

Data Privacy in Hungary

Dr. Zoltán Alexin, PhD.
University of Szeged,
Department of Software Engineering
H-6720 Szeged Árpád tér 2.
e-mail: alexin@inf.u-szeged.hu
<http://www.inf.u-szeged.hu/~alexin>



<http://www.futureict.eu>



http://www.cost.eu/domains_actions/ict/Actions/IC1206

XXVI. Neumann Kollokvium, Italian-Hungarian Workshop, 2013. Veszprém, Hungary

Who am I

- Since 2004, I began studying privacy issues
- Member of a regional medical research ethics committee
- Member of the Association on Fair Data Processing
- Member of the presidential board of the Hungarian Data Protection Society
- Blogger (www.magyarorszag.hu, www.tisztesslegesadatkezeles.hu)
- Has cases before Civil Courts, Hungarian Constitutional Court, European Commission, ECtHR on fundamental questions of medical data processing
- Achievements: excluding unsubsidized care events from the National Health Insurance Fund database, ethics approval of medical research projects without intervention

Highly visible and embarrassing headlines

July 2009 - New Federal, State Law Raise the Stakes When Dealing with Employees Who Snoop into Patient Health Records

July 2009 - HHS Hiring to Expand Privacy Enforcement

HITECH Act Means More Aggressive HIPAA Enforcement

Kaiser Fined for Octomom Records Snooping

The state has fined Kaiser Permanente \$250,000 for violating patient privacy laws when several hospital employees inappropriately accessed medical records for octuplet mother Nadya Suleman.



**FBI looking at UMC records leak
Agent says 'multiple federal laws' might have been violated**

University Medical Center, which is Clark County's only publicly funded hospital.



UCLA Medical Center is taking steps to fire at least 13 employees and is disciplining other, including doctors, for looking at pop star's confidential files.

CVS Caremark Settles FTC Charges:

Failed to Protect Medical and Financial Privacy of Customers and Employees; CVS Pharmacy Also Pays \$2.25 Million to Settle Allegations of HIPAA Violations.

"Scam Guy" Hit 50,000 Hospital ID Theft

Spree: ...employee charged with selling patient information as part of wide-scale identity theft. Illegally accessed nearly 50,000 patient files.

Key Canadian Findings

- 43.2% of Canadian patients stated they have withheld or would withhold information from their care provider based on privacy concerns
- 31.3% stated they have or would postpone seeking care for a sensitive medical condition due to privacy concerns
- More than 2 out of 5 Canadian patients, 42.9% indicated they would seek care outside of their community due to privacy concerns





2012 © FairWarning, Inc. – Private and Confidential



<http://www.fairwarning.com>

How privacy behaviors & beliefs impact patient treatments & care



Patient privacy behavior or belief				
Believe care provider has ethical and legal obligation to protect privacy	97 %	97 %	93 %	98 %
Patient postpones treatment due to privacy concerns	28 %	38 %	22 %	31 %
Patient willing to travel outside of community for care due to privacy concerns	51 %	45 %	32 %	43 %
Patient withholds medical information due to privacy concerns	27 %	54 %	54 %	43 %
Serious or repeated breaches reduce confidence in quality of care from provider	64 %	73 %	41 %	62 %
Believe care providers should monitor who looks at medical records and detect misuse of access	66 %	87 %	47 %	90 %
If the chief executive and senior management were made aware of risks but failed to act and there is a serious breach, they should be fined or lose job		87 %	91 %	84 %

PS PUBLIC SERVICE.CO.UK
analysis+opinion+debate

eHealthNews.eu
The First European eHealth News Portal



DÉCIDEUR PUBLIC
SYSTÈMES D'INFORMATION

CMAJ



2012 © FairWarning, Inc. - Private and Confidential

Patient Privacy, Treatment and Outcomes Survey Results in Order of Release

United States, September 13th, 2011 – <http://www.fairwarning.com/documents/2011-WHITEPAPER-US-PATIENT-SURVEY.pdf>

United Kingdom, October 13th, 2011 – <http://www.fairwarning.com/documents/2011-WHITEPAPER-UK-PATIENT-SURVEY.pdf>

France, January 17th, 2012 – <http://www.fairwarning.com/documents/2011-FR-SURVEY-FINAL.pdf>

Canada, January 26th, 2012 – <http://www.fairwarning.com/documents/Canada/2011-CanadaSurvey.pdf>

<http://www.fairwarning.com>

Unique feature of Hungarian data protection legislation

- EU 95/46/EC Data protection directive, Article 7.
- Member States shall provide that personal data may be processed only if:
 - (a) the data subject has given his consent; or
 - (b) processing is necessary for the performance of a contract to which the data subject is party; or
 - (c) processing is necessary for compliance with a legal obligation to which the controller is subject; or
 - (d) processing is necessary in order to protect the vital interests of the data subject; or
 - (e) processing is necessary for the performance of a task carried out in the public interest; or
 - (f) processing is necessary for the purposes of the legitimate interests pursued by the controller or by the third party.
- **The red points are not implemented.**

Recommendation R(97) No. 5. of the Council of Europe

- Article 4.3 Medical data may be collected and processed:
 - a. if provided for by law for (obligatory):
 - i. public health reasons; or
 - ii. subject to Principle 4.8, the prevention of a real danger or the suppression of a specific criminal offence; or
 - iii. another important public interest; or
 - b. if permitted by law:
 - i. for preventive medical purposes or for diagnostic or for therapeutic purposes with regard to the data subject or a relative in the genetic line; or
 - ii. to safeguard the vital interests of the data subject or of a third person; or
 - iii. for the fulfilment of specific contractual obligations; or
 - iv. to establish, exercise or defend a legal claim; or
 - c. if the data subject or his/her legal representative or an authority or any person or body provided for by law has given his/her consent for one or more purposes, and in so far as domestic law does not provide otherwise.

