws
 - HIPAA
 - “New” Enforcement Actions
 - “New” Civil Suits
 - Your are responsible for your vendors
- Law of the Press
 - Company is ALWAYS wrong
 - Consumer is NEVER wrong
 - Your are responsible for your vendors

Press is driven by brand – your brand



4 Way Privacy Pressure = 4 X Privacy Risk



Risk: Cost of Privacy Incidents - Escalating

2000

| Small.com, Inc. | | | BigCompany, Inc. | | |
|--|--------------|----------|--|--------------|-------------|
| Action | Time (hours) | Cost | Action | Time (hours) | Cost |
| • CEO/president time | 86 | \$7,100 | • CEO/president time | 48 | \$8,100 |
| • Management time | 95 | \$5,544 | • Management time | 620 | \$38,889 |
| • PR meetings and calls | 40 | \$1,067 | • PR meetings and calls | 800 | \$21,333 |
| • Management press calls | 26 | \$1,778 | • Management press calls | 76 | \$5,456 |
| • Management review of privacy practices | 15 | \$833 | • Management review of privacy practices | 250 | \$13,889 |
| • Customer service calls and emails | 88 | \$1,944 | • Customer service calls and emails | 18,750 | \$416,667 |
| • Employee communications and training | 1 | \$1,333 | • Employee communications and training | 18,770 | \$335,889 |
| • External consultants | | \$22,500 | • External consultants | | \$181,250 |
| • Travel | | \$2,000 | • Travel | | \$16,500 |
| Grand total | | \$44,099 | Grand total | | \$1,037,973 |

| | | |
|----------|--|-------------------------|
| 2002 add | | FTC settlement |
| | | 20 Yrs monitoring |
| | | State Attorneys General |
| | | Civil Suits |
| Sub | | ~ \$ 2,000,000.00 |
| Total | | ~ \$ 3,000,000.00 |

WHY are Costs Rising?

DoubleClick

Eli Lilly

Microsoft

Ziff-Davis

USBancorp

Eckerd



When Companies Make Privacy Mistakes

- **Eli Lilly Prozac Email Incident**
 - FTC settlement, lasts 20 years
 - State fines
- **Microsoft Passport**
 - FTC settlement
 - Fines if broken (\$11K per incident)
- **DoubleClick**
 - Class action, FTC, \$400K states
- **Ziff Davis**
 - Exposed credit cards on Web,
 - Identity theft resulted, \$125K to states
- **Eckerd Drug**
 - Drug signature sheets as permission to market—settled with Florida AG for \$1 million (endows a university chair in Ethics)

Consider the Fallout:
Stock price takes a hit
Press “goes negative”
Brand name tarnished
Resources diverted
Opportunity costs mount
e.g. Marketing, PR, Staff,
Managers, Lawyers

Training Specified in Privacy Settlements

- Microsoft: this risk assessment should include consideration of risks in each area of relevant operation, including:
(1) employee training and management...
- Ziff Davis: address these risks by means that include:
(i) management and training of personnel...
- DoubleClick: will undertake reasonable efforts to educate its clients in technical and business practices that promote Users' privacy.... will employ reasonable technical and employee education procedures and mechanisms to safeguard the security and integrity of User Data...
- Eli Lilly: including any such risks posed by lack of training, and addressing these risks in each relevant area of its operations, whether performed by employees or agents...

