UNIVERSITEIT TWENTE

Centre for eHealth & Wellbeing Research

BIG DATA FOR PERSONALIZED & PERSUASIVE COACHING VIA SELF-MONITORING TECHNOLOGY

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Persuasive Health Technology Lab
Center for eHealth and Wellbeing Research

University of Twente
Enschede, the Netherlands

eTelemed
Venice, April 24, 2016

OVERVIEW

13:30 - 13:45 Opening & welcome (Prof. Dr. Lisette van Gemert-Pijnen)

13.45 - 14.00 Logdata for personalized technologies (Floor Sieverink)

14.00 - 14.15 Visualization of big data (Olga Kulyk)

14.15 - 14.40 Hopes, challlenges & risks of Big data for Personalizing Healthcare (Annemarie Braakman-Jansen)

14.40 – 16.00 Interactive group discussions (15 minutes each) & wrap up

- User empowerment
- Profiling
- Trust
- Data Wisdom

A QUICK INTRODUCTION

Prof. dr. Lisette van Gemert - Pijnen

Annemarie Braakman - Jansen PhD

Floor Sieverink, MSc.
PhD Candidate

Olga Kulyk PhD

Centre for eHealth & Wellbeing Research
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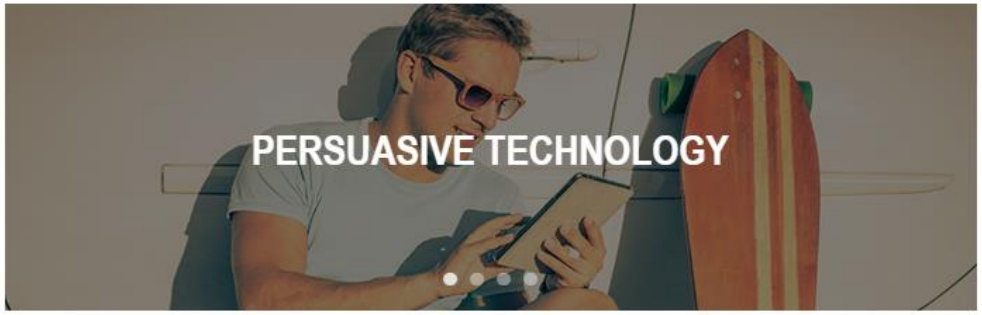
SEARCH



The Centre for eHealth and Wellbeing Research is a leading research centre for personalized health care. The Centre captures the available scientific expertise within the Department of Psychology, Health and Technology.

Our mission is to apply psychological knowledge in the design and evaluation of technological innovations that contribute to well-being, health and personalized healthcare.

