Bioethical Foundations in mHealth and Big Data

Global Ministerial Summit 2017
Patient Safety

Prof. Dr. Christiane Woopen

Universität zu Köln

ceres
cologne center for
ethics, rights, economics, and social sciences
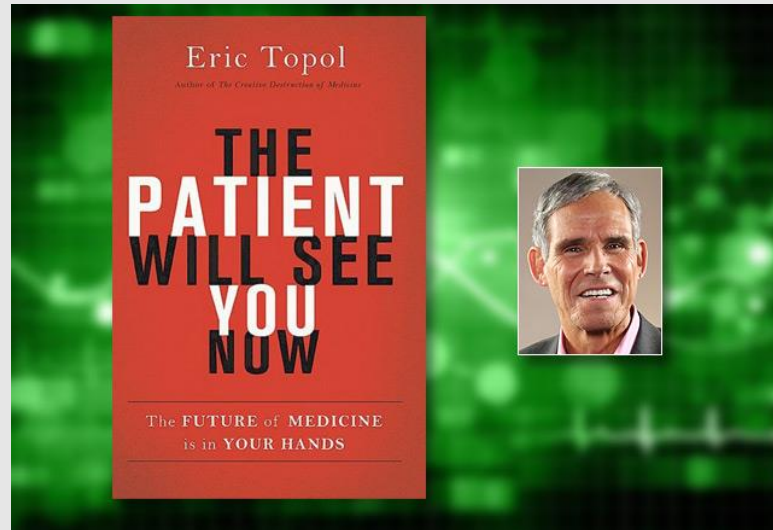of health

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

https://ec.europa.eu/digital-single-market/en/mhealth

Universität
zu Köln

ceres
cologne center for
ethics, rights, economics, and social sciences
of health

„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."

ceres
cologne center for
ethics, rights, economics, and social sciences
of health

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

Universität zu Köln

ceres
cologne center for
ethics, rights, economics, and social sciences
of health

1. Why patient safety is an ethical requirement

Beneficence Nonmale-ficance

Autonomy

Privacy and Data Protection

Non-discrimination Justice

- Quality of data

- Safety of health apps

→ *Evidence-based mHealth*

→ *Learning Healthcare Systems*

Beneficence

Nonmale-ficance

Universität zu Köln

ceres
cologne center for
ethics, rights, economics, and social sciences
of health

FIGURE S-2 Schematic of the health care system today.

