

1<sup>a</sup> MESA: INFORME DE LA UNESCO SOBRE BIG DATA Y SALUD



#### **Prof. Dr. Christiane Woopen**

Cologne Center for Ethics, Rights, Economics, and Social Sciences of Health
University of Cologne

Big Data and Health

Preliminary Draft Report of the IBC

Madrid 2017

Prof. Dr. Christiane Woopen
Cologne Center for Ethics, Rights, Economics, and
Social Sciences of Health
University of Cologne



#### The story of Felix, 4 years old

"Paper-Felix" of traditional medicine

"Digital Felix"



#### Continous assessment of

- Blood sugar
- Heart rate
- Skin resistance
- Sweating
- Movement
- → Individual administration of insulin
- → 40% less time of aggression and apathy

#### Big Data. The 5 Vs



The size of data



 The speed at which the data is collected, processed and applied



The different types of data from different sources



The meaning of data



The quality of data









21.3.2017

Prof. Dr. C. Woopen

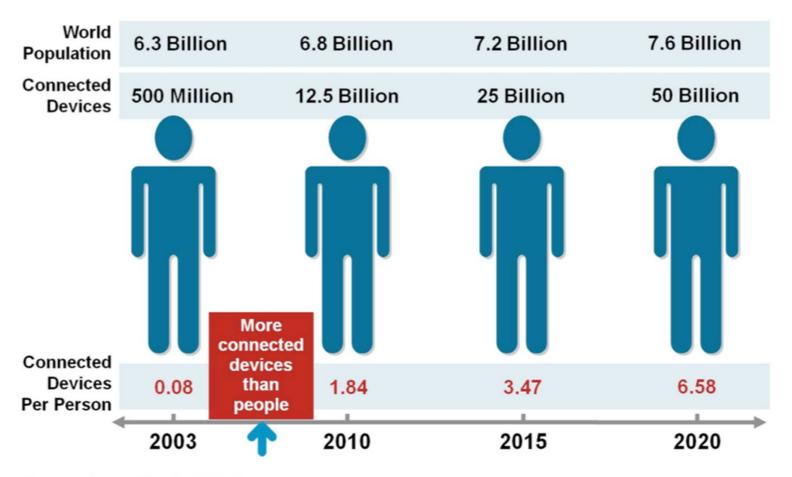
Slide 5

10 SEPTEMBER, 2015

## U.S. FDA Accepts First Digital Medicine New Drug Application for Otsuka and Proteus Digital Health

- The first Digital Medicine, a drug/device product, combines Otsuka's ABILIFY® (aripiprazole) for serious mental illness, embedded with the Proteus® ingestible sensor in a single tablet to digitally record ingestion and, with patient consent, share information with their healthcare professionals and caregivers
- Otsuka and Proteus are pursuing a regulatory filing for a drug-device combination across multiple divisions of the FDA to support the unique system
- First opportunity to demonstrate the potential of Digital Medicines to provide an objective measure of medication adherence and physiologic response

Figure 1. The Internet of Things Was "Born" Between 2008 and 2009

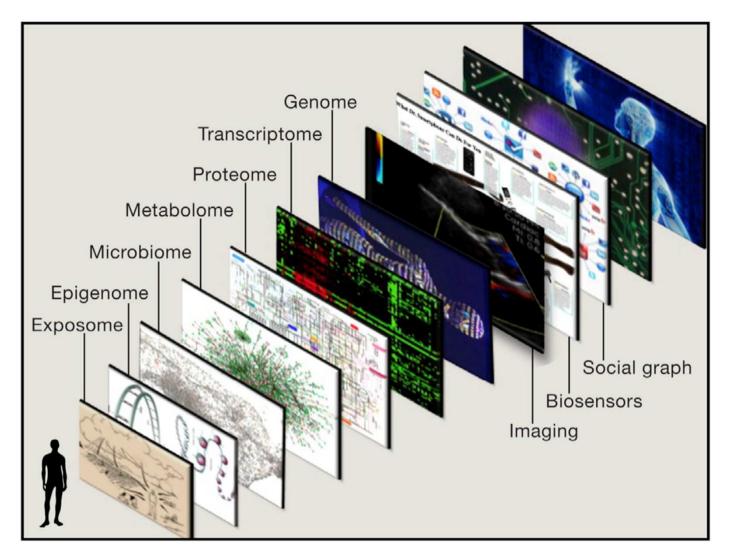


Source: Cisco IBSG, April 2011



21.3.2017

Prof. Dr. C. Woopen



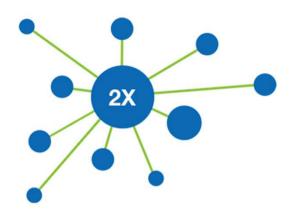
"The panoromic view"

#### Geographic Information System of a Human Being

Topol, Cell 157, March 27, 2014

21.3.2017

Prof. Dr. C. Woopen



#### **The Data Explosion**

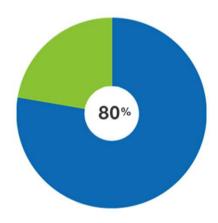
Medical data is expected to double every 73 days by 2020.