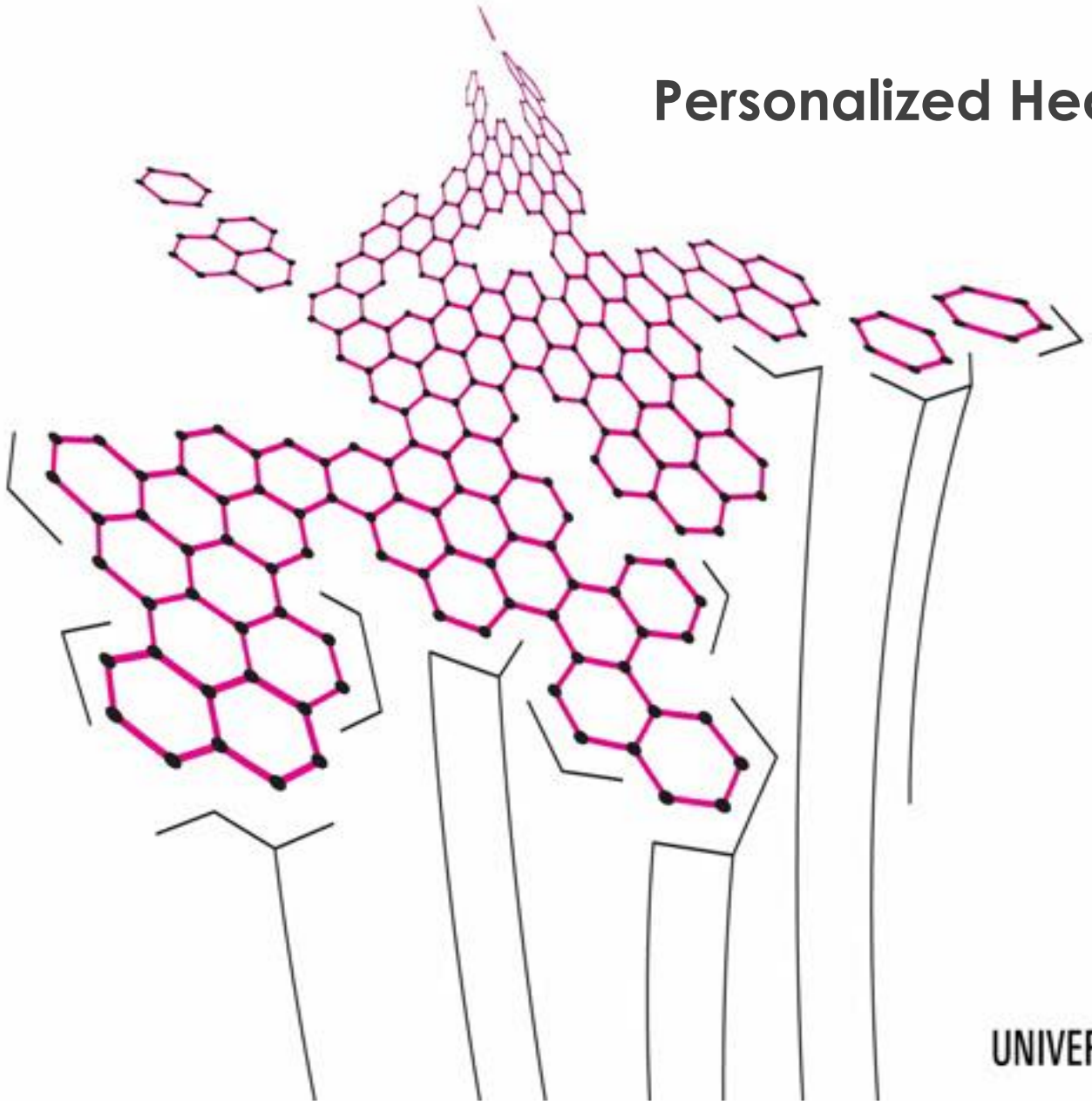
OUR VISION | NEWS | RESEARCH LABS

PERSUASIVE HEALTH TECHNOLOGY | POSITIVE PSYCHOLOGY & TECHNOLOGY

SELF-MANAGEMENT & HEALTH ASSESSMENT | STORY LAB

PEOPLE | PARTNERS | EDUCATION

Personalized Healthcare



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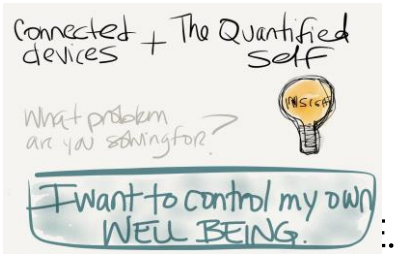
PERSONALIZED HEALTHCARE
IN A DATA DRIVEN SOCIETY

- Personalized healthcare
  - **Tailoring** products, services to needs of *individual* patients
  - From disease-centered to **patient-centered**; *health as the ability to adapt and to self manage*, (Huber, 2011)

- Rapid growth of data collected via technology
  - **new ways** for personalizing healthcare; data from several sources
  - data management: **ethical, clinical, behaviour challenges**..



