HIT Summit West
March 7, 2005

Building a
Common Framework
for Health Information Exchange
Privacy Policy

(last updated 01/04/05)

Protecting privacy is always a ChoicePoint priority. To underscore our fundamental commitment to privacy and our vision that good privacy is good business, we have adopted an online privacy policy for each of our websites: www.choicepoint.com, www.choicepoint.net and www.choicepointinc.com. This policy reflects and implements— in an online setting— our corporate privacy principles and Fair Information Practice Principles of notice, choice, access, security, and accountability.

This online privacy policy applies to choicepoint.com, choicepoint.net and choicepointinc.com, which are operated by ChoicePoint Inc., 1000 Alderman Drive, Alpharetta, GA 30005, privacy@choicepoint.com, (877) 301.7097. This site is not directed at children. Please note, this policy does not apply to the following subdomains that have their own privacy statements posted: www.findnewcustomers.choicepoint.com, www.minimizebusinessrisk.choicepoint.com, www.employeewisecollections.choicepoint.com.

To demonstrate our further commitment to online privacy, ChoicePoint is a licensee of the TRUSTe® Privacy Program. TRUSTe is an independent, non-profit organization whose mission is to build users’ trust and confidence in the Internet by promoting the use of fair information practices. TRUSTe’s certification covers the Web sites gathering and dissemination of information not any services or products. We have disclosed the information practices of our Web site to TRUSTe, and TRUSTe has reviewed and approved our online privacy practices for compliance with TRUSTe’s online privacy standards. If you have questions or concerns regarding this statement, you should first contact us at:

ChoicePoint Inc.
Office of Privacy Compliance
1000 Alderman Drive
Alpharetta, GA 30005
Telephone: 877.301.7097
Fax: 770.752.5935
Email: privacy@choicepoint.com

If you do not receive acknowledgment of your inquiry or your inquiry has not been satisfactorily addressed, you should then contact TRUSTe at www.truste.org/consumers/whatscomplaint.php. TRUSTe will then serve as a liaison to resolve your concerns.

INFORMATION COLLECTION
Privacy Policy

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ChoicePoint Data Cache Became a Powder K

Identity Thief's Ability To Get Information Puts Heat on Firm

By Robert O'Harrow Jr.
Washington Post Staff Writer
Saturday, March 5, 2005; Page A01

The man on the phone called himself James Garrett.

Speaking with a lilting accent, the man said he was an executive with a Angeles company called M.B.S Financial. He told an employee at ChoicePoint Inc. that he wanted to open an online account with the company to receive electronic reports on people.

It was the kind of request that ChoicePoint, one of the nation's largest information services, gets all the time. Thousands of corporate and government clients rely on the company to provide them with publicly available information on people for help in hiring, fraud...
Purpose of Connecting for Health

Catalyze changes on a national basis to create an interconnected, electronic health information infrastructure to support better health & healthcare.
What is *Connecting for Health*?

- Broad-based, public-private coalition
- More than 100 collaborators
  - Providers (AMA, ACP, AAFP, ACEP, Presbyterian, Partners)
  - Patients (IAM, NCCS)
  - Suppliers (RxHub, Surescripts, J&J, Pfizer)
  - Payers (CAQH, AHIP, BCBSA, GE, Leapfrog, PBGH)
  - Accreditors (NCQA, JCAHO, URAC)
  - Government agencies (CMS, AHRQ, CDC, FDA, VA)
  - Researchers (AHRQ, CDC, AMIA)
  - IT vendors (Siemens, CSC, IBM, Microsoft, Allscripts)
- Founded and supported by **Markle Foundation**, with additional support from **Robert Wood Johnson Foundation**
- See [www.connectingforhealth.org](http://www.connectingforhealth.org)
Eight Key Areas of Roadmap Recommendations

1. Engaging the American Public
2. Designing for Privacy & Security
3. The Infrastructure—technical architecture & approach
4. Accurate Linking of Patient Information
5. Data Standards
6. Clinical Applications
7. Funding & Incentives
8. Legal Safe Harbors
Principles of the Connecting for Health Common Framework

- Safeguards privacy
- Built without a national patient ID
- Leverages both “bottom-up” and “top-down” strategies
- Builds on existing systems (“incremental”)
- Consists of an interoperable, standards-based “network of networks” built on the Internet
- Patient information remains where it is now and is not kept in a central database (“decentralized”)
- Data-sharing initiatives have local autonomy but follow certain standards and policies to enable interoperability (“federated”)
Provider asks if there are records for his/her patient. The patient index sends the location of any records. Source sends index information.

Provider asks for and receives records. Records are sent to the provider.

Source may push data for reporting.