29.3.2017

Prof. Dr. C. Woopen

Slide 7

Universität zu Köln

ceres
cologne center for
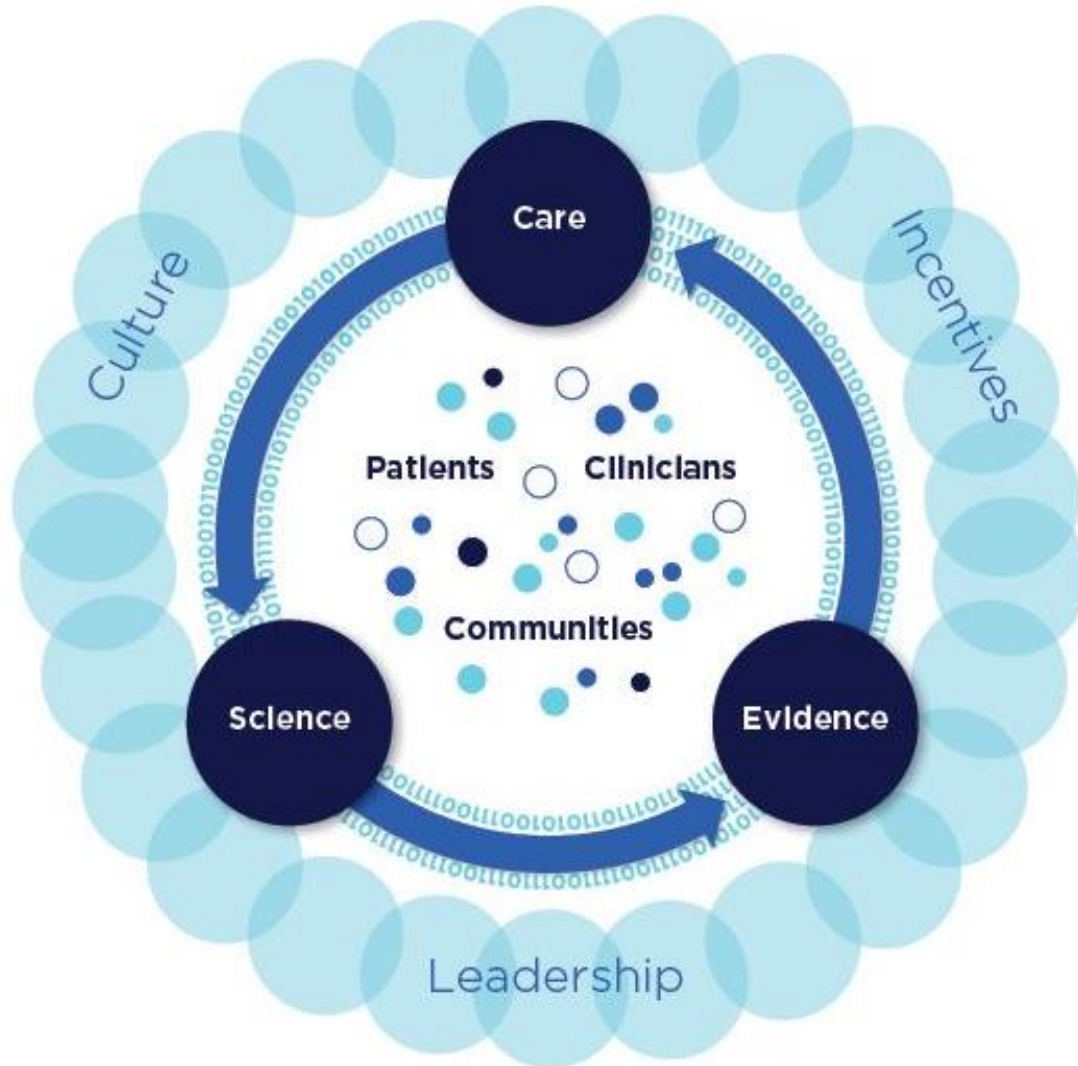ethics, rights, economics, and social sciences
of health

FIGURE S-3 Schematic of the continuously learning health care system.

http://theincidentaleconomist.com/wordpress/wp-content/uploads/2015/03/learning-hcs.jpg

29.3.2017

Prof. Dr. C. Woopen

Slide 8

Universität zu Köln

ceres
cologne center for
ethics, rights, economics, and social sciences
of health

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.

Universität zu Köln

ceres
cologne center for
ethics, rights, economics, and social sciences
of health

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."*

Universität zu Köln

ceres
cologne center for
ethics, rights, economics, and social sciences
of health

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.

