Secondary use of health data

Some scenarios and solutions

AMIA conference
Reston, June 14, 2007

Antoine Geissbuhler, MD
Scenarios

- Confidentiality is one of the criteria for trust in online medical information

- Enabling medical research while protecting patient’s privacy
  - General authorization for the use of PHI for retrospective research
  - Networks for federated, distributed biomedical research

- Monitoring for quality and efficiency
  - The problem of transparency
  - Trust centers
HONcode: the Health On the Net code of conduct

- **Authoritativeness**: Indicate the authors’ qualifications
- **Complementarity**: Information should support, not replace, the doctor-patient relationship
- **Privacy**: Respect the privacy and confidentiality of personal data submitted to the site by the visitor
- **Attribution**: Cite the source(s) of published information, date and medical and health pages
- **Justifiability**: Site must back up claims relating to benefits and performance
- **Transparency**: Accessible presentation, identities of editor and webmaster, accurate e-mail contact
- **Financial disclosure**: Identify funding sources
- **Sponsorship**: Clearly distinguish advertising from editorial content
HONcode facts

- Voluntary accreditation
- 5,533 sites
- 72 countries
- 32 languages
- 1,200,000 web pages accredited
- 50% of sites in Europe
- HONcode team: 13 persons
  - 6 physicians
  - 1 pharmacist
  - 1 Ph.D. in molecular biology
  - 2 law graduates
  - 3 medical students
General authorization to use personal health information for retrospective research (« authorization to release professional secrecy for research purposes »)

- Granted by the Swiss federal commission on privacy protection to the medical director of the institution
- Based on an explicit, audited institutional process, including IRB approval and non-objection by all medical services
- Only possible when consent cannot reasonably be obtained
- Data must be anonymized at the start of the research
- Based on the institution’s EPR
aneurIST: a prototypical EU project

Biomedical infostructure

- To federate data from multiple clinical centers across Europe
- To enable distributed research (flow simulation, implant design, population studies, genetic studies)
- To implement algorithms for improving rupture-risk assessment
aneurIST: a prototypical EU project

Integrated biomedical informatics for the management of cerebral aneurysms

GRID
- population studies
- quality control
- data mining

flow simulation
image analysis
implant design
virtual patient

hospital
connector
hospital
connector
hospital
connector

De-indentification
Re-identification
Normalization
• Issues
  • Multiple countries, multiple IRBs, multiples rules
  • Informed consent vs selection bias
  • Pseudonymization issues (incl. images), third trusted party
  • Live links to clinical information systems
  • Getting back to the patient with relevant information
  • Patient’s intellectual property rights?
Reestablishing the Researcher-Patient Compact

Isaac S. Kohane,1,2,3* Kenneth D. Mandl,1,2,3 Patrick L. Taylor,2,4 Ingrid A. Holm,2,5 Daniel J. Nigrin,1,2,3 Louis M. Kunkel2,5,6

Well-intentioned regulations protecting privacy are denying important information to patient subjects. Advances in information technology mean that a better approach to clinical research is possible.
• Shared, distributed patient health record

• All care professionals publish useful information on the network

• The patient has the key needed to access the information

• The access requires the existence of a « therapeutic relationship » materialized by the two cards (patient and professional)

• Information stays at its source, it can be consolidated but never centralized

• Used only for healthcare
Technical architecture

- No centralized patient list
- The network is able to connect to other similar networks
- The network is open to commercial value-added services
- No compromise on security
Who wants transparency?

- More than privacy, transparency is a key issue for the acceptance of a trans-institutional health information exchange

  - For citizens
  - For care providers
    - Vis-à-vis payers
    - Vis-à-vis peers
Protecting care providers’ and patients’ privacy

- Reimbursement claims are validated by the trust center, then pseudonymized before they are transmitted to the payer.

- Payers and care providers can access statistical data.