Personalized self-care PHR

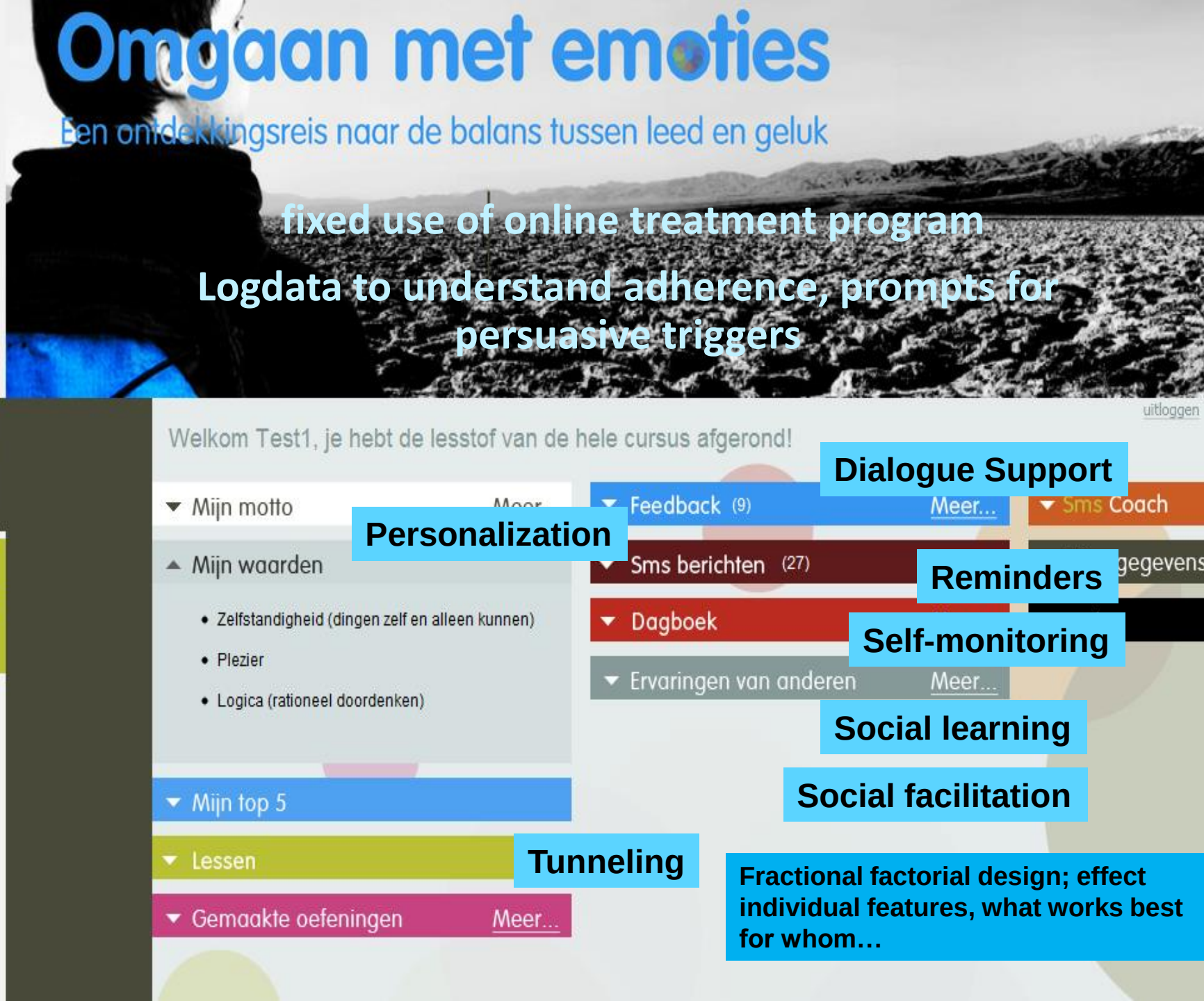
Logdata & interviews to understand use of system and content

PHR content Chronic care
- Education
- Monitoring
- Coaching

Free use of PHRs

- Adherence?
- Profiling?
- Integration with practice?
- Connection with other services?

Floor Sieverink; Saskia Akkersdijk; eTelemed 2016


Omgaan met emoties
Een ontdekkingsreis naar de balans tussen leed en geluk
fixed use of online treatment program
Logdata to understand adherence, prompts for persuasive triggers
Cockpit
Les
uitloggen
Welkom Test1, je hebt de lesstof van de hele cursus afgerond!
Mijn motto
Mijn waarden
Zelfstandigheid (dingen zelf en alleen kunnen)
Plezier
Logica (rationeel doordenken)
Mijn top 5
Lessen
Gemaakte oefeningen
Meer...
Feedback (9)
Meer...
Sms Coach
Sms berichten (27)
Dagboek
Ervaringen van anderen
Meer...
Dialogue Support
Personalization
Reminders
Self-monitoring
Social learning
Social facilitation
Tunneling
Fractional factorial design; effect individual features, what works best for whom…

