

PRIVACY AND PROTECTION OF PERSONAL DATA

Lasse Lehtonen, M.D., LL.M

Helsinki University Central Hospital

Hippocratic oath

- "... What I may see or hear in the course of treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep myself holding such things shameful to be spoken about..."

Modern challenges

- Accumulation of data to electronic health registries
- Multiple users (some of which may be other than health care professionals)
- Utilization of the registries in health care planning (and surveillance) by the payer organizations (including employers)
- New types of medical data (genetic information)

Restrictions of privacy

- European convention on human rights article 8
 - There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

E.g. welfare benefits

- *M.S. v. Sweden* [1997], ECHR 20837/92, 27 August 1997
 - under the Swedish system, the contested disclosure depended not only on the fact that the applicant had submitted a compensation claim to the Social Insurance Office but also on a number of factors beyond her control. It could not therefore be inferred from her request for compensation that she had waived in an unequivocal manner her right to respect for private life with regard to the medical records at the clinic.
 - Accordingly Article 8(1) applied. The medical records in question contained highly personal and sensitive data about the applicant. Although they remained confidential, they had been disclosed to another public authority and therefore to a wider circle of public servants. The collection and storage of information at the clinic and its subsequent communication to the Office had served the different purposes - disclosure thus entailed an interference with applicant's right to respect for private life. *The requirement 'in accordance with law' was satisfied as the interference had a legal basis and was foreseeable.* The communication of data was potentially decisive for allocation of public funds to deserving claimants. *It was therefore legitimate for the protection of the economic well-being of the country:* the medical data were communicated by one public institution to another in the context of an assessment of whether the applicant satisfied the legal conditions for obtaining a benefit which she herself had requested.

The right to privacy is a human right

- Medical decision making and confidentiality of discussions between the patient and the doctor belong to the core area of privacy

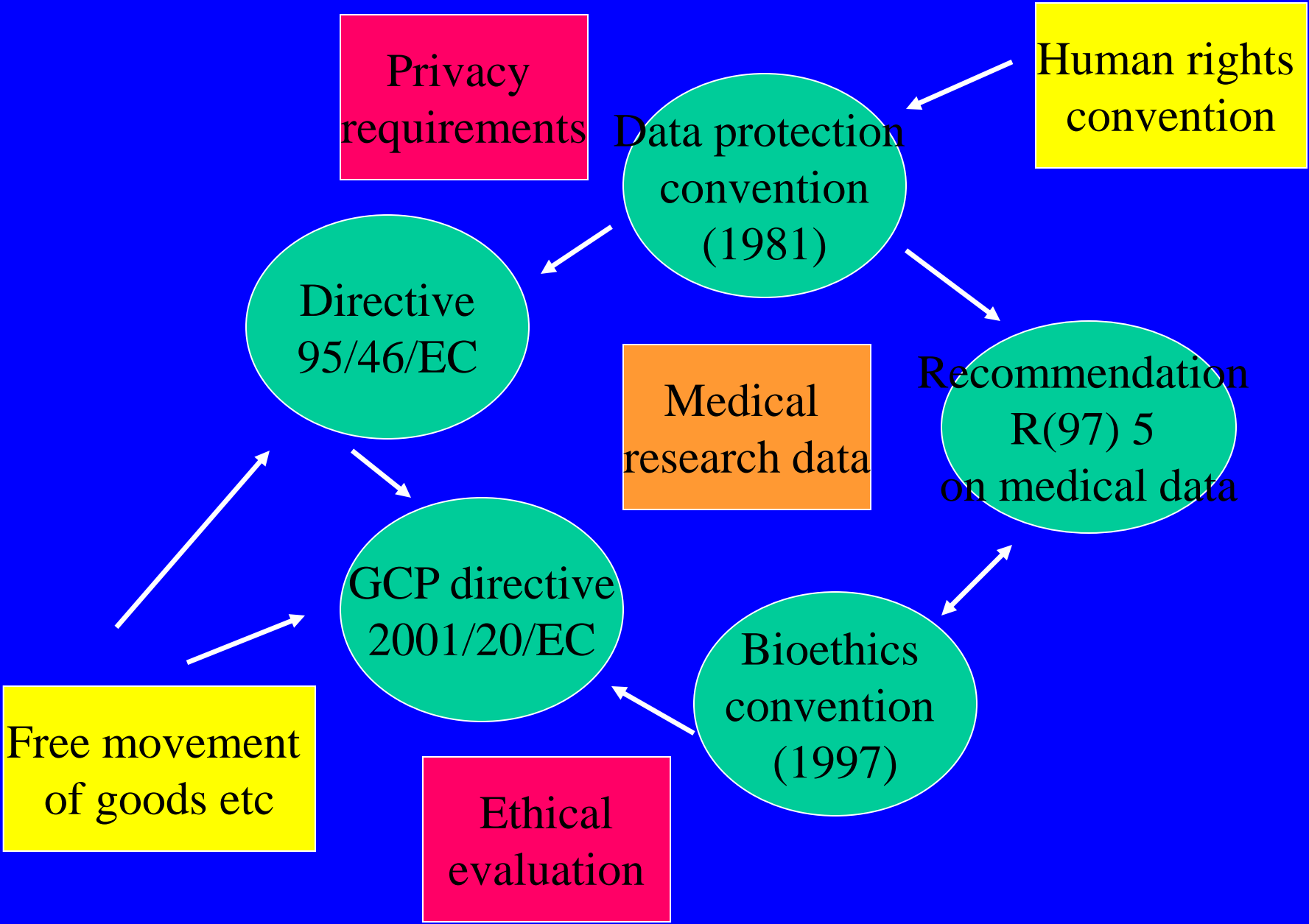
Szuluk v United Kingdom [2009]
ECHR 36936/05 (2 June 2009)

