PANEL

Topic: Patient Role in Mobile Adaptable Healthcare: Awareness and Accessibility

Tuesday, April 26 2016, 18:15

MODERATORS:

Anne G. Ekeland, Norwegian center for e-health research

Marianne Trondsen, Norwegian center for e-health research

www.telemed.no

Mobile adaptable healthcare

The use in health care of new cloud, mobile, wearable and device technologies that are:

- Adaptable and easily allow other tools and applications to link and integrate with them

- Focused on user experience and user-centered design

- Data driven - create and present data to the user in order to help improve decision making

The topic of the panel

- These technologies support a goal of wider transformation of the health care system, usually changing the relationship between the patient and professionals
- Discussion: The **patient role** in this development, with a specific focus on **awareness** and **accessibility:**
  - From patient to consumer?
  - From consumer to producer of data?
  - From contributor of data to decision maker?
  - From passive recipient to owner of means?
  - From access for all to access for the few?

Panelists

Moderators

Anne G. Ekeland and Marianne Trondsen, Norwegian center for e-health research

Panelists

- Maja van der Velden, University of Oslo, Norway

- Olga Kulyk, University of Twente - Enschede, the Netherlands

- Branko Celler, CSIRO - Australian eHealth Research Centre, Australia

- Iryna Lishchuk, Institute for Legal Informatics, Leibniz Universität Hannover, Germany

- Gerdienke Prange-Lasonder, Roessingh Research and Development, the Netherlands

- Trine Bergmo, University Hospital of North Norway, Norway

- Carl Brandt, Research unit of General Practise, Instittute of Public Health University of Sourthern Denmark, Denmark

- Sherri Portnoy, NHS Human Services, USA

Telehealth – is this the best that we can do? Predictive analytics, better monitoring etc
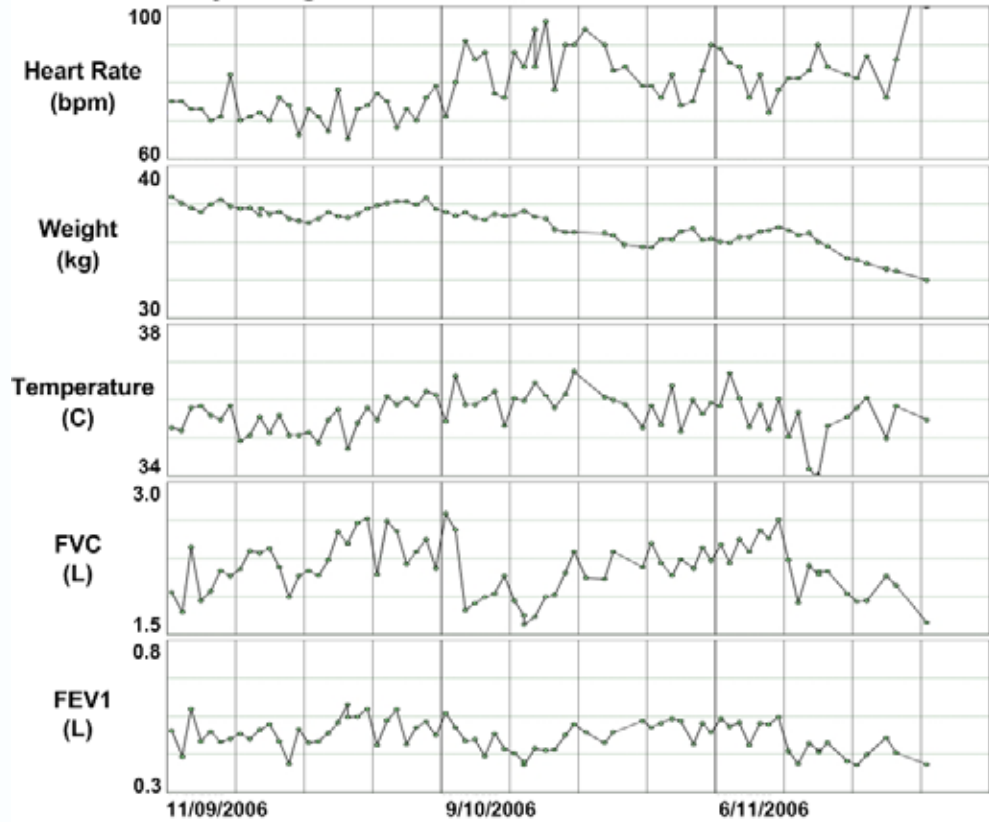
Branko Celler, Ross Sparks, Chris Okugami & Adrien Ickowicz
eTelemed 2016

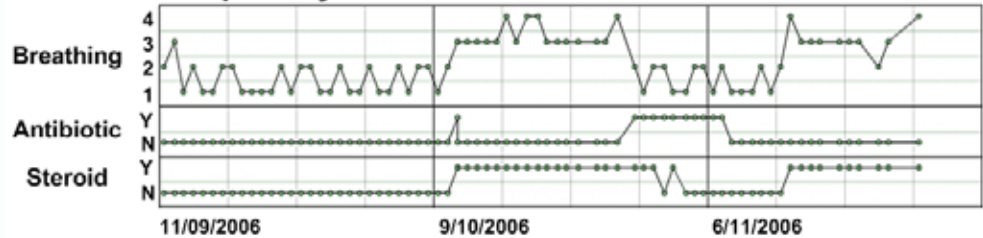**DIGITAL PRODUCTIVITY FLAGSHIP**
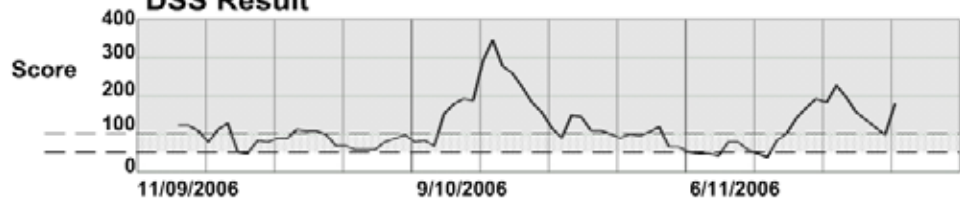www.csiro.au

CSIRO

Contact: branko.celler@csiro.au

Physiological Measurements

Heart Rate (bpm)
Weight (kg)
Temperature (C)
FVC (L)
FEV1 (L)

11/09/2006   9/10/2006   6/11/2006

Respiratory Questionnaire

Breathing
Antibiotic
Steroid

11/09/2006   9/10/2006   6/11/2006

DSS Result

Score

11/09/2006   9/10/2006   6/11/2006

Priority Key: Low   Medium   High

Outline Risk Monitoring
Multivariate disease surveillance

- Individual patient daily risk assessment

  - *Sick but stable,*

  - *Early signs of exacerbation of their chronic condition,*

  - *Acute signs of exacerbation, requires immediate attention*

- Statistical significance versus clinical significance – very early trend detection?

- Nurse care coordinator's view

- Global risk assessment across the whole project

CSIRO

DAILY Overview of patient data for one test site – the OVERVIEW Plot

Overview plot for 2014-03-17 Mon - Tasmanian Health Organisation - North