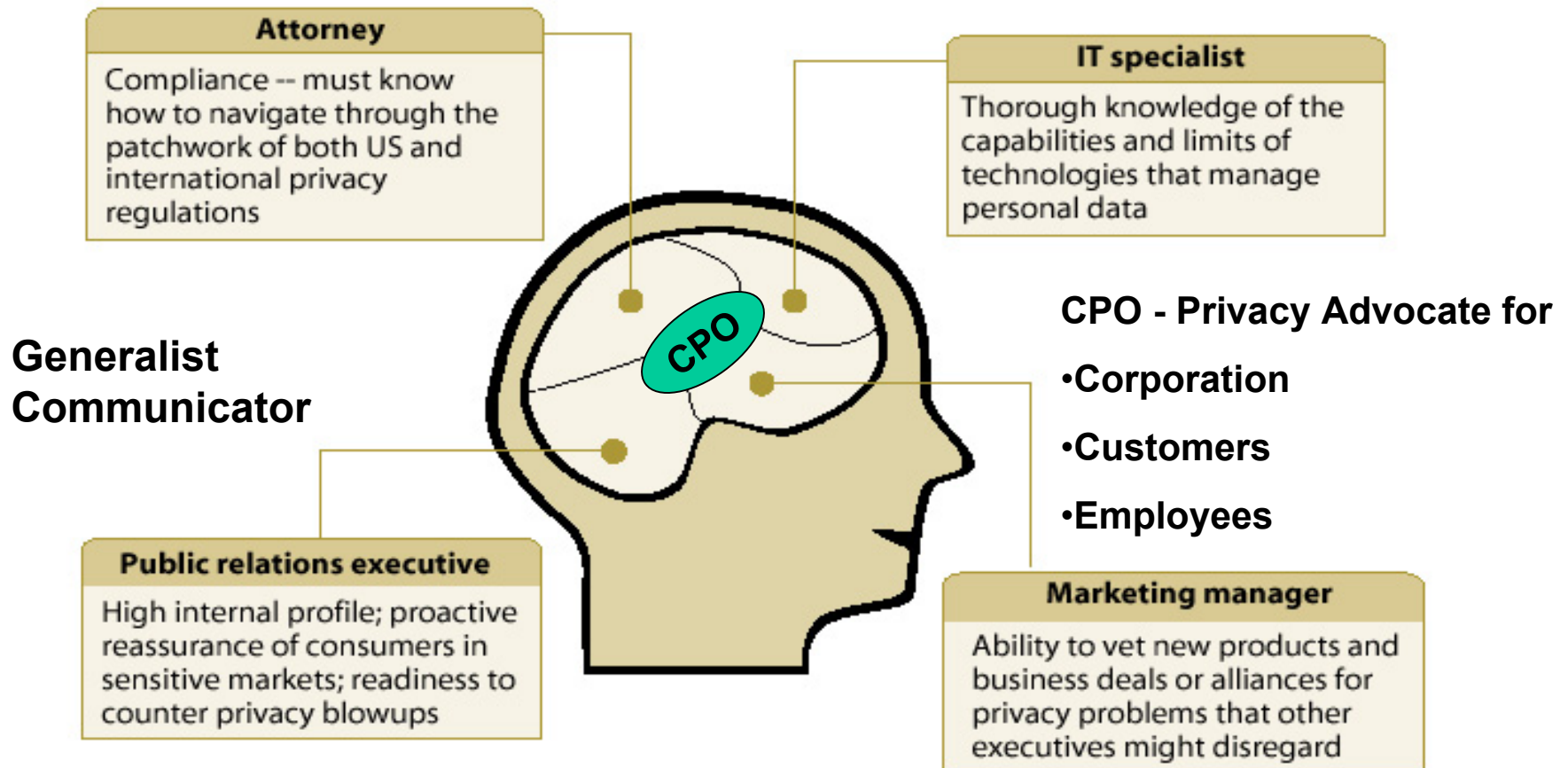


So you **STILL** want to be a CPO?

What it takes to do it right

The Warped Mind of a CPO

The Mindset And Various Skills Of A Chief Privacy Officer.



The ABCs of a Strong CPO

- **Accountability & Authority**
 - CPO responsible for all aspects of corporate privacy
 - CPO must have authority if accountable
- **Breadth of Influence & Budget**
 - Able to get a “big picture,” strategic view of today’s operations and tomorrow’s planning
 - Positioned in company to review all operational areas
 - Institutionalized as a part of the decision process for any activities involving gathering, use of PII
 - Own budget
- **Clout**
 - Positioned on org. chart as peer to key managers
 - Strong backing of CEO and Board



What the “Whole View” Approach Means

- First, Company must recognize that privacy is a core issue in all dealings with customers – It’s about TRUST
- Second, development of a coordinated privacy strategy requires top-to-bottom assessment of online and offline data gathering and usage
- Whole View requires Four Pieces:
 1. An empowered CPO
 2. Discover and document the flow of PII
 3. Develop privacy policies and procedures
 4. Institutionalize privacy protection measures

1. An empowered CPO

Tasks:

- Build a privacy team
 - Recruit a *de facto* team from key departments

Example: 3000 person consumer facing company, 40 privacy
- Strengthen your influence base
 - “Privacy Committee” CPO often not a “C” or an “O”
 - Strength = support from above
- Compliance is key
 - Understand the processes, technologies
 - If you don’t, hire someone who does
- Avoid becoming a bottleneck
 - Learn the alternatives
 - ...but hold your ground when you’re right.