- The European Court of Human Rights has held that it is a disproportionate interference with an individual's right to privacy to monitor their confidential medical correspondence with their specialist. The prison governor had directed that the applicant's correspondence with his specialist be opened and inspected by the prison medical officer to ensure that there were no illicit enclosures.

Requirement for proportionality

- The restriction of the basic right has to be necessary in a democratic society
 - the member states of the Council of Europe have margin of appreciation in their national legislation

Complex legal regulation in
addition of professional standards



The international regulations are implemented by the national laws

- E.g. the act on personal data (523/1999) in Finland

Council of Europe: Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data. January 28, 1981 (ratified in Finland Dec. 2, 1991)

- **Article 6 – Special categories of data:** Personal data revealing racial origin, political opinions or religious or other beliefs, as well as personal data concerning **health** or sexual life, may not be processed automatically unless domestic law provides appropriate safeguards.
- **Article 8 – Additional safeguards for the data subject:** Any person shall be enabled:
 - **a.** to establish the existence of an automated personal data file, its main purposes, as well as the identity and habitual residence or principal place of business of the controller of the file;
 - **b.** to obtain at reasonable intervals and without excessive delay or expense confirmation of whether personal data relating to him are stored in the automated data file as well as communication to him of such data in an intelligible form
 - **c.** to obtain, as the case may be, rectification or erasure of such data if these have been processed contrary to the provisions of domestic law giving effect to the basic principles set out in Articles 5 and 6 of this convention
 - **d.** to have a remedy if a request for confirmation or, as the case may be, communication, rectification or erasure as referred to in paragraphs b and c of this article is not complied with.

Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data

- ...(10) Whereas the object of the national laws on the processing of personal data is to protect fundamental rights and freedoms, notably the right to privacy, which is recognized both in **Article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms** and in the general principles of Community law; whereas, for that reason, the approximation of those laws must not result in any lessening of the protection they afford but must, on the contrary, seek to ensure a high level of protection in the Community;
- (11) Whereas the principles of the protection of the rights and freedoms of individuals, notably the right to privacy, which are contained in this Directive, give substance to and amplify those contained in **the Council of Europe Convention of 28 January 1981 for the Protection of Individuals with regard to Automatic Processing of Personal Data...**

Directive 95/46/EC

- **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.