ceres

cologne center for
ethics, rights, economics, and social sciences
of health

Universität zu Köln

APPLE'S 'DIFFERENTIAL PRIVACY' IS ABOUT COLLECTING YOUR DATA—BUT NOT *YOUR* DATA

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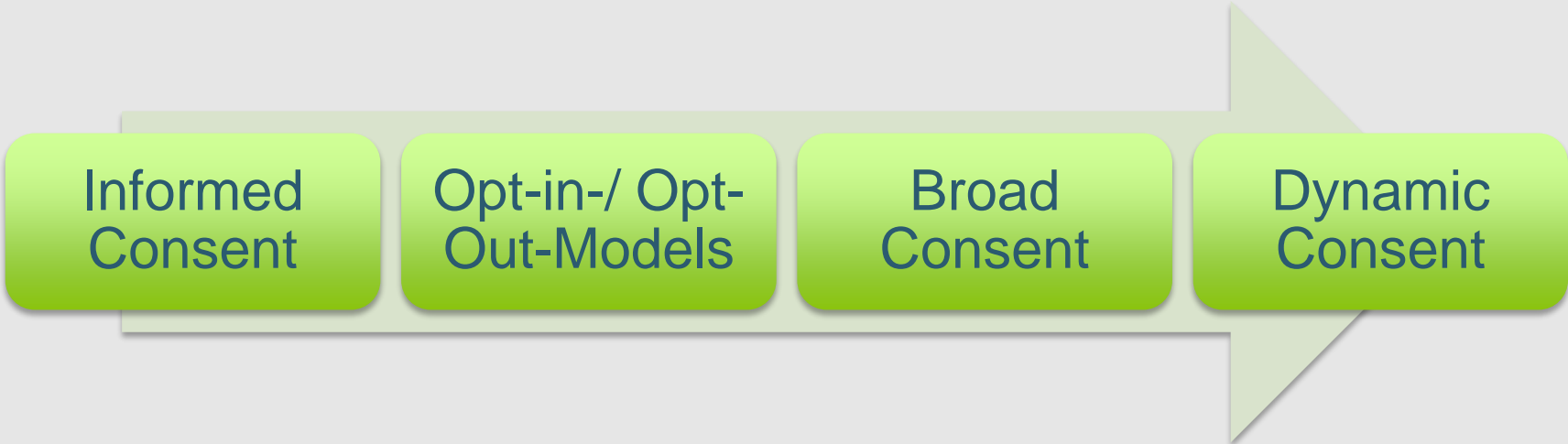
Differential privacy is the statistical science of trying to learn as much as possible about a group while learning as little as possible about any individual in it.

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."

Senior vice president of software engineering Craig Federighi.   📷 JUSTIN KANEPS FOR WIRED

https://www.wired.com/2016/06/apples-differential-privacy-collecting-data/
29.3.2017

Prof. Dr. C. Woopen

Slide 12

ceres
cologne center for
ethics, rights, economics, and social sciences
of health