2. Discover and document the flow of PII

Tasks:

- Prevention – Target, Treat, Train –
 - Practical Privacy – fix the obvious
 - PICC – Privacy Incident Cost Containment
- Key areas: IT, HR, Marketing, Vendors
- Survey the entire corporation
 - If you can't do it in-house, decide who's going to help
- Document data sources, uses, access policies
- Identify current and potential problem areas

3. Develop privacy policies and procedures

Tasks:

- Assemble current policies and assess inconsistencies
- Benchmark against
 - Applicable laws, regs
 - Industry standard practices
- Draft a unified privacy policy, key SOPs
- Assess obstacles to implementation
 - Prioritize implementation to address worst exposures first
- Craft a public privacy policy document
 - Don't let the lawyers do the first draft
 - If you have a lousy policy, say it proudly

4. Institutionalize privacy protection measures

Tasks:

- Instill a culture of privacy in the corporation
 - Culture starts from the top down
 - Compliance starts from the bottom up:
 - Training is the key
- Set up internal monitoring procedures
 - Implement procedures for regular review of PII systems
 - Implement regular internal and external audits
 - Don't forget 3rd party service providers, partners
- Prepare for blowups - Contingency planning
 - Recognize, React & Respond
 - Develop an investigatory process
 - Develop a PR plan
 - Involving privacy advocates early builds credibility



Getting started?

Be smart, be fast, be practical

Manage today's risk – Today!

Privacy incidents & investigations

Bad questions to have to answer

- “What did you know?”
- “When did you know it?”
- “Why didn’t you know sooner”

Really bad questions to have to answer

- “Why didn’t you act after you new?”
- “How long didn’t you act after you new?”

- Tip: Always be truthful – there is always a trail

Practical Privacy: Triage - fix the obvious!

3-step Privacy Incident PREVENTION Program

1. Target

- Find current privacy exposures and prioritize
- (Talk to department heads, map data flows, ask questions, especially of marketing)

2. Treat

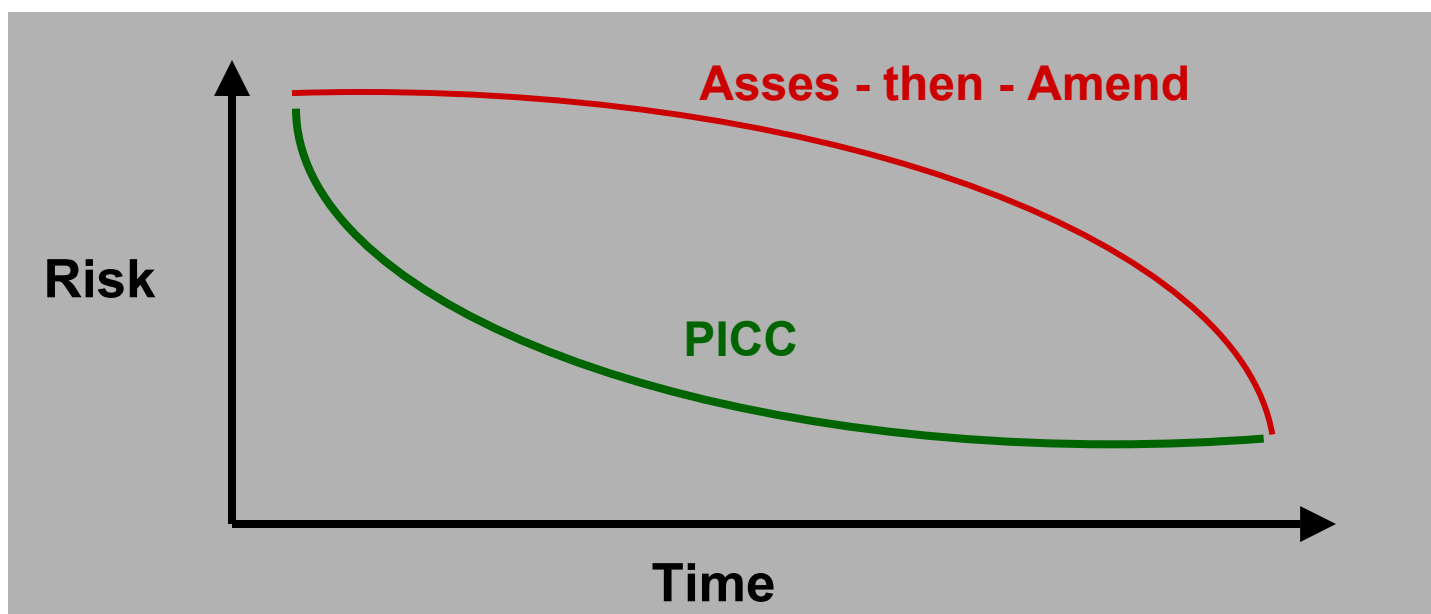
- Make necessary changes and then institute policies and procedures to prevent recurrence

