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

Lisette van Gemert-Pijnen
Annemarie Braakman-Jansen
Floor Sieverink
Olga Kulyk
Liseth Siemons

Persuasive Health Technology Lab
Center for eHealth and Wellbeing Research

University of Twente
Enschede, the Netherlands
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)

14.40 – 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

Floor Sieverink, MSc.
PhD Candidate

Annemarie Braakman - Jansen
PhD

Olga Kulyk PhD

Centre for eHealth & Wellbeing Research
Persuasive Health Technology Lab

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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.
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

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Tunneling

Dialogue Support

Personalization

Reminders

Self-monitoring

Social learning

Social facilitation

fixed use of online treatment program

Logdata to understand adherence, prompts for persuasive triggers

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?

[Image: Quantified Self @ Work]

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.

Hanneke Kip, project May 2016-2020
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

Annemarie Braakman; eTelemed 2016

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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
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

eHealth: Combining Psychology, Technology and Health

How can technology make you healthy? Learn about the design, application, implementation and evaluation of eHealth.

Go to course – starts 23 May

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 well-being. 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

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EDUCATORS
Saskia Kelder
Moor Sieverink
Hannske Kip
Lisette van Gemert-Pijnen
Supporting health by technology VII

27 May 2016, Euroborg, Groningen - The Netherlands

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
HOPES, CHALLENGES & RISKS OF BIGDATA FOR PERSONALIZING HEALTHCARE

Annemarie Braakman-Jansen

Persuasive Health Technology Lab
Center for eHealth and Wellbeing Research
University of Twente
Enschede, the Netherlands
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!

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

But advanced analytics allows us to leverage all types of data to gain insights and add Value.
CONCERNS
MEDICAL, ETHICAL AND TECHNOLOGICAL CHALLENGES

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

Hey! What about my privacy??

They say that people who worry about their privacy have something to hide...
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
  - Philosophy
  - 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?
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.
RESULTS FROM AN EXPERT GROUP

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

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<thead>
<tr>
<th></th>
<th>Profession</th>
<th>Experience (working years)</th>
<th>Professional experience with eHealth technology</th>
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<tbody>
<tr>
<td>1</td>
<td>Quality officer</td>
<td>11</td>
<td>Telemonitoring</td>
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<td>2</td>
<td>Nurse practitioner cardiology</td>
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<td>Researcher cardiology</td>
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<td>4</td>
<td>Nurse practitioner COPD</td>
<td>15</td>
<td>Telemonitoring &amp; portal</td>
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<td>5</td>
<td>Internist</td>
<td>19</td>
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<tr>
<td>6</td>
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<tr>
<td>7</td>
<td>Cardio-thoracic surgery</td>
<td>25</td>
<td>None</td>
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<tr>
<td>8</td>
<td>Medical microbiologist</td>
<td>7</td>
<td>Apps</td>
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<td>9</td>
<td>Medical microbiologist</td>
<td>27</td>
<td>eHealth portal infection control</td>
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<tr>
<td>10</td>
<td>Cardiologist</td>
<td>25</td>
<td>Telemonitoring</td>
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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 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"
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"
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! "

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"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. “
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“
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: 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 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"*

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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 issue per sticky note
- Place your sticky note(s) on flip-over paper while making a rough categorization

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