#### **A Quick Study**

Watson can read 40 million documents in 15 seconds.





#### **The Great Unknown**

80% of health data is invisible to current systems because it's unstructured. Watson Health can see it.

21.3.2017

Prof. Dr. C. Woopen

# **Value Chain of Big Data** Data Storage

21.3.2017

Prof. Dr. C. Woopen

#### **Constitution of the World Health Organization**

THE STATES Parties to this Constitution declare, in conformity with the Charter of the United Nations, that the following principles are basic to the happiness, harmonious relations and security of all peoples:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.

The health of all peoples is fundamental to the attainment of peace and security and is dependent upon the fullest co-operation of individuals and States.

adopted 22 July 1946, New York

#### Vision of Big Data and health: Precision medicine and telemedicine

#### Personalized prevention and treatment

- → targeted advice and
- → the right intervention
- → e.g. the right dosage of drugs
- → at the right time
- → for a specific person
- → regardless where on this world



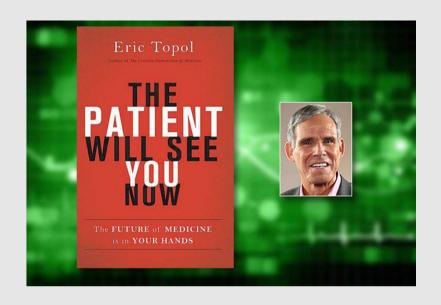
# **Converging Technologies and Cybernetic Loops**

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

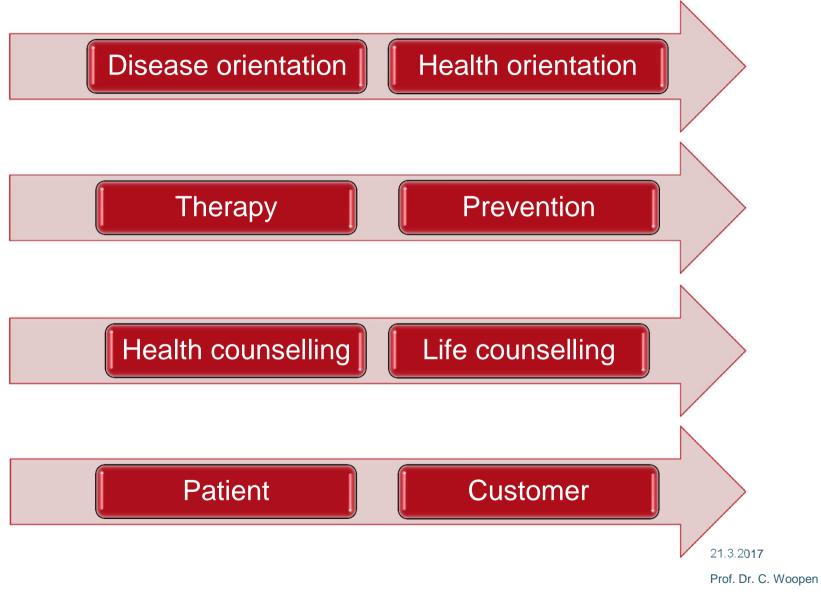


"So while individuals are becoming increasingly transparent, our technological environment is becoming ever more opaque."

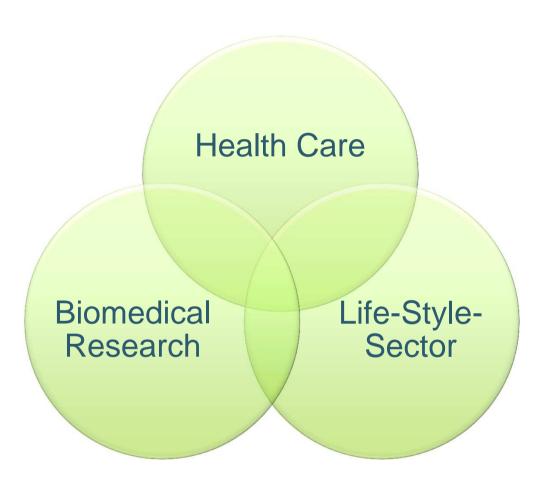


"We are embarking on a time when each individual will have all their own medical data and the computing power to process it in the context of their own world."