3. Train

- Train yourself, IAPP, train your team, train your boss
- Make sure everyone understands the importance of privacy, especially anyone who touches PII
- (This goes a lot further than customer service, e.g. contracts, programming, product development)

Privacy Incident Cost Containment Model

- **“Asses-then-Amend”** prolongs risk of privacy incidents
 - Can actually increase risk
- **PICC** reduces privacy risks right away
 - Resources immediately applied against risk



CPO Enlightenment

1. There is no magic technology solution
 - Part of the solution
2. There is no magic legal notice
 - Backlash against legalese
3. You can't do it alone
 - Lots of Privacy touch points
 - Eli Lilly Florida
 - New exposures created
4. You can't do it without budget
5. Vendors are your privacy responsibility

Train your team - Train ALL potential touch points

Train your vendors



HIPAA Training – Set Expectations

TRUST•e

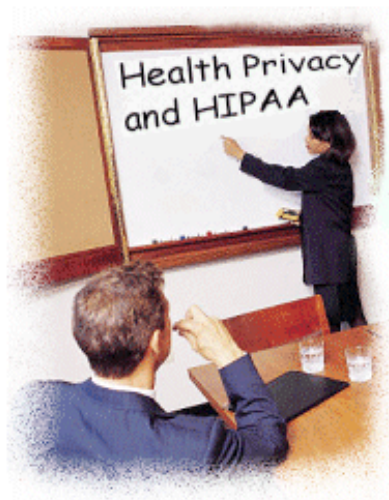
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TRAINING**

Health Privacy Module A:
Health Privacy Awareness

1 of 10

26 Mar 2002

Health Privacy Awareness



- The purpose of this class is to help you deal more effectively and appropriately with issues of health privacy that arise in your work
- Answer questions
 - What are health privacy issues?
 - When do they arise?
 - What is HIPAA?
 - What does it mean to your company and your job?
- Increase your health privacy awareness
 - Spot problems before they occur
 - Solve problems by doing the right thing
- Understand how good health privacy practice makes good company practice

Increasing health privacy awareness and understanding
makes for better business

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HIPAA Training – Don't Skip Why

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Health Privacy Module A:
Health Privacy Awareness

7 of 10

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What the Heck's a HIPAA?

- The Health Insurance Portability and Accountability Act of 1996
- An attempt to make health insurance easier and cheaper by using electronic data interchange technology (EDI)
- EDI saves money if you have standard codes for processes such as billing, and HIPAA standardizes health care codes
- Assumes more use of computers in health care, and so a need to protect the privacy of patient data, hence:
 - HIPAA Privacy Rule
 - Effective April 14, 2003
- Requires policies and procedures for handling PHI, protected health information
- There are stiff fines for violations



**HIPAA makes protection of health information
a part of Federal law.**

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Why? – Increased Sensitivity

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Health Privacy Module A:
Health Privacy Awareness

4 of 10

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Why Is Health Privacy Such An Issue Today?

- The idea that people who handle health information should respect the privacy of individuals is not new
- But people today more concerned about possible threats to their privacy as a result of developments in computers and communication
- Computer networks make gathering and sharing information easier than ever and some of that information is IIHI
- Health privacy is impacted by the extensive use of computers in health insurance, payment, research, and marketing



People have always been concerned about privacy,
but today's level of concern about health privacy is unprecedented

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Compliance is a Business Need

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Health Privacy Module A:
Health Privacy Awareness

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Privacy Acronyms

Privacy, like other aspects of business, has its own terminology and acronyms. This is particularly true of health privacy. Here are four that you are bound to encounter:



- PII = Personally Identifiable Information
 - Information that relates to an individual who can be identified, directly or indirectly, from the data, particularly by reference to an identification number or aspects of his or her physical, mental, economic, cultural, or social identity
- IIHI = Individually Identifiable Health Information
 - Like PII, but referring specifically to a person's health information
- PHI = Protected Health Information
 - This is a sub-set of IIHI which requires special attention under HIPAA
- HIPAA = Health Insurance Portability and Accountability Act
 - Federal legislation which, among many other things, requires protection of an individual's health information