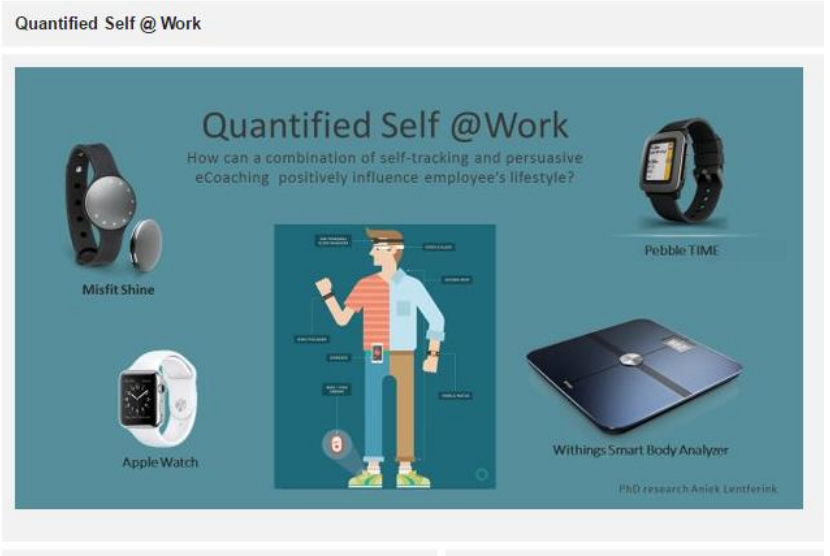
Personalized Coaching via WEARABLES

24h Lifelogging

Logdata from *several* devices

24h monitoring data: activities, nutrition, sleeping , stress etc

- Reliable?
- Supportive?
- Engagement?
- Persuasive feedback?
- Integrated with practice, daily life
- Connected with others/devices?



www.healthbytech.com (27th May Groningen, workshop)

Safe Self care via ambient environments

24h Data from several sources/devices

- Profiling?
- Persuasive feedback?
- Interoperable (social; system)

Olga Kulyk, eTelemed 2016

Safe, self care support using data from *several* sources

technology to better measure, aggregate and make sense of **behavioral, psychosocial, biometric and geodata**, to develop personalized treatments to support people with disruptive behaviors.

MENTAL HEALTH

Can Big Data Help Psychiatry Unravel the Complexity of Mental Illness?

Hanneke Kip, project May 2016-2020

3 GOOD HEALTH AND WELL-BEING

Ensure healthy lives and promote well-being for all at all ages

- **Infection prevention & control**
- GeoHealth: **digital surveillance** to track, trace infections and to develop a **predictive model to detect and prevent outbreaks**
- Highly Resistant Micro Organism, e.g. MRSA; Zoonotics (Animal>humans)

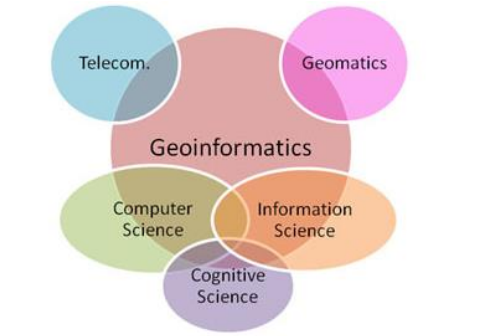
Data to support proactive decision making in HRMO

- targeting HCWs, Health policy makers
- integrating *geospatial data with epidemiological and clinical* data to develop a smart surveillance system (EWS)
  - path of movements (HCWs inside/outside hospital)
  - pathogens and HRMO are monitored real-time (over 5 years)
- persuasiveness and usability of a Data dashboard system