Health Data Protection Act of Hungary

- Article 4.3 Medical data may be collected and processed:
 - a. if provided for by law for (obligatory):
 - i. public health reasons; or
 - ii. subject to Principle 4.8, the prevention of a real danger or the suppression of a specific criminal offence; or
 - iii. in important public interest; or
 - **iv. for preventive medical purposes or for diagnostic or for therapeutic purposes with regard to the data subject or a relative in the genetic line; or**
 - **v. to safeguard the vital interests of the data subject or of a third person; or**
 - **vi. for the fulfilment of specific contractual obligations; or**
 - **vii. to establish, exercise or defend a legal claim; or**
 - **viii. doing research on existing medical data**
 - b. if the data subject or his/her legal representative or an authority or any person or body provided for by law has given his/her consent for one or more purposes, and in so far as domestic law does not provide otherwise.

Helsinki Declaration

- Paragraph 32. For medical research using identifiable human material or data, such as research on material or data contained in biobanks or similar repositories, physicians must seek informed consent for its collection, storage and/or reuse. There may be exceptional situations where consent would be impossible or impracticable to obtain for such research. In such situations the research may be done only after consideration and approval of a research ethics committee. (Version 19 October 2013.)
- Act of Health No. CLIV of 1997. and Decree on Medical Research Involving Human Subjects No. 23/2002. (V. 9.): In the case of retrospective medical research done without intervention (i.e. database research), **subjects need not be informed and consent need not be sought.**
- National databases (registries) are established by the force of law and not supervised by ethics committees.

Electronic Health Records

- Currently:
 - Accounting data is used for health purposes
 - Dates, institutions and interventions / prescriptions can be retrieved
 - Simple control: all data back to 15 years can be accessed uncontrollably, or
 - Patients may object, then no data can be accessed
- Planned:
 - Nationwide EHR system, all people will have records obligatory
 - Upload data will be obligatory
 - Patients can control access of their doctors to data (we do not know how)
 - No responsibility, no sanctions
 - Government bodies have full access to any portion of data, even personal data when they want
- Fascicolo Sanitario Elettronico
- Article 29. Working Group recommendation on EHR systems.

Private and public care

- The Constitutional Court decision No. 29/2009. (III. 20.)
 - The national social security identifier (TAJ) cannot be used in private care (in unsubsidized care)
- Biggest problem is prescription data (100 million unsubsidized prescription per year)
- The state did not understand the decision
 - IVF clinics have to report cases by TAJ – in 2011
 - Private clinics have to report cancer screening results by TAJ – in 2012
 - Unsubsidized prescriptions still contains TAJ – impossible to remove from them, the Data Protection Authority did not do anything against this practice.
- Italy: The data protection law itself contains that unsubsidized prescriptions must not contain national health ID, personal data are covered by an adhesive tab, address is not necessary.

Italian prescriptions

- Decreto legislativo 30 giugno 2003, n. 196 Codice in Materia di Protezione dei Dati Personali
- Section 87 (Drugs Paid for by the National Health Service)
 - 1. Prescriptions concerning medical drugs that are charged, even only in part, to the National Health Service shall be written by using the form referred to in paragraph 2. Said form shall be designed so as to allow establishing the data subject's identity only if this is necessary in order to check that the prescription is correct or else with a view to administrative controls or for epidemiological and research purposes, in compliance with the applicable rules of conduct.
- Section 88 (Drugs Not Paid for by the National Health Service)
 - 1. The data subject's name shall not be specified in the prescriptions made on paper forms with regard to drugs that are not charged, even in part, to the National Health Service.
 - 2. In the cases referred to in paragraph 1, a physician may specify the data subject's name exclusively if he/she considers that it is indispensable to make said data subject personally identifiable on account of an actual requirement that is related either to the data subject's specific condition or to the special arrangements to be made for preparing or using the drug.

The future

- GDPR (General Data Protection Regulation)
 - Unofficial Version After LIBE Committee Vote Provided By The Rapporteur 22 October 2013
 - CHAP (2011) 02536 infringement procedure against Hungary
 - The reason: abusing obligatory data processing
 - Lex Hungary:
 - Prevent member states from passing laws on obligatory data processing (especially when health data is processed)
 - Preliminary approval of laws by the European Commission
 - Medical data can be processed for research purposes by consent
 - Right to object is explicitly granted
-
- The attitude towards data processing shall be completely changed
 - Constitutional Court initiative against DPA, and for medical secrecy



Thanks for the attention!