#### (At least) Four Paradigm Shifts in health care and public health

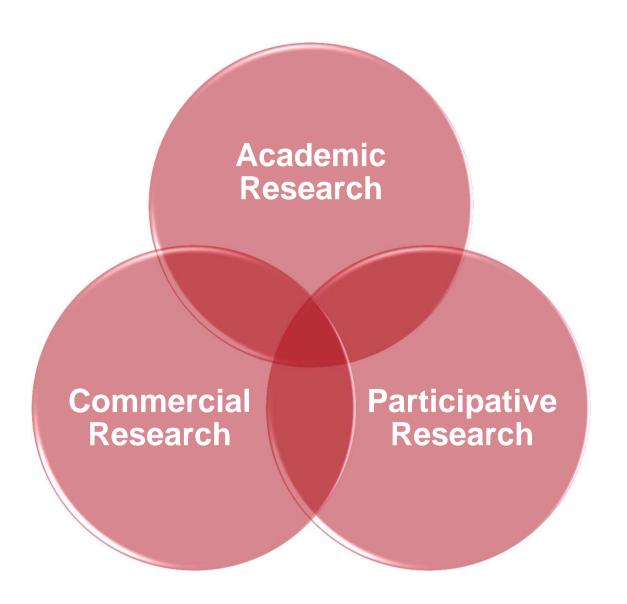


### **Blurring Lines**



21.3.2017

Prof. Dr. C. Woopen



21.3.2017

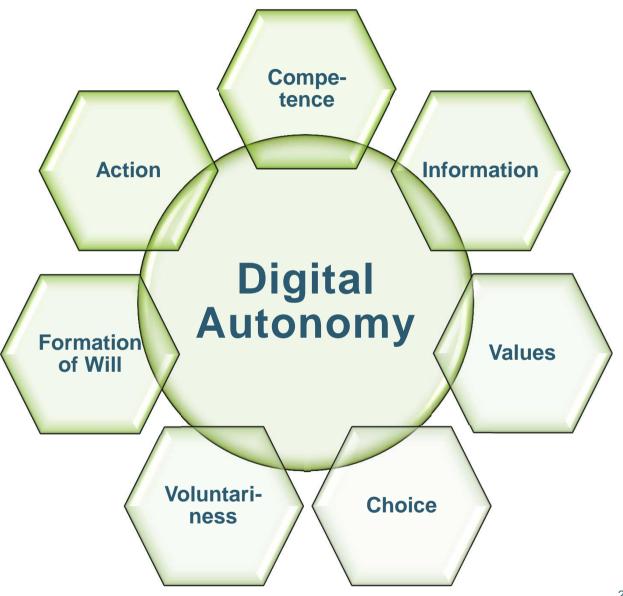
Prof. Dr. C. Woopen

#### **Ethical Aspects**



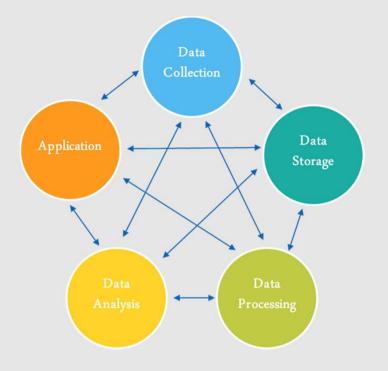






21.3.2017

Prof. Dr. C. Woopen



Informed Consent

Opt-in-/ Opt-Out-Models Broad Consent

Dynamic Consent

21.3.2017

Prof. Dr. C. Woopen

#### **UDBHR Article 9 – Privacy and confidentiality**

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.

# Traditional Principles of Data Protection are mainly counteracted by Big Data

Purpose binding and limitation

Data scarcity and minimization

Special protection of sensitive data

Data protection by technique and organization

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 advertisement, recommendations and offers



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



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

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."

21.3.2017

Prof. Dr. C. Woopen

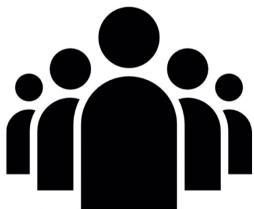
## Human Rights

# Groups

# Public Good







21.3.2017

Prof. Dr. C. Woopen



"Sometimes the only way to protect the individual is to protect the group to which the individual belongs."

Luciano Floridi



21.3.2017

Prof. Dr. C. Woopen

#### **Justice**

- Digital gap / divide
  - → Access to health information and healthcare for everyone

    Prerequisite: Access to ICT, sufficient equipment, motivation and skills
- Non-stigmatization and non-discrimination
- Sustainability: energy and environment



Personal

**Employers** 

Advisers

**Healthcare Providers** 

FREE QUOTE HELPLINE: 0333 331 4199



Health insurance

Get healthier with Vitality



Member

**GET A QUOTE** 

# Vitality - Health & Life Insurance That Rewards You For Being Healthy



#### Health Insurance

Our award-winning private health insurance gives you access to the best possible medical care if you get ill and need treatment. You won't just get looked after when you're in hospital - our care starts the minute you call us.



#### Life Insurance

Our philosophy is simple. Award-winning Life Insurance, Serious Illness Cover and Income Protection Cover that helps protect you and your family from the financial impact of illness, injury, disability and death.

21.3.2017

Prof. Dr. C. Woopen

Solidarity based Healthcare Individual Responsibility

Three groups of persons might be discriminated against:

- Who don't want to share their data
- ♦ Who cannot meet given standards
- ♦ Who don't want to meet given standards



Thank you very much for your attention!

21.3.2017

Prof. Dr. C. Woopen