



**YOUTAKE  
CONTROL**

# **You Take Control (YTC)**

**New Mechanisms Put Patients in Complete Control of Personal Health Information (PHI)**

**Tenth National HIPAA Summit  
Marriott Waterfront Hotel  
Baltimore, Maryland  
7 April 2005**



# Privacy Concerns on the Rise

**“Anyone today who thinks the privacy issue has peaked is greatly mistaken...we are in the early stages of a sweeping change in attitudes that will fuel political battles and put once-routine business practices under the microscope.”**



***Forrester Research***

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# Today, Understandably, Privacy Concerns Abound

*Growing Avalanche of Demand for Access to SPI*

Today, there is no easy means of getting express consent today

Today, every conceivable scheme for gaining access to SPI is in full swing

SDPs today are inundated with requests or offers to purchase SPI\*

SPI is delivered to requestors without your consent

Today, individuals have no control over access to their own SPI, and privacy rights are routinely being trampled upon

Today, there is widespread and utter disregard for the privacy rights of individuals, e.g., 57 million people have signed up for the Do Not Call list



\* **SPI = Sensitive Personal Information**



# Evidence of Escalating Privacy Concerns

Sixty percent—**representing 120 million consumers**—say that they decided not to do business with a company because they were not sure of its privacy policies.

August 12, 2004 Hackensack, NJ: Consumers taking privacy-assertive actions are up almost 30% since 1999, according to the latest Consumer Privacy Activism Survey commissioned by *Privacy & American Business (P&AB)* and fielded by Harris Interactive

What the Consumer Privacy Activism Survey Findings Tell Us  
“**...American consumers are taking privacy protection into their own hands,**” said Dr. Alan Westin, President & Publisher of *P&AB*



# Evidence of Escalating Privacy Concerns

**23 February 2005: Between 62 and 70% of adults** are worried that sensitive health information might leak because of weak data security, that there could be more sharing of patients' medical information without their knowledge.

**82% say that offering consumers tools** to track their own personal medical information in the new EMR system and to assert their privacy rights **is important to implement at the start** of any EMR system.

"I am convinced that **how the public sees the privacy risks** and responses from EMR managers will be absolutely crucial to the EMR systems' success—**or will be a major factor in its failure,**" said, Dr. Alan F. Westin *Professor of Public Law & Government Emeritus, Columbia University* and Director of the Program on Information Technology, Health Records, & Privacy at Privacy and American Business (P&AB).





# Evidence of Escalating Privacy Concerns

“Public confidence that personal medical records are being protected has increased, a recent Harris Interactive poll shows, but **many Americans are still concerned that electronic medical records may create security risks.**”

“A majority of Americans say they aren't aware of proposals for a patient electronic medical records system, which President Bush and others say will help contain the costs of U.S. health care and improve patient care. **But 70% of those polled say such a system may allow sensitive personal information to be leaked or that records could be shared without their knowledge.**”

“Still, 48% believe that the benefits of electronic medical records outweigh the risks, according to the survey, while **47% believe the risks outweigh the benefits.** Nearly half of adults (45%) say it is very important for patient to be able to track their own personal medical information in these electronic records.”

*The Wall Street Journal, 24 February 2005*



# If Consumers Could Take Control...

“If individuals can be given the rights to control their data, or more precisely, if those who would use data had first to secure the right to use it, then a negotiation could occur over whether, and how much, data should be used. The market, that is, could negotiate these rights, if a market in these rights could be constructed.”

Lawrence Lessig  
“The Architecture of Privacy”



