Bioethical Foundations in mHealth and Big Data

Global Ministerial Summit 2017
Patient Safety

Prof. Dr. Christiane Woopen
Definition

*mHealth is a sub-segment of eHealth in terms of ‘medical and public health practice supported by mobile devices. It especially includes the use of mobile communication devices for health and well-being services and information purposes as well as mobile health applications.’*

European Commission, Digital Single Market

„We are embarking on a time when each individual will have all their own medical data and the computing power to process it in the context of their own world.“

„Just as Gutenberg democratized reading, so there is the chance that smartphones will democratize medicine.“
Purposes

- Monitoring, tracking (disorders, life-style)
- Health information
- Communication (health professionals, companies, peers ...)
- Service (automated settlement ...)
- Diagnosis (pictures, speech analysis, heart attack ...)
- Therapy (adherence, self management, training, bridging of waiting time until doctor´s appointment ...)
- Data Storage (electronic health record on the smartphone)
- Research
1. Why patient safety is an ethical requirement

- Beneficence
- Nonmaleficence
- Autonomy
- Privacy and Data Protection
- Non-discrimination
- Justice
• Quality of data
• Safety of health apps

→ Evidence-based mHealth
→ Learning Healthcare Systems
FIGURE S-2  Schematic of the health care system today.


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Prof. Dr. C. Woopen
Slide 7
FIGURE S-3  Schematic of the continuously learning health care system.
UDBHR Article 9

The privacy of the persons concerned and the confidentiality of their personal information should be respected. To the greatest extent possible, such information should not be used or disclosed for purposes other than those for which it was collected or consented to, consistent with international law, in particular international human rights law.
Converging Technologies and Cybernetic Loops

Rules for the digital human park
Two paradigmatic cases of breeding and taming human beings: Human germline editing and persuasive technology

Rinie van Est, Jelte Timmer, Linda Kool, Niesl Nijsingh, Virgil Rerimassie, Dirk Stemerding

„So while individuals are becoming increasingly transparent, our technological environment is becoming ever more opaque.“
In times of Big Data the right to respect for private life is more than data protection and entails intrusion into the private sphere by unwanted personalized advertisement, recommendations, offers, and information sorting.
APPLE’S ‘DIFFERENTIAL PRIVACY’ IS ABOUT COLLECTING YOUR DATA—BUT NOT YOUR DATA

Differential privacy is the statistical science of trying to learn as much as possible about a group while learning as little as possible about any individual in it.

“We believe you should have great features and great privacy,” Federighi told the developer crowd. “Differential privacy is a research topic in the areas of statistics and data analytics that uses hashing, subsampling and noise injection to enable... crowdsourced learning while keeping the data of individual users completely private. Apple has been doing some super-important work in this area to enable differential privacy to be deployed at scale.”
Informed Consent  
Opt-in-/Opt-Out-Models  
Broad Consent  
Dynamic Consent
Digital Autonomy

- Competence
- Information
- Choice
- Values
- Voluntariness
- Formation of Will
- Action
Sørensen, K. et al. for European Consortium European Health Literacy Project (2012)
Individual health literacy

Skills/Abilities

HEALTH LITERACY

Demands/Complexity

Health literacy environment

Potential discrimination of three groups of persons by behavior-based benefits:

- don’t want to share data
- cannot meet standards
- don’t want to meet standards

Solidarity based Health Care

Individual Responsibility

Non-discrimination Justice
Global Multi-level Ethical Governance

- Responsibility of all stakeholders
- Education, digital literacy, health literacy
- Legal regulation, self-commitment
- Vigilance systems, reporting mechanisms
- Ethical oversight
- Research