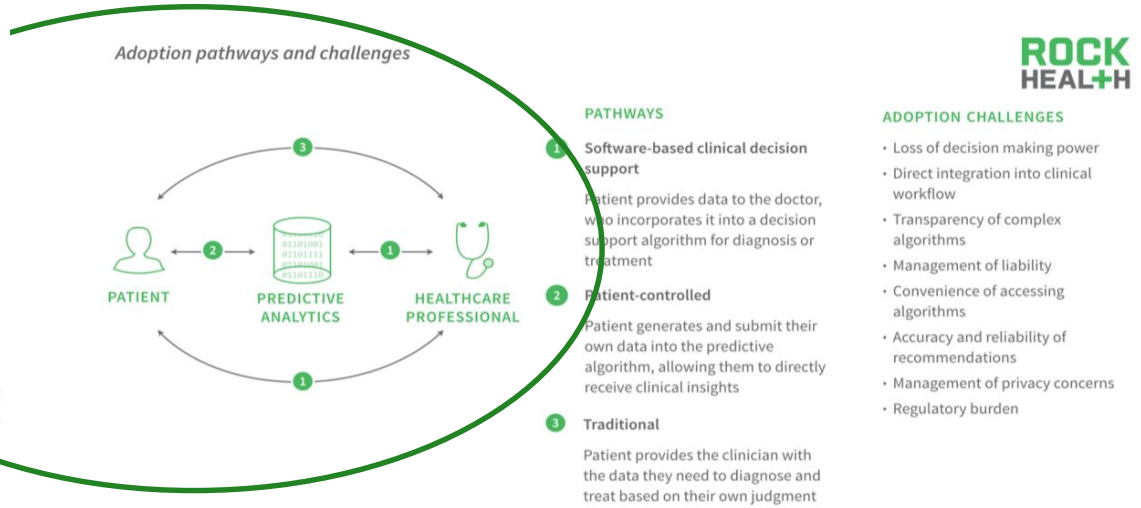
- new computational methods for analysing *geospatial* and *laboratory data* and *user centred methods* for visualization of data

Predictive modelling using data from several sources, devices, 24h

- ability to use technology to better *measure, aggregate, and make sense of data.*
- multidisciplinary research
- innovations in healthcare



Relationships between Geoinformatics and other disciplines



Can user experience and design influence decision making so deeply as to be regulated?

Challenge: new ways for personalized healthcare

What are the hopes, challenges and dangers?

Volume, Velocity, Variety, Veracity, **Value** of Data

How to analyze, present data in a useful, meaningful and persuasive way?

MOOC eHealth

View transcript

Download video: standard or HD

ABOUT THE COURSE

eHealth refers to the use of technologies to improve well-being, health, and healthcare. It is an umbrella term that captures concepts about the health context, technology, and people.

In this free online course, we will provide you with insight into the domain of eHealth, describe methods to develop eHealth, and explain theories that enable behaviour change and facilitate implementation. You will also understand how eHealth technologies are developed and used in practice, by means of a variety of case studies, assignments and examples.

This course pays attention to the perspectives of the eHealth developers, patients, healthcare professionals and healthy people who want to improve or maintain their health and wellbeing. These perspectives are applied to the three main topics of this course:

- During Weeks 1 and 2, we will introduce eHealth and show you how eHealth technologies are used to enable or improve self-care and prevention, supportive care, and societal health.
- Weeks 3 and 4 will focus on design. You will learn how to design eHealth that fits the user and the context, and is able to seduce or support people into changing their behaviour.

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FREE online course

Duration: 6 weeks

3 hours pw

Certificates available

SHARE

EDUCATORS


Saskia Kelders


Floor Sieverink


Hanneke Kip


Lisette van Gemert-Pijnen

www.healthbytech.com www.cewr.nl (persuasive technology lab)

SUPPORTING HEALTH BY TECHNOLOGY VII

The conference on supporting health by tech

In collaboration with the University Medical Center Groningen and the Center for eHealth &Wellbeing Research, the Institute for Innovation and Governance studies of the University of Twente presents a new edition in the successful 'Supporting Health by Technology' series.

This year's theme is: **Personalized Healthcare, Persuasive Coaching using Technology**

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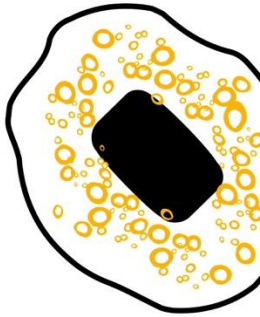
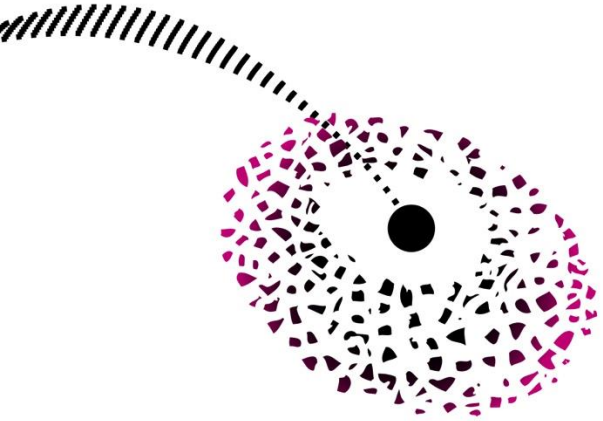