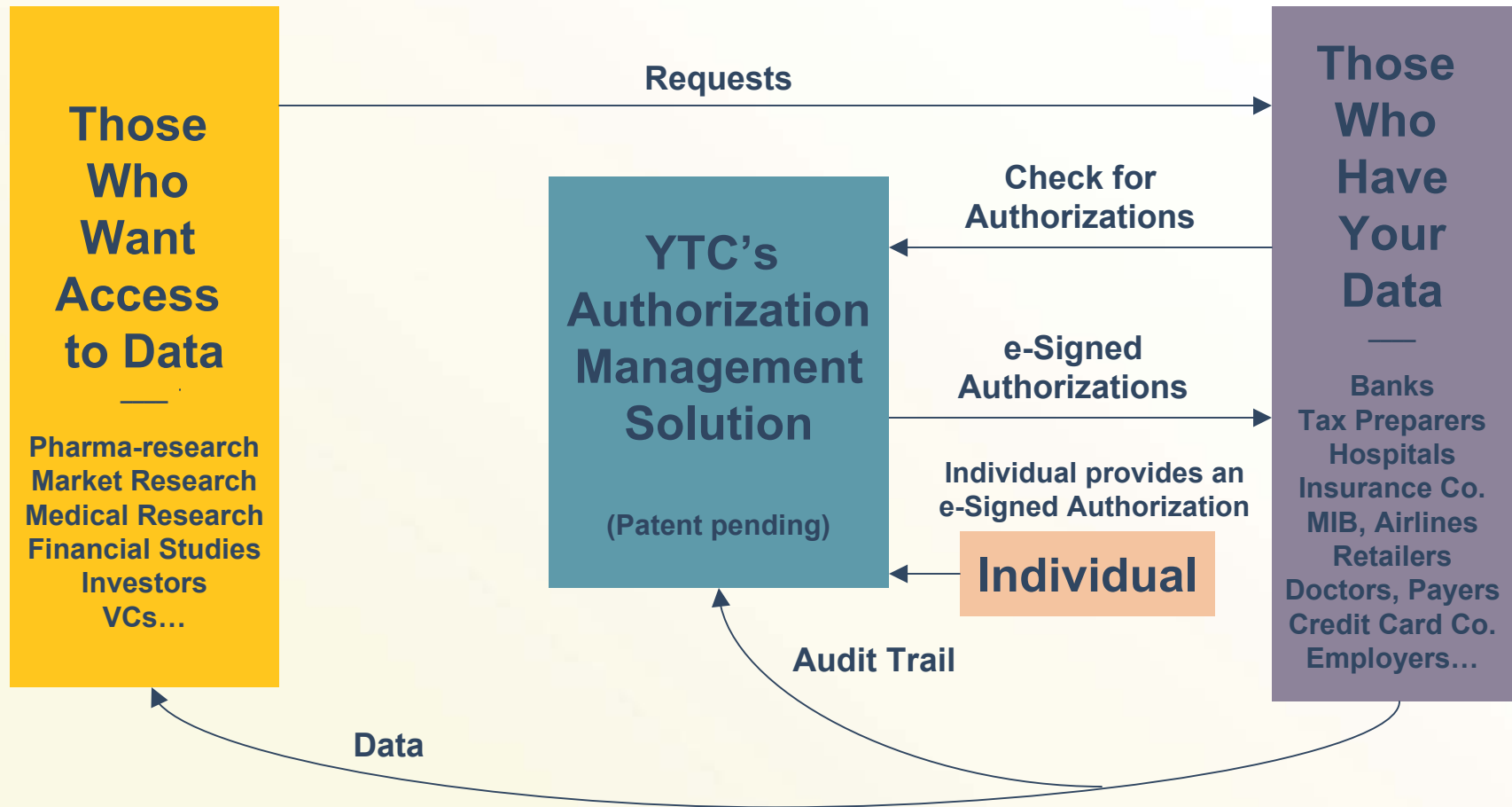


# YTC is in the “Get Them Together” and “Keep Them Apart” Business

- **Individuals want to control their data**
- **Entities want access to that data**
- **Some individuals are willing to allow access to their data**
  - IF it benefits them and IF their information will not be misused
  - Especially if they're paid
- **HIPAA and GLB protect those who don't want to grant access**
- **BUT they present an obstacle to parties who do**
  - HIPAA and GLB require signed authorization
- **Signed authorizations remove this barrier**
- **Everyone wins with YTC's authorization management solution:**
  - Individuals win
    - **Maintain control over their data**
    - **Get compensated for releasing their data**
    - **Know who is requesting their information**
  - Requestors of data win
    - **Get the data**
    - **Get it more quickly and more reliably**
  - Those who hold your data win
    - **Get to grant authorized access**
    - **Project a more positive perception to the public of their privacy policies**
    - **Get increased revenues and more revenue opportunities**
  - The individual ALWAYS gets to decide, on a case by case basis, if, when, and who may have access to their data



# Privacy Solution Overview



NOTE: YTC is the Trusted Consumer Advocate in the middle, and YTC never sees or stores your data



# You Take Control: Overview

## YTC Achieves a “Win, Win, Win”:

**YTC enables a relationship of true informed consent between individuals and the entities that hold data pertaining to them – YTC provides a complete Authorization Management solution.**

- **Individuals Take Control:** YTC enables Individuals to take control over who may—or may not—have access.
- **Organizations Benefit:** YTC enables organizations—both public and private—to enjoy the public’s positive perception of their privacy policies YTC acts as an added “safety-net”
- **Government is Assisted:** YTC enables governments to get out of the privacy “hot seat” where the individual’s personal information is at issue.