Privacy acronyms can be a useful shorthand,
but don't assume everyone knows what they mean

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Quizzes for Learning and Measuring

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Health Privacy Module A:
Health Privacy Awareness

5 of 10

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Health Privacy, Module A, Quiz 1

Computer data files would be considered
IIHI if they:

- A. relate to individuals who can be identified from the data. ☐
- B. contain information on the identity of human individuals. ☐
- C. relate to the health of individuals who can be identified from the data. ☐
- D. contain de-identified health data. ☐

Submit

Select one of the 4 choices above
and then click the Submit button.

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Help

Testing to Teach

Reduce risks
not increase

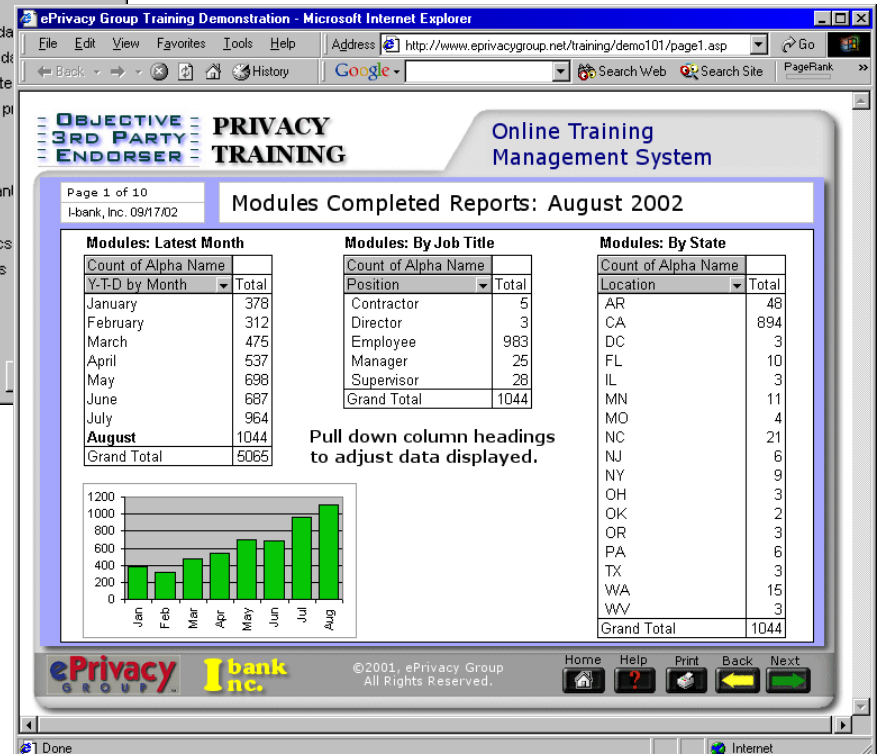
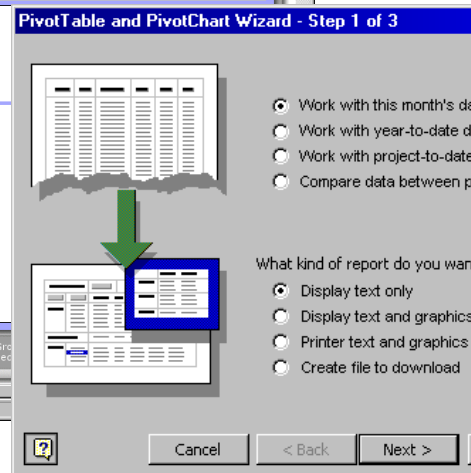
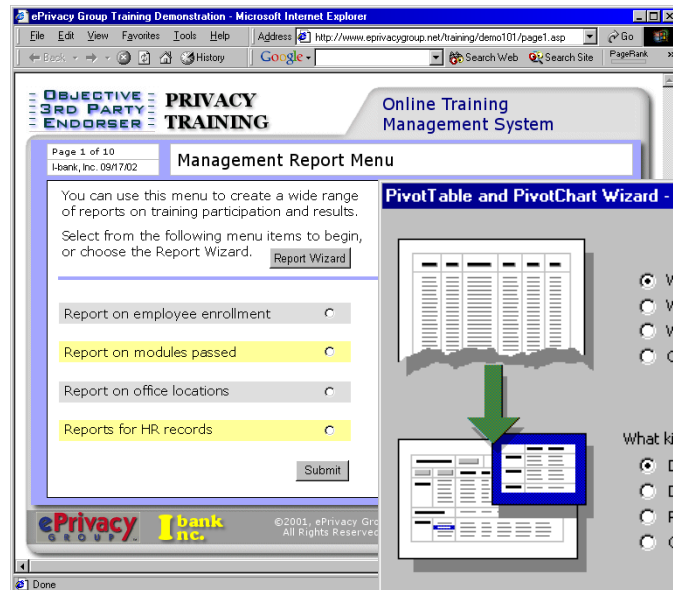
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Document Compliance