Universität
zu Köln

Autonomy

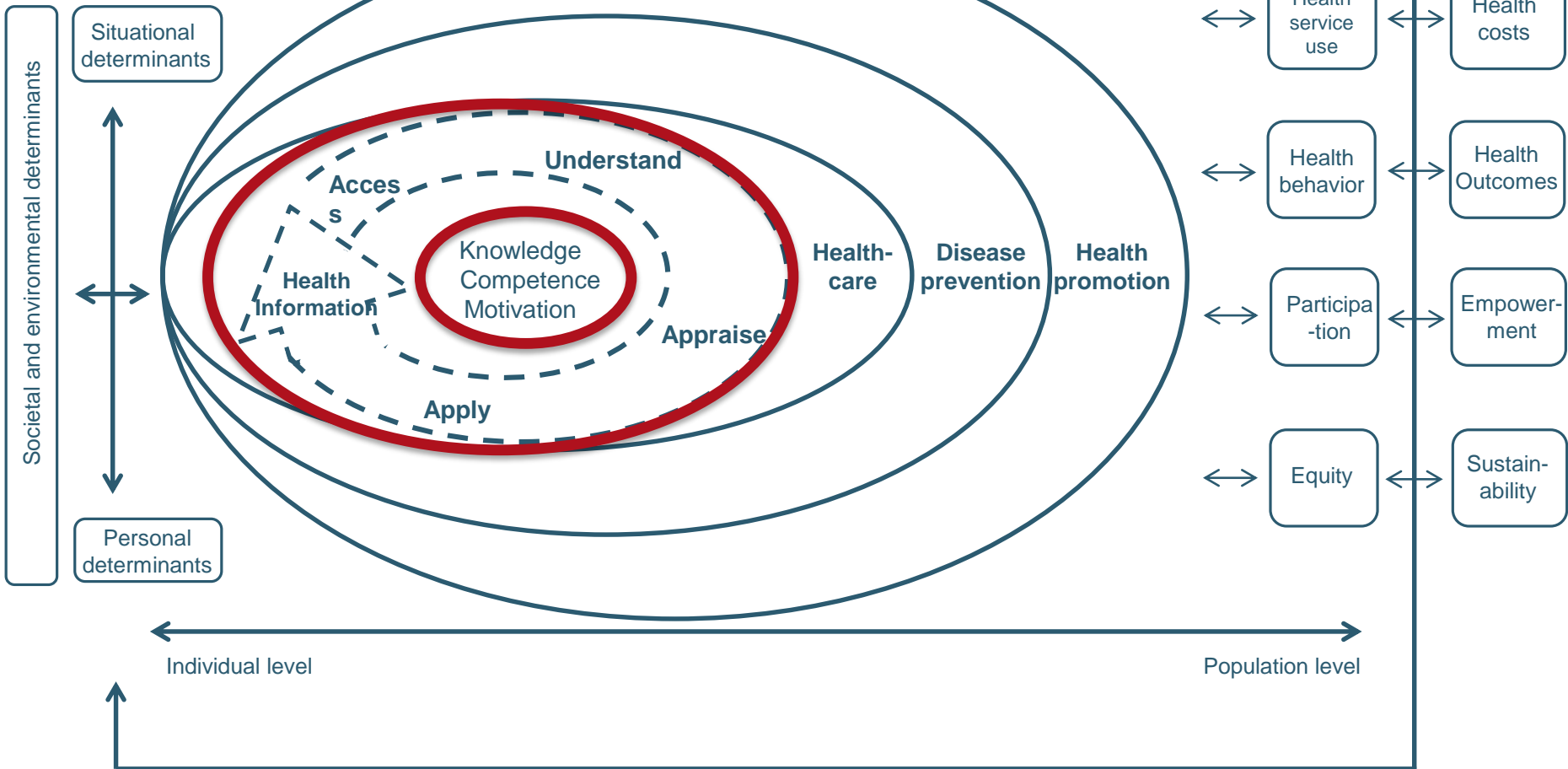| Informed Consent | Opt-in-/ Opt-Out-Models | Broad Consent | Dynamic Consent |

Mertz M, Jannes M, Schlomann A, Manderscheid E, Rietz C, Woopen C (2016)
Digitale Selbstbestimmung. ceres, Köln

29.3.2017

Prof. Dr. C. Woopen

Slide 14

Life course

Societal and environmental determinants

Situational determinants

Personal determinants

Individual level — Population level

Access

Understand

Appraise

Apply

Health Information

Knowledge
Competence
Motivation

Health-care

Disease prevention

Health promotion

Health service use ↔ Health costs

Health behavior ↔ Health Outcomes

Participa-tion ↔ Empower-ment

Equity ↔ Sustain-ability

Sørensen, K. et al. for European Consortium European Health Literacy Project (2012)
Health literacy and public health: A systematic review and integration of definitions and models. In: Public Health, 12 (80), S. 9.

29.3.2017

Prof. Dr. C. Woopen

Universität zu Köln

ceres
cologne center for
ethics, rights, economics, and social sciences
of health

Source: Parker R, *Measuring health literacy: Why? So what? Now what?* In: Hernandez L (ed), *Measures of Health Literacy: Workshop Summary; Roundtable on Health Literacy.* 2009.

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

Non-discrimination Justice

| Solidarity based Health Care | Individual Responsibility |

- ✧ don´t want to share data

- ✧ cannot meet standards

- ✧ don´t want to meet standards

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

control

trust

Universität zu Köln

ceres
cologne center for
ethics, rights, economics, and social sciences
of health