- 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

Data protection principles

- Personal data is:
 - Fairly and lawfully processed
 - Processed for limited purposes (Sic!)
 - Adequate, relevant and not excessive
 - Accurate and up to date
 - Not kept for longer than is necessary
 - Processed in line with your rights
 - Secure
 - Not transferred to other countries (outside EU) without adequate protection

I v Finland [2008], ECHR 20511/03, (17 July 2008)

- The applicant “I”, now 48, stated that her private medical records were accessed by the other people (as a result of which she possibly lost her job as a nurse). The access was not recorded, as there was no records of this at the time (around 1992)
- The Court decided that as the hospital was controlled by the State, and as such Finland was responsible for the actions there. The court also stated that *personal information relating to a patient undoubtedly belongs to his or her private life*. Therefore Article 8, freedom to a private life, is applicable in this case.
- The European Court of Human Rights found that a person’s right to respect for their private life (under the ECHR,) may be breached where *the State fails to take appropriate steps to secure data, so that it cannot be accessed improperly*.

**COUNCIL OF EUROPE COMMITTEE OF MINISTERS:
RECOMMENDATION No. R (97) 5
OF THE COMMITTEE OF MINISTERS TO MEMBER STATES ON
THE PROTECTION OF MEDICAL DATA**

- **3. Respect for privacy**

- 3.1. The respect of rights and fundamental freedoms, and in particular of the right to privacy, shall be guaranteed during the collection and processing of medical data.

- **5. Information of the data subject**

- 5.1. The data subject shall be informed of the following elements:
 - **a.** the existence of a file containing his/her medical data and the type of data collected or to be collected;
 - **b.** the purpose or purposes for which they are or will be processed;
 - **c.** where applicable, the individuals or bodies from whom they are or will be collected;
 - **d.** the persons or bodies to whom and the purposes for which they may be communicated;
 - **e.** the possibility, if any, for the data subject to refuse his consent, to withdraw it and the consequences of such withdrawal;
 - **f.** the identity of the controller and of his/her representative, if any, as well as the conditions under which the rights of access and of rectification may be exercised.

Processed for limited purposes

- E.g. social worker does not have right to access electronic health records without the consent of the data subject

**COUNCIL OF EUROPE COMMITTEE OF MINISTERS:
RECOMMENDATION No. R (97) 18
OF THE COMMITTEE OF MINISTERS TO MEMBER STATES
CONCERNING THE PROTECTION OF PERSONAL DATA
COLLECTED AND PROCESSED FOR STATISTICAL PURPOSES**

- "Sensitive data" means personal data revealing racial origin, political opinions, religious or other beliefs, as well as personal data concerning health, sexual life or criminal convictions, and other data defined as sensitive by domestic law.
- General conditions for lawful collection and processing for statistical purposes:
 - 4.1 Personal data collected and processed for statistical purposes shall serve only those purposes. They shall not be used to take a decision or measure in respect of the data subject, nor to supplement or correct files containing personal data which are processed for non-statistical purposes.
 - 4.8 If sensitive data are to be processed for statistical purposes, these data should be collected in a form in which the data subjects are not identifiable.

What is personal data?

- Directive 45/96/EC article 1:
 - 'personal data' shall mean any information relating to an identified or identifiable natural person ('data subject'); an identifiable person is one who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity

S and Marper v United Kingdom [2008], ECHR 30562/04, 4 December 2008

- The applicants complained that on being arrested on suspicion, samples of their DNA had been taken, but despite being released without charge, the samples had retained on the Police database.
- The retention was unlawful. Though other member states retained some DNA samples in certain conditions, the UK was the only signatory state to permit the systematic and indefinite retention of DNA profiles and cellular samples of persons who have been acquitted or in respect of whom criminal proceedings have been discontinued.

S and Marper v UK

- The DNA profiles' capacity to provide a means of identifying genetic relationships is in itself sufficient to conclude that their retention interferes with the right to the private life of the individuals concerned.

National registries

- Several countries (including Finland) are currently in process of establishing a national health care database.
 - These databases have variable consent requirements for the use of data