HOPES, CHALLENGES & RISKS OF BIGDATA FOR PERSONALIZING HEALTHCARE



Annemarie Braakman-Jansen

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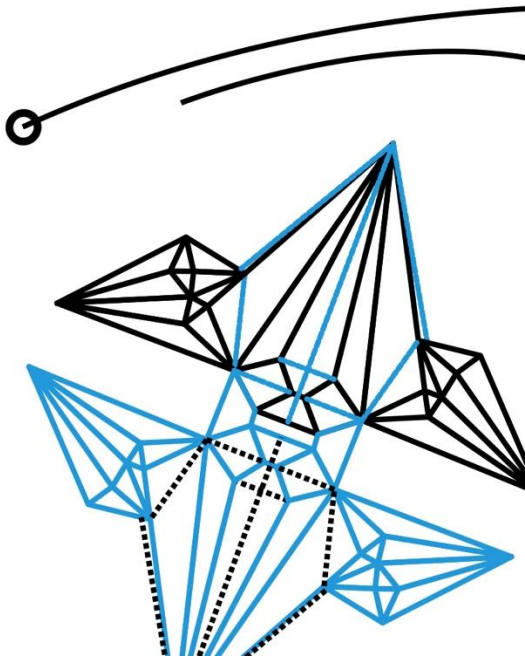

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BIG DATA AND PERSONALIZED HEALTH CARE

- There is boundless data in healthcare about every patient, condition, procedure and drug use across multiple providers & organizations

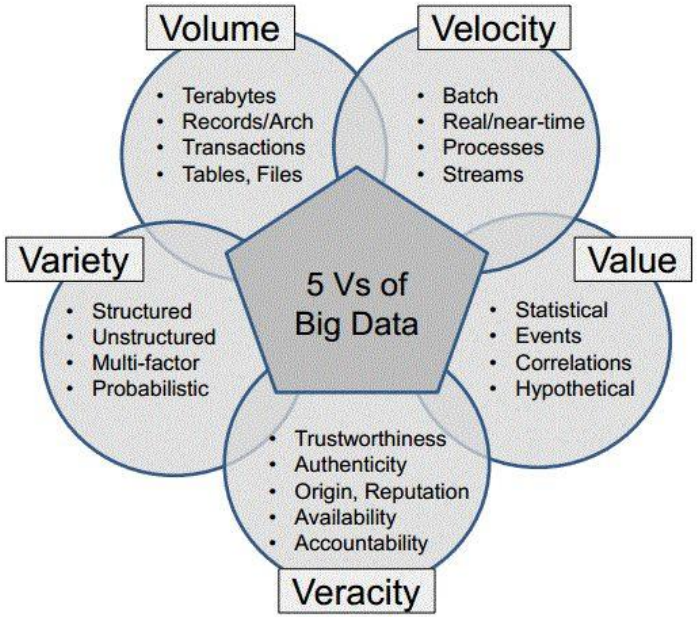
- Potential for personalized healthcare:
  - Tailoring decisions, medication, products to the needs of an individual, instead of what's best for a group of patients
  - Real-time 24/7
  - High Reach at low cost

Healthcare informatics and advanced analytics (data science) will increasingly be important!

THE 5V MODEL OF BIG DATA (MARR 2015)

- The datification of our world gives us boundless data in terms of Volume, Velocity, Variety and Veracitiy.

- But advanced analytics allows us to leverage al types of data to gain insights and add **Value**



CONCERNS

MEDICAL, ETHICAL AND TECHNOLOGICAL CHALLENGES

- Privacy
- Security
- Safety
- Purpose limitation
- Liability
- Profiling
- Data ownership
- …

RESEARCH QUESTIONS

- What are the **hopes**, **challenges** and **risks** for personalized healthcare from different perspectives?