# YTC Enables: The ONCHIT Framework

## How YTC supports and enables the ONCHIT Framework for Strategic Action

### Inform Clinical Practice:

- **Incentivize EHR Adoption**
  - Support and encourage the individual's use of PHRs, which feed data into EHRs
  - Reduce caregiver concerns over EHR Privacy issues
  - Increase the potential for entirely new data revenue streams to practices
- **Reduce Risk of EHR Investment**
  - Enable authorized aggregation of identifiable clinical data for funded or sponsored new studies
  - Reduce liability via data feeds from external source data providers (e.g., Labs, Rx)
  - Improve the bottom line from entirely new data revenue streams
- **Promote EHR Diffusion in Rural and Underserved Areas**
  - Enable clinicians and patients in such settings to become part of the mainstream
  - Enhance the opportunity for virtually all types of authorized data sharing activities
  - Improve patient safety and the quality of patient care in such settings



# YTC Enables: The ONCHIT Framework

## How YTC supports and enables the ONCHIT Framework for Strategic Action

### Interconnect Clinicians:

- **Foster Regional Collaborations**
  - Enable and encourage individuals to make their EHR data more readily available
  - Reduce barriers for such regional collaborations by dealing with privacy issues
  - Realize entirely new data revenue streams to all of the participants
- **Develop a National Health Information Network**
  - Enable more effective authorized data sharing over such a network
  - Prove the value for such a network due to more Patient-Authorized transactions
  - Expand the potential funding opportunities required to create such a network
- **Coordinate Federal Health Information Systems**
  - Enable more powerful MPI technologies to improve accurate patient identification
  - Enhance opportunities for more effective data sharing among all federal systems
  - Provide technology fundamental to achieving semantic interoperability of PHRs & EHRs



# YTC Enables: The ONCHIT Framework

## How YTC supports and enables the ONCHIT Framework for Strategic Action

### Personalize Care:

- **Encourage Use of PHRs**

- Support and encourage individual use of PHRs which feed data into EHRs
- Our PHR work with MedicAlert® may be a model worthy of widespread adoption
- PHR technologies coupled with Authorizations offer enhanced benefits to patients

- **Enhance Informed Consumer Choice**

- Enable patients to Authorize and engage in any worthy uses of their data
- Inform patients more quickly concerning the full spectrum of choices now available
- Multiply opportunities for patients to engage in mutually beneficial data sharing

- **Promote Use of Telehealth Systems**

- Encourage clinicians and patients to share clinical data enabled by Authorizations
- Improve accuracy of MPI data spread across an array of dispersed treatment centers
- Improve care and advance patient safety by Authorized remote data integration





# YTC Enables: The ONCHIT Framework

## How YTC supports and enables the ONCHIT Framework for Strategic Action

### Improve Population Health:

- **Unify Public Health Surveillance Architectures**
  - Enable and encourage individuals to share their data for the “public good”
  - Enable a crucial infrastructure component (Authorizations) for such architectures
  - Make it possible to detect and understand more quickly important “Trends” (including early detection of bio-terrorism events or threats)
- **Streamline Quality and Health Status Monitoring**
  - Improved data sharing Authorized by patients enhances quality initiatives
  - Patients can more readily participate in monitoring and sharing health status data
  - Learn more readily what really works and what does not—get early warning signals
- **Accelerate Research and Dissemination of Evidence**
  - Reverse “the HIPAA-effect” which has effectively shut off lots of desirable research
  - Combination of data from MANY diverse sources made possible via Authorizations
  - Providing rapid dissemination of information directly to patients improves patient safety



# Patient Safety Enhanced via Authorizations

## DEMONSTRATION



## Background



# You Take Control: Key Roles

## Key Roles YTC Performs

**Individuals Take Control: YTC enables individuals to be the true gatekeepers of their own personal and private information.**