De-Identified Data.
2005: A Regional Prototype

• Within 12 months: a concrete, functional demonstration of the critical common standards-based components of an interoperable, community-based infrastructure

• Common Framework of public domain standards, policies and methodologies that can be quickly replicated to provide:
  – Secure connectivity
  – Reliable authentication
  – Information exchange for selected use cases

• Demonstrate that adhering to the Common Framework ensures that data exchange pilots, personal health records and regional systems can interoperate
Six Elements for a National Health Information Environment

1. An environment – not a network
2. A common framework
3. Standards and Policies Entity
4. Record Locator Service
5. Patient control
6. Financing and incentives
Element #1 – *an environment, not a network*

U.S. can create an *environment* with specific characteristics, so that any appropriate and authorized entity can participate in information sharing – a doctor, an individual, a pharmacy, a hospital, a public health agency.
Element #2 – a Common Framework

This environment will be enabled by general adoption of a set of specific, critical tools, including technical standards for exchanging clinical information, explicit policies for how information is handled, and uniform methods for linking information accurately and securely.
The Proposed Stack of Standards

• (Local application logic)
• Health-care specific message contents
• Envelope with delivery instructions
• "On the wire" encryption
• Transport and low-level application logic
• Logical network
• (Physical network)
The Proposed Stack - standards

- HL7 where applicable + necessary specifications
- SOAP
- SSL
- http
- Internet
- Health-care contents
- Envelope
- Encryption
- Transport
- Physical network
Proposed Deliverables: Technical

- Standards and practices for describing health data
- Standards and practices for using the Internet securely
- Components for building a local Record Locator Service
Proposed Deliverables: Security

• Advise Technical Working Group on security parameters
  – Technical
  – Physical
  – Mirroring
  – Incomplete data/liability
  – Enforcement policy
Proposed Deliverables: Policy

• Backgrounder on core privacy and security principles
• General guidance document—includes minimum necessary participation in governance and structure, key stakeholder requirements, and general approaches
• Community sharing “rules of the road” document
• Survey of community current information sharing policies
• Survey of community perceived policy challenges and needs
• Model consent language
• Model Data Use and Access language for creating a multilateral agreement at the regional/ community level
• Model Privacy Practices
• Identification of areas where state-specific accommodations needed
Element #3 – a new Standards and Policies Entity

This toolkit must be uniform, so must be defined by a single, national entity – the Standards and Policies Entity – which reflects public and private sector participation, is transparent, accountable, and operates in the public interest.
Element #4 – a Record Locator Service

New indices that indicate where patient information is stored must be created, particularly within geographic regions. These “Record Locator Services” must be standardized and able to link to other indices that are not regional, such as Medicare, VA, national health plans, public health networks, etc.
Accurate Linking

• Linking of patient information for high-quality care can and should be done without a National Health ID
  – National ID is not a magic bullet—it’s just another identifier and would be difficult and costly to implement even if available
  – Political culture in U.S. is not amenable to national identifier
  – Risk of privacy spills is a significant disadvantage

• Linking is accomplished by directories pointing to the sources of the records
  – The directory system knows where the records are, not what is in them
  – Patients determine locally with their providers what information to link and disclose, and to whom
RLS and Gateway Components

Single Enterprise

Web Server / Presentation Layer
- Identity Management Registration / Self-Service
- Login
- Enter Patient Demographics
- Review / Select Patient Index Entries
- View Aggregated Medical Records

Database Server
- Cached Record Pointers (optional)
- Audit History
- Work-in-Process Messages
- Patient Index (optional publish to CMPI)

Clinical Exchange (ClinEx) Gateway

Business Applications
- Visit History Maintenance / Retrieval
- Problem List Maintenance / Retrieval
- Notes / Report Delivery / Retrieval
- Medication List / Drug History Maintenance / Retrieval
- Allergy List Maintenance / Retrieval
- Lab / Rad / Micro Result Maintenance / Retrieval
- Rx Routing (Rx Gateway)

Common Utility Services
- Record Locator
  - Publish / Maintain Patient Index
  - Read Patient Index
  - Medical Record Request
- Record Transport
  - Record Retrieval (from source)
  - Record Delivery (to requestor)
  - Record Format Validation
- Security Services
  - (Limited) Identity Management / Directory Services
  - Identification / Authentication
  - Role- and Process-Based Access Control
- Session Management Services
  - Network / Connection Management
  - Thread / Queue Management
  - Transaction / Data Management Services
  - Logging

Legacy / Core System
- Extract Service / Message Adaptor
- Record Translation
- Operational Data Source

Other Clinical Exchange Gateways / Proxies
- Secure Internet
- Hosted Clinical Data Exchange Services

Enterprise Message Bus / Intranet

Community Master Patient Index

= Required by RLS
= Other core utility service
= Business / Line of Service Offering (including Med List)
= Responsibility of participating organization
Element #5 – *patient control*

To merit the trust of the public, people must have significant personal control over the sharing of their information. The system must also ensure that providers have the information they need to provide high quality, safe care.
Element #6 – financing and incentives

1. The national health information environment is funded from both public and private sources.
2. Federal funding is needed to launch the national Standards and Policy Entity; and to provide seed grants and for Record Locator Services and regional start-ups.
3. Both should receive private support over time and be self-sustaining.
4. Adoption of compatible IT by end-users (e.g., doctors, pharmacies, hospitals) will be stimulated by incentives built into routine payment that are tied to the use of the Common Framework.
Summary of Proposed Deliverables

1. Backgrounder on core privacy and security principles
2. Policy manual, including:
   - Community sharing “rules of the road” document
   - Survey of community current information sharing policies
   - Survey of community perceived policy challenges and needs
   - Model consent language
   - Model multilateral agreement Model Privacy Practices
3. Security policies and standards
4. Standards and practices for describing health data
5. Standards and practices for using the Internet securely
6. Components for building a local Record Locator Service
The Hymnal…

• Uniform core messages across all audiences
  – Animation and graphics
  – Slide materials
  – Handouts

• Tailored messages for each stakeholder
  – FAQs

• Coordinated consumer messaging