- How to add value to the data?

METHOD (1)
PERSPECTIVE OF SCIENTIFIC EXPERTS

First exploration among:

- Focus group
- 6 Scientific Big Data experts the field of:
  - Psychology
  - Philosopy
  - Computer Science
  - Business Administration
  - Law
  - Data Science

RESULTS FROM THE EXPERT GROUP (1)

USER EMPOWERMENT

User empowerment

- Users need expertise to understand and judge their own health data.
- Sharing data without taking the risk that it will be used for other purposes.
- Keeping a grip on profiling.
- What if algorithms predict how we think, life, work… Are we still in control?

RESULTS FROM THE EXPERT GROUP (2)

PROFILING

Profiling

Assigning persons to a group/a profile based on the collected data:

- Based on what information are groups created?
- Can you leave a group, once assigned?
- Who is responsible for wrong decisions that are made, based on a profile?

RESULTS FROM THE EXPERT GROUP (3)

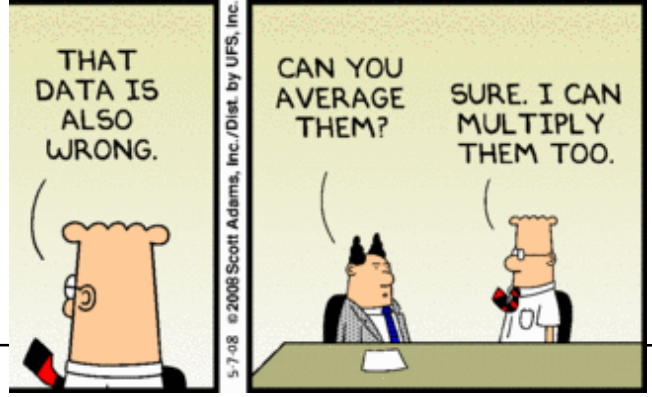
TRUST

"Before I write my name on the board, I'll need to know how you're planning to use that data."

Trust

Data-driven healthcare demands unconditional trust:

- In decisions that are made, based on data.
- In safe data storage.
- In the use of data for improvements in healthcare.



Data wisdom

Big Data demands data-wisdom:

- To get a grip on new developments and possibilities of technology.
- To make sure that not only a small group understands the data analyses and consequent interpretations.

METHOD (2)
PERSPECTIVE OF HEALTH PROFESSIONALS

Interviews with Health professionals

	Profession	Experience (working years)	Professional experience with eHealth technology
1	Quality officer	11	Telemonitoring
2	Nurse practitioner cardiology	26	Telemonitoring
3	Researcher cardiology	16	Telemonitoring
4	Nurse practitioner COPD	15	Telemonitoring & portal
5	Internist	19	Telemonitoring
6	Internist	40	Telemonitoring
7	Cardio-thoracic surgery	25	None
8	Medical microbiologist	7	Apps
9	Medical microbiologist	27	eHealth portal infection control
10	Cardiologist	25	Telemonitoring

USER EMPOWERMENT: CHALLENGES

RESULTS FROM HEALTH PROFESSIONALS

Patients have to be coached with the interpretation of their data

"... I think you also have to provide some guidance for patients to understand the data. As a patient suddenly sees that his blood pressure is decreasing from 120 to 90, he might think: "oh, I'm dying". However, it's still within the norm. So someone has to tell the patient: "No mister, you are okay. Don't worry, your blood pressure is still within the range of normal blood pressure. It should just not be lower than 90".

PROFILING: HOPES

RESULTS FROM HEALTH PROFESSIONALS

Profiling is not new, big data just has the potential to increase the accuracy

"… Profiling is nothing new ... profiling is something we've always done, otherwise you cannot start any treatment. During the anamnesis you have to obtain useful information from the patient to formulate a diagnosis and to provide medical care to the patient. If I could make profiles based on data of big populations, my medical care will only become more accurate."