# You Take Control: Key Roles

## Key Roles YTC Performs

**Organizations Benefit: YTC empowers organizations—both public and private—that hold information about individuals to always check on the individual’s privacy preferences at YTC before releasing sensitive personal information. This improves the public’s perception of their privacy policies, so YTC acts as their “safety net” for privacy.**



# You Take Control: Key Roles

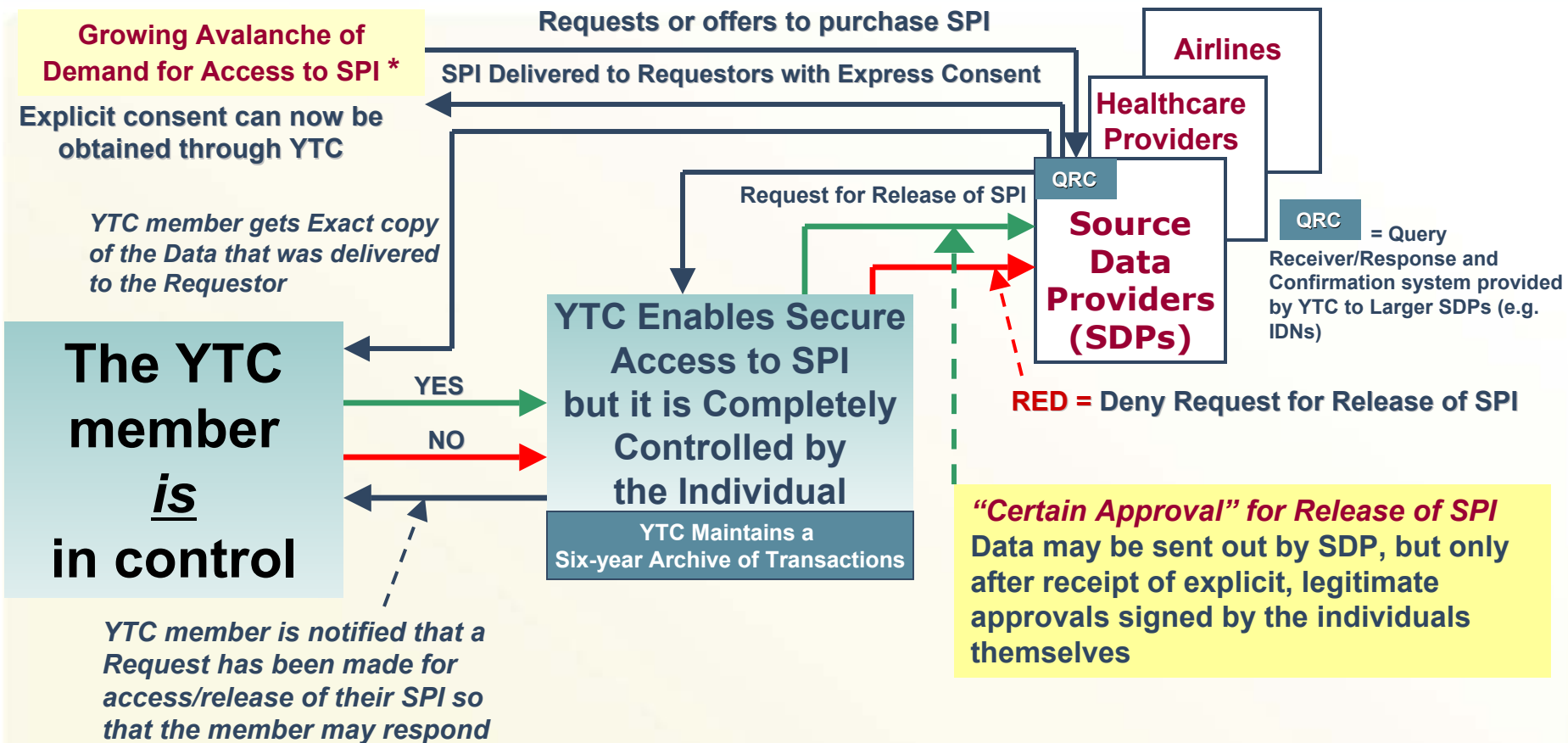
## Key Roles YTC Performs

**Assists Government:** YTC reduces government's burdensome legislative and policing roles where the individual's privacy is concerned, passing that responsibility to its rightful custodian: the individual citizen. This enables government to get out of the privacy "hot seat."





# How YTC Benefits Each Participant...



**\* SPI = Sensitive Personal Information**



# You Take Control – Contact Data

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