

Processing Personal Health Data in Legitimate Interest

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>

TeleMediCare 2014, IV. International Conference on
TeleMedicine & TeleCare, 2-3 October, 2014. Desio, Italy

Who am I

- Mathematician, PhD. on application of machine learning algorithms to text analysis
- Since 2004, I began studying privacy issues
- Working Group leader on Data Protection in FuturICT.hu national project
- Member of a regional medical research ethics committee
- Blogger (www.magyarorszag.hu)
- I had cases before Civil Courts, Hungarian Constitutional Court, European Commission, ECtHR on fundamental questions of medical data processing
- Achievement: excluding data from the National Health Insurance Fund database related to unsubsidized care events, necessary ethics approval of medical research projects without intervention, and other minor results

Content

- Purposes, for which medical data can be processed.
- What does legitimate interest mean?
- Recent decisions of ECJ and its consequences
- Examples
- Conclusion

Significance of the EU 95/46/EC Data Protection Directive

- The European Charter of Fundamental Rights entered into force on 1st December 2009. Last signer was the Czech Republic on 30th November evening.
- Personal data protection became a fundamental right of European citizens
- Cases were sent to the European Court of Justice after 2010 referring to the Charter
- The Court had to take into consideration the Data Protection Directive as a sole possible EU legal text
- The Court began to execute the principles of the Directive

EU 95/46/EC Directive

- Article 8. The processing of special categories of data
 - 1. Member States shall prohibit the processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and the processing of data concerning health or sex life.
 - 2. Paragraph 1 shall not apply where:
 - (a) the data subject has given his explicit consent to the processing of those data, except where the laws of the Member State provide that the prohibition referred to in paragraph 1 may not be lifted; or
 - (c) processing is necessary to protect the vital interests of the data subject or of another person where the data subject is physically or legally incapable of giving his consent; or
 - 3. Paragraph 1 shall not apply where processing of the data is required for the purposes of preventive medicine, medical diagnosis, the provision of care or treatment or the management of health-care services, and where those data are processed by a health professional subject under national law or rules established by national competent bodies to the obligation of professional secrecy or by another person also subject to an equivalent obligation of secrecy.

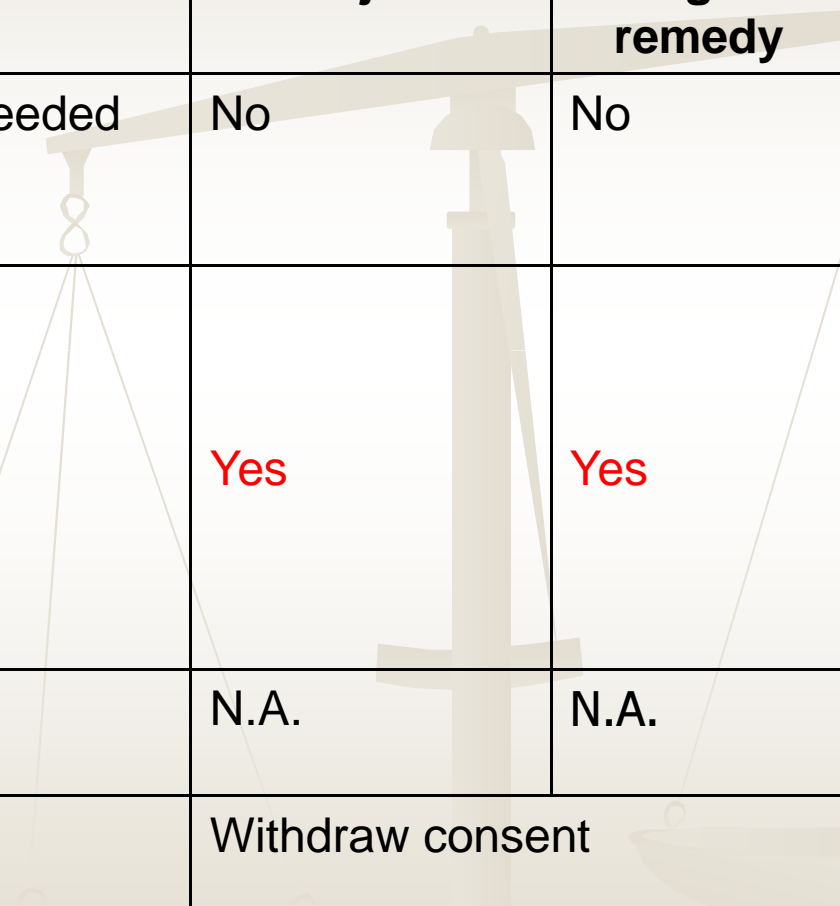
EU 95/46/EC Directive

■ Article 7.

Member States shall provide that personal data may be processed only if:

- (a) the data subject has unambiguously given his **consent**; or
- (b) processing is necessary **for the performance of a contract** to which the data subject is party or in order to take steps at the request of the data subject prior to entering into a contract; 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 in the exercise of official authority vested in the controller or in a third party to whom the data are disclosed; or
- (f) processing is necessary **for the purposes of the legitimate interests** pursued by the controller or by the third party or parties to whom the data are disclosed, except where such interests are overridden by the interests for fundamental rights and freedoms of the data subject which require protection under Article 1 (1).