Involve employees and supervisors
send confirmation of course
completion.

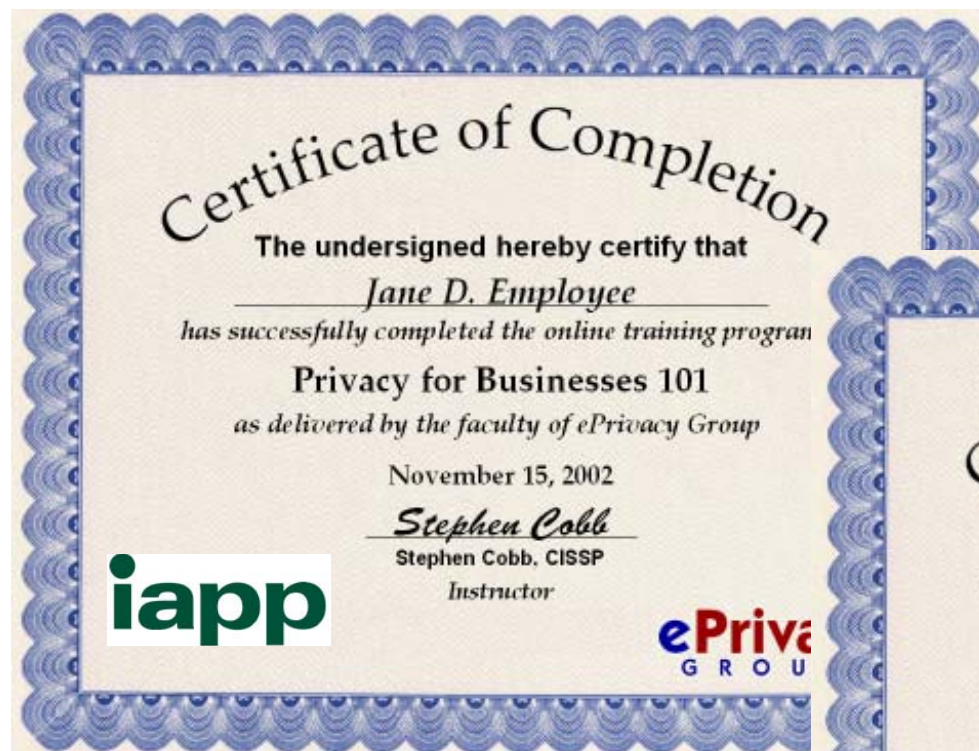


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Acknowledge Employees with Certificates



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CPO's Top Ten Challenges

1. Data = corporate “family jewels,” but value = use
2. Contractual protections helpful, but not enough
 - breach, leakage
3. Security threats: hackers & the marketing dept.
4. New products/services requiring review of data policies
5. New partnerships/alliances requiring coordination of policies
6. Data “bumps” (combining databases, augmenting data)
7. M&A issues (merging differing policies), Bankruptcy
8. Monitoring for compliance in fast-moving organizations
9. Consumer fears as high as ever, media enjoys feeding fear
10. Legislators/regulators eager to turn that fear to their advantage

Conclusions

- **Embracing Privacy is a corporate necessity**
- **A “Whole View” approach is required**
 - Addressing Privacy begins with a strong CPO or CPP
 - Practical Privacy – fix the obvious
 - Target, Treat, & Train
 - Assessing the data flow is key to understanding exposures and liabilities
 - Establish policies and procedures
 - Institutionalize privacy protection

Conclusions

- **Incidents will happen**
 - Plan for blow-ups
 - Recognize, React & Respond
 - Scenario planning effective way to get attention & budget
- **Training is the key for Prevention & Response**
 - It works
 - Single most effective means to reduce risks



Contacts

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