Improvement Quality of care:

"I am quite sure that when you use the right algorithm, it will perform much better than solely the patient, nurse and doctor"

PROFILING: RISKS

RESULTS FROM HEALTH PROFESSIONALS

Having control

"... The idea is that insurance companies allow us to use telemonitoring. They should not use these data to harm the patient financially"

Precision is limited

"While creating user profiles you have to be aware that the precision is limited… as it is based on some features… and some social demographic characteristics like gender, age and race…. You have to be aware that you can predict only 60%...I'm afraid that essential information is excluded"

PROFILING: CHALLENGES

RESULTS FROM HEALTH PROFESSIONALS

Physicians need to know the reasoning of algorithms

"I want to know the reasoning. Why do you think we have standards and guidelines? Well, this is because the reasoning behind is clear and then it's up to people to follow the protocol or not. I should accept this from a computer although I would never ever trust the computer blindly. Forget it! "

LIABILITY: PERSPECTIVE HEALTH PROFESSIONALS

RESULTS FROM HEALTH PROFESSIONALS

Doctor is responsible as he started treatment agreement

"The doctor who started the treatment is responsible. Very simple. He started the treatment agreement and should be convinced to give the best treatment. That is not different from now. Because now you also have to deal with information from radiology, long-term research etcetera. Whether you make choices based on big data or whatever doesn't matter. You just have to keep thinking as a doctor. "

LIABILITY: PATIENT PERSPECTIVE

RESULTS FROM HEALTH PROFESSIONALS

The patient must be well informed about his rights and liability

"I think it is important that the patient is informed at an early stage about his actual rights and who is liable when something goes wrong… For example, the patient wears a smartwatch that registers the blood pressure. When this device has a defect, who is liable? I would say, the manufacturer or the supplier of the device. But how to deal with liability when the patient uses the device ignorant or not in the right way. Then what? Who has to prove what and how is it regulated? That will be a long juridical procedure"

REWIND OF DATA-SHARING: CHALLENGES

RESULTS FROM HEALTH PROFESSIONALS

Patients can not turn back their choice of data-sharing: technically impossible

"There is a significant group who will think: "I don't know for what I've give my approval, is it possible to withdraw my approval later on?" If those data are already shared with anyone, how to ensure that they are disaggregated and not providing insight anymore ? You have to deal with a potential irreversibility of the process... And you have to take this into account during the design stage. But technically it is just impossible"

TRUST: CHALLENGES

RESULTS FROM HEALTH PROFESSIONALS

Trust: to lose your clinical view

"... That you doesn't see the patient anymore, you lose your clinical eye"

Trust system: algorithms

*"... In fact, You allow the computer to decide by some rules you have given. And decision rules are very nice. However, they just **always** will go wrong somewhere on the track.. "*

DATA WISDOM: CHALLENGES

RESULTS FROM HEALTH PROFESSIONALS

Data-ownership: authority

"... I would like to have an authority, just as there is now a privacy authority who will close down the doors when it's necessary. You should have an independent authority that controls the data and takes care of encryption of the data.... "

Data valorisation

"3th party players like health insurance companies give too much importance to the data. They idolize the data"

ARCHITECTURAL FRAMEWORK: CHALLENGES

RESULTS FROM HEALTH PROFESSIONALS

Architectural framework datasystem

“without my computer from the lab and the system of the hospital, I cannot give my patient a decent advice. ... To perform my job you large amounts of data are needed to predict a frequency pattern ... So there comes a time that you have to build a system … preferably hand-held or something like that ... Which gives you easy access to **all** kinds of databases that you can use ... And this system should classify the data in such a way that you can **use it easy and fast**… so a 'medical decision aid'-like support system.”

DATA ACCESS: CHALLENGES

RESULTS FROM HEALTH PROFESSIONALS

Goal setting data-communication system

When aggregating big datasets and you also want to share this information with patients by using a portal, you'll have an extreme high risk in terms of security. So when the patient says, "I want to see all my data," this will be technically almost impossible and your system will be very very prone for hacking as long as you have not decided about data transport mechanisms and safety issues.

Restricted access

"Restricted access, just be sure that your system is not connected to everything and everyone. I would stay out of the internet. Otherwise the Chinese people or NSA have data access"

DISCUSSION

What are **your ideas** on the use of big data for personalized healthcare?

Big data issues (15 minutes per issue)

1. User Empowerment
2. Profiling
3. Trust
4. Data Wisdom

- Write your ideas on sticky note(s)
- One issues per sticky note
- Place your sticky note(s) on flip-over paper while making a rough categorization