Data Protection and Ethics in Healthcare

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Overview

- Goal: Protection of people
- Specific legal setting for medical data
- Security and Privacy protection goals
- Recap and conclusion

- This had been topic at Geneva meeting? =>
Data protection is about people and their fundamental rights.

To be checked while developing technologies for connected cars:
- impact on persons
- impact on society
Protection of Medical data (verified for D, AT, CH)*

- At least in Germany this is similar for other occupations with professional secrecy including other medical professions such as dentists, apothecaries, psychologists but also advocates, notaries, tax consultants, etc.
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Punishment for breaking secrecy.
CH: up to 3 years
AT: up to 6 month
D: 1 year
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Patient makes own claims in civil law courts, e.g. for damages, information.
Protection of Medical data (verified for D, AT, CH)*

Professional secrecy

Reasoning:
Protection of the doctor-patient relationship. Patients must feel their data to be save and secure with the health provider to have trust. Otherwise necessary information may be withheld and cause threat to success of treatment and patient safety.

General rules and specific requirements for special categories of data – genetic, biometric and health data

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Topic at Workshop Geneva
Protection of Medical data (verified for D, AT, CH)*

- So far strict rules on medical data, specifically enforced as professional secrecy

- Opening clause in Art. 90 GDPR for member states to adopt specific regarding the enforcement of obligations of professional secrecy

⇒ Remains to be seen how members states react

⇒ Highly relevant for the health sector as professional secrecy applies to physicians and many healthcare professionals
Security Protection Goals
"The protection goal of Confidentiality is defined as the property that (privacy-relevant) data and services that process such data cannot be accessed by unauthorized entities.”
Confidentiality applied to health data

- Protection of patients data
- Separation of data necessary for different tasks / roles, separation of different
- Even the information, that health related or AAL devices exist in a household is subject to confidentiality
- Timely deletion of unnecessary data
Confidentiality

Implementation Techniques:

- **Data Encryption**
  - in transit (TLS, HTTPS, SSH, ...)
  - at rest (PGP, S/MIME, TrueCrypt, ...)
  - Encryption special to national health record system
  - ...

- **Data Segregation**
  - Secret Sharing, Secure Multiparty Computations

- **Access Control Enforcement**
“The protection goal of \textit{Integrity} is defined as the property that (privacy-relevant) data and services that process such data cannot be modified in an unauthorized or undetected manner.”
Integrity for health data

- Access to unchanged and accurate information in health files
- Detect unauthorized changes
- What if ransomware randomly changes values in patient files?
- Protection of access and medical devices e.g. for pacemakers, insulin pumps
Implementation Techniques:

- Digital Signatures
- Hash Values
- Access Control Enforcement
- Low energy cryptography for implantable devices
Availability

“The protection goal of Availability is defined as the property that access to (privacy-relevant) data and to services that process such data is always granted in a comprehensible, processable, timely manner.”
Availability for health data

- Have data available when needed
- Processes for loss of data (Backups)
- Accessibility when and where necessary (mobile access, home visits)
Implementation Techniques:

- Backups
- Load Balancers
- Failovers
- Redundant Components
- Avoidance of Single-Points-of-Failure
- Watchdogs / Canaries
Privacy Protection Goals
“The protection goal of Unlinkability is defined as the property that privacy-relevant data cannot be linked across domains that are constituted by a common purpose and context.”
Unlinkability for health data

- Central health records: measures against forcing patients into giving away the data e.g. plausible deniability
- Use of pseudonyms in research and allow identity management
- Well considered architecture decisions, e.g. between centralized / cloud based solutions vs. decentralized user-controlled systems

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Unlinkability for health data

- Research databases: share unlinkable data (e.g. based on concepts such as k-anonymity, l-diversity etc.)
- Research databases: multiparty computation
- Research databases: publication of aggregated data only
**Unlinkability**

**Implementation Techniques:**

- Data Avoidance / Reduction
- Access Control Enforcement
- Aggregated data
- Separation / Isolation
- Avoidance of (unique) Identifiers
Think of it as ...
“The protection goal of Transparency is defined as the property that all privacy-relevant data processing – including the legal, technical, and organizational setting – can be understood and reconstructed at any time.”
Transparency for health / ambient assisted living

- Information must be understandable and "digestible" for target audience
- For digital screens: scalable text, no ads that can hide the information
- Multi-layered policies with pictures and diagrams
- Computer readable privacy policies
- Understandable controls e.g. I/O buttons
Implementation Techniques:

- Logging and Reporting
- User notifications
- Documentation of services
- Privacy policies
- Transparency Services for patient files
- (useful) Data breach notifications
Transparency

Think of it as ...
“The protection goal of \textit{Intervenability} is defined as the property that intervention is possible concerning all ongoing or planned privacy-relevant data processing.”
Intervenability

• Control in hands of the patients, e.g. allowing interruption of surveillance and tracking e.g. for monitoring devices in sports, in ambient assisted living granting moments of privacy

• Design: Address special requirements of target audience (sick, injured, elderly, or confused persons)
Intervenability

- Provide transparency and way for informed consent / right to object for any change of purposes and secondary use of data.
- Quality of life: Allow patients to stay at home and provide necessary aid when necessary.
**Intervenability**

Implementation Techniques:

- Configuration Menu
- Help Desks
- Stop-Button for Processes
- Break-Glass / Alert Procedures
- Manual Override of Automated Decisions
- External Supervisory Authorities (DPAs)
Intervenability

Think of it as …
The whole picture
Data protection goals

Confidentiality

Unlinkability

Integrity

Intervenability

Transparency

Availability
Data protection goals

Confidentiality

Integrity

Transparency

Availability

Unlinkability

Intervenability
Data protection goals

Confidentiality

Integrity

Unlinkability

Intervenability

Transparency

Availability

Legal ground

&

Ethic considerations
Conclusion
Conclusion

• Protection Goals have proven very useful

• How to bring ethics and privacy to practice?
  ▪ Insert in existing testing and evaluation processes
    ▪ Include ethic aspects in privacy assessments by DPOs / DPA
    ▪ Consider privacy aspects in assessments by ethic boards
  ▪ Construction of an additional protection goal, but if so – what could it be
  ▪ Include ethic aspects into other assessment steps:
    ▪ Weighing process of legal ground, e.g. as “suitable safeguard for rights and freedoms” or “proportionate processing” (Art. 9 GDPR)
    ▪ Mandatory consideration points in public calls for tenders by hospitals, social security and health insurances
Conclusion
(last minute slide)

- Suggestion for a statement in the paper on this conference:
  Make security, data protection and ethical aspects integral part of investment decisions.
  Make it mandatory where possible (public health insurance, all investments and call for tenders by public bodies such as university and municipal hospitals).
  Entry points in Art. 32 and 25 GDPR
More about the Standard Data Protection Model

- Content
  - Methodology
  - Data Protection Goals
  - In progress: catalogues with measures

- V.1.0 recommended for intensified testing by the conference of German data protection authorities.

- One of three existing DPIA frameworks (Fr, GB, D) mentioned by Art. 29 WP in working paper 248 in April 2017.

Latest versions and translations are and will be available at:
https://www.datenschutzzentrum.de/sdm/
Data Protection in Ambient Assisted Living (2011)

- Content
  - Early evaluation of the whole upcoming branch of ambient assisted living technologies (AAL)
  - Structured on basis of the data protection goal methodology
  - Data protection requirements
  - Research questions

German version only:
https://www.datenschutzzentrum.de/projekte/aal/
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Thank you for your attention
Questions? Comments?

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