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Privacy Guidelines for Telemedicine Developers

Carew, P.; Stapleton, L.

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Presentation

Privacy Guidelines for Telemedicine Developers

Peter J. Carew & Larry Stapleton

ISOL Research Centre, Waterford Institute of Technology, Ireland.

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Contents

- Overview of international privacy policies, practices and standards.
- The ethical position of privacy in the information society.
- Privacy framework for information systems development. [1]
- Privacy analysis of healthcare informatics. [2]
- 12 guidelines for telemedicine developers.

Privacy Milestones

- Milestones that have influenced privacy policy, thinking and legislation internationally:
  - 1948: UN Universal Declaration of Human Rights
  - 1970: Hesse, Germany. First data protection law in world.
  - 1973: US Dept of Health, Education and Welfare Code of Fair Information Practices
  - 1980: OECD Guidelines on the Protection of Privacy and Transborder Flows of Personal Data
  - 1981: Council of Europe Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data
  - 1995: EU Data Protection Directive 95/46/EC
  - 1998/1999/2000: FTC Privacy Reports to Congress
  - 2000: Charter of Fundamental Rights of the European Union
  - 2001: USA Patriot Act. Draconian anti-privacy legislation.
- The list is not exhaustive, and focuses largely on EU and US privacy developments.
- Many other countries have also passed national privacy legislation. [3]

International Privacy Practice

- Human Rights Charters. [4, 12, 13, 14, 15]
- Fair Information Practices (FIPs). [5, 6, 16, 17]
  - (1) Notice (2) Choice (3) Access (4) Security
- Council of Europe Convention. [3, 18]
- OECD Guidelines. [5, 7, 19]
  - (1) Collection limitation (2) Data quality (3) Purpose specification
  - (4) Use limitation (5) Security safeguards (6) Openness
  - (7) Individual participation (8) Accountability.
- EU Directive. [3, 8, 9, 20]
- Legislation vs. Self-Regulation. [3, 9, 10]
- International Privacy Standards. [8, 11, 21]

Privacy and Ethics

- Broadly, the ethical arguments for and against privacy can be summed up as:

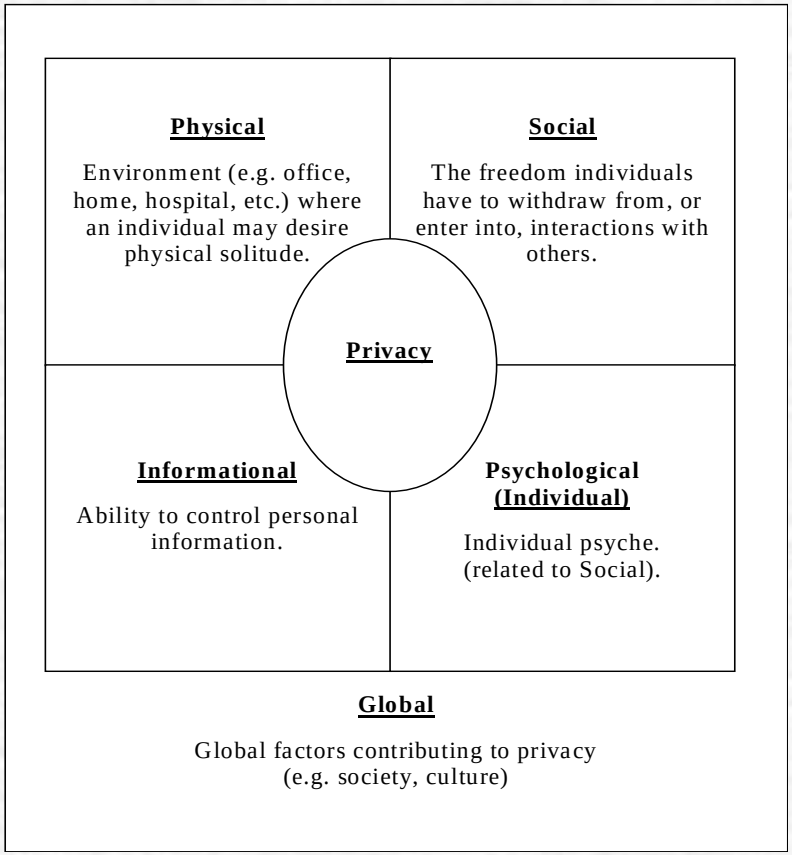
	For Privacy	Against Privacy
Privacy Perspective	Human Rights	Communitarian
Normative Ethics Category	Deontological	Utilitarian / Consequentialist

- There are arguments for both sides!
- Which ethical position is stronger remains an open question.

Privacy Guidelines for Telemedicine

- There are many generic privacy guidelines and perspectives.
- The guidelines presented here are based on an amalgamation of:
  - A recent ISD privacy framework. [1]
  - A recent privacy analysis of healthcare informatics. [2]
  - OECD Guidelines.

Privacy Framework [1]



Dimension/Id	Factor	Class
Physical		
P1	Environment	T
P2	Territoriality (Property)	T
P3	Territoriality (Body)	T
P4	Solitude (Physical)	T
P5	Repose	T
P6	Physical Access	C
P7	Sensory and Comms Channels	C
P8	Violator (Relationship)	C
Social		
S1	Intimacy (External)	T
S2	Intimacy (Internal)	T
S3	Territoriality (Status)	T
S4	Solitude (Social)	T
S5	Anonymity	T
S6	Autonomy	T
S7	Interactions and Comms	C
S8	Units	C
S9	Formality	C
S10	Personalness of Topic	C
Psychological (Functions)		
Y1	Self-Identity	F
Y2	Personal Growth	F
Y3	Autonomy	F
Y4	Contemplation	F
Y5	Self-Protection	F
Y6	Confiding	F
Y7	Emotional Release	F
Y8	Rejuvenation	F
Y9	Creativity	F
Informational		
I1	Territoriality (Knowledge)	T
I2	Reserve	T
I3	Release of Personal Info	C
I4	Distribution of Personal Info	C
I5	Use of Personal Info	C
Global		
G1	Control	C
G2	Personal Chars and Circumstance	C
G3	Organisational	C
G4	Cultural	C
G5	Societal	C

Privacy Analysis of Healthcare Informatics

- The main findings of the analysis for patients and healthcare workers (the 2 main privacy stakeholders) identified in [2] are:

	Patients	**Healthcare Workers**
Major Privacy Themes	Safety Empowerment Confiding Third Party Data Use	Territoriality Sentience & Embodiment Social Issues Autonomy

Analysis Method

- OECD Guidelines on Y axis. Privacy framework dimensions on X axis.
- Individual guidelines are considered for each dimension.
  - Dimension factors identified as relevant.
  - Privacy themes are also included as appropriate.
- A set of generic guidelines are established to mitigate privacy risks.

Analysis Results

	Physical	Social	Psychological	Informational	Global	Guideline
Collection Limitation and Consent	P7	S5	Y3, Y4, Empowerment	I3	G1, G2, G3	1 2 3
Data Quality	Disembodiment, Safety	S7, S10, Social Issues (Empathy)	Y6, Confiding	I1, I2, I3	-	4
Purpose Specification	P5	S3	Y3, Y5, Empowerment	I1, I4, I5	G1	5 2
Use Limitation	P2, P3	S1, S2, S5	Y7	I5, Third Party Use	G3	6
Security Safeguards	Safety	S5, S6	Y5	I4	G3	7 8
Openness	P8	S2, S7	Y1	I1, I4, I5	G3	9
Individual Participation	P1, P2, P3, P7	S3, S7, S6, Empowerment	Y3, Empowerment	I1, I2, I3, I4, I5, Empowerment (Access & Control of Data)	G2, G4	6 2 10 11
Accountability	P1, Disembodiment (Risk)	S3, S9	Y3, Y5	I4, I5	G5	7 12

Guidelines

1. **Limit Collection.** Only collect what is relevant and required. Unethical to gather superfluous data without careful analysis.
2. **Consent Management Facility.** Allow patients to change consent associated with individual data stored on them via some convenient interface (e.g. Web based). All consents should be "opt out" by default, as patients should explicitly authorise specific uses. Consent should be revocable at any time. Beware of coercion vs. consent.
3. **Patient Information and Training Facility.** Develop easily accessible tutorials, etc. so patients understand how data is collected (sensors), types of data collected (e.g. video, vital signs) and how it is used (e.g. in treatment, third party). Necessary for informed consent.
4. **Improved Sensors to Improve Realism in Telemedicine.** Disembodiment in telemedicine applications can be somewhat addressed in this way.
5. **Purpose Specification.** Specify purpose of all data collected at collection time (e.g. any third party use).
6. **Use Limitation.** No use beyond that specified and consented to (e.g. third party access, data mining). Data destroyed after use where possible.

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7. **Security Principle.** Data stored should be kept secure from unauthorised access. Access on "need to know" basis only.
8. **Anonymity.** Patient anonymity should be supported as desired (e.g. verification vs. identification). Patient's identifying information could be stored separate from the medical data.
9. **Support Patient Data Access.** Patients should be able to easily access their data and see what uses it is being put to. Transparency.
10. **Control Principle.** Patients should remain in control of their own data and treatment wherever possible.
11. **Individuality Principle.** Different people have differing attitudes to privacy based on their personality, culture, etc. which must be supported.
12. **Professional Responsibility.** All involved in telemedicine development must take responsibility for privacy issues. It is unacceptable for engineers to dismiss privacy as a managerial issue.

Conclusions

- There are a plethora of privacy guidelines and conventions.
- No dedicated international privacy standard exists.
- The right to privacy has a predominantly deontological ethics value position.
- Privacy has many dimensions: physical, social, psychological, informational, global. All must be considered when developing information systems.
- Different stakeholders have differing privacy value positions.
- 12 general guidelines for telemedicine developers are provided.

Q&A

Contacts:
Peter Carew pcarew@wit.ie
Larry Stapleton lstapleton@wit.ie

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