Legal bases for data processing



Type	Interests	Preliminary information	Right to object	Right to legal remedy
Obligatory by law	Higher-level interests of the society	Not needed	No	No
Permitted by law	Performance of a contract			
	Public interest	Yes	Yes	Yes
	Legitimate interest			
	Vital interest	N.A.	N.A.	N.A.
Consent		Yes	Withdraw consent	

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.

Different purposes

Type	Interests	Purposes of data processing
Obligatory by law	Higher-level interests of the society	public health reasons prevention of a real danger or the suppression of a serious criminal offence
Permitted by law	Performance of a contract	supply data for a life or accident insurance
	Public interest	cost effective national health system, prevention, medical research
	Legitimate interest	preventive medical purposes, diagnostic or therapeutic purposes, management (improve service, financial gain, research) establish, exercise or defend a legal claim
	Vital interest	save life (data subject or third person)
Consent		any other purpose

ECJ (European Court of Justice) decisions I.

- Case No. C-468/10 and C-469/10, 24th November 2011.
- Parties: Asociación Nacional de Establecimientos Financieros de Crédito (ASNEF) (C-468/10) and Federación de Comercio Electrónico y Marketing Directo (FECEMD) (C-469/10) vs. Spain
- Telecom/financial companies cannot transfer data in their legitimate interests to an EU member state because Spanish law requires consent
- The decision:
 - 1. Article 7(f) of Directive 95/46/EC must be interpreted as precluding national rules which, in the absence of the data subject's consent, and in order to allow such processing of that data subject's personal data as is necessary to pursue a legitimate interest of the data controller or of the third party or parties to whom those data are disclosed, require not only that the fundamental rights and freedoms of the data subject be respected, but also that the data should appear in public sources, thereby excluding, in a categorical and generalized way, any processing of data not appearing in such sources.
 - 2. Article 7(f) of Directive 95/46 has direct effect in all member state.

ECJ (European Court of Justice) decisions II.

- Case No. C-543/09, 5th May 2011.
- Parties: Deutsche Telekom AG vs. Germany
- The GoYellow GmbH and the Telix AG bought data from the Deutsche Telekom AG and operate an internet based, Universal service directory. Not only the Telekom AG's own data but third party data were passed without consent and despite of objection according to a German law (Bundesverwaltungsgericht). Telekom AG obtained third party data upon consent, but consent was not renewed when data were passed to other companies.
- The decision:
- 2. Article 12 of Directive 2002/58/EC must be interpreted as not precluding national legislation under which an undertaking publishing public directories must pass personal data in its possession relating to subscribers of other telephone service providers to a third-party undertaking whose activity consists in publishing a printed or electronic public directory or making such directories obtainable through directory enquiry services, and under which the passing on of those data is not conditional on renewed consent from the subscribers, provided, however, that those subscribers have been informed, before the first inclusion of their data in a public directory, of the purpose of that directory and of the fact that those data could be communicated to another telephone service provider and that it is guaranteed that those data will not, once passed on, be used for purposes other than those for which they were collected with a view to their first publication.

Summary of ECJ decisions

- Processing personal data in legitimate interests shall be implemented in all member states in the same way. The Article 7 (f) has direct effect.
- Right to protect personal data is not absolute, See Jeanne Pia Mifsud Bonnici: Exploring the non-absolute nature of the right to data protection, International Review of Law Computers and Technology, Vol. 28. No 2. pp. 131-143 (2014).
- When data are processed in the legitimate interests of the controller then the rights of data subjects and the interests of the controller shall be balanced.
- There might be cases when objections are not accepted, the courts may decide so that the rights of the controller prevail the rights of data subjects.

Administration and research

What is the difference?

- Committee on the Role of Institutional Review Boards in Health Services Research Data Privacy Protection, National Academy Press, Washington, D.C. 2001: Protecting Data Privacy in Health Services Research, page 11.
- The following are characteristics of projects using HSR (Health Science Research) methods that are research, not Quality Assessment or Quality Improvement:
 - It explores previously unknown phenomena.
 - It collects information beyond that routinely collected for the patient care in question.
 - It compares alternative treatments, interventions, or processes.
 - It manipulates a current process.
 - The results are expected to be published for general societal benefit.

Medical research vs. administration

- When doing medical research, objections shall be respected. See Declaration of Helsinki, Ethical Principles for Medical Research Involving Human Subjects, Paragraph 26.
- When doing administration (in the legitimate interests of a medical service provider) and processing personal data:
 - Preliminary information on data processing shall be provided to patients
 - Objections may not be accepted, but there should be clear reasons
 - Reasons must be defensible before the court
- Article 29 Data Protection Working Party, Opinion 6/2014 on the notion of legitimate interests of the data controller under Article 7 of Directive 95/46/EC, 9th April 2014.
 - Detailed document on the topic, 68 pages long. Freely downloadable.

Summary

- Medical service providers (and insurance companies) have legitimate interests to exploit advantages of processing personal health data
 - From legal points of view this is recognized by the Directive 95/46/EC
 - Patients must be fully informed beforehand
 - Generally they have right to object
 - In exceptional cases objections may be rejected
 - Medical privacy must be respected
- Care.Data project in UK
 - Maximum that is allowed by the Directive
 - The legal norms may be changed due to the debate among data protection experts



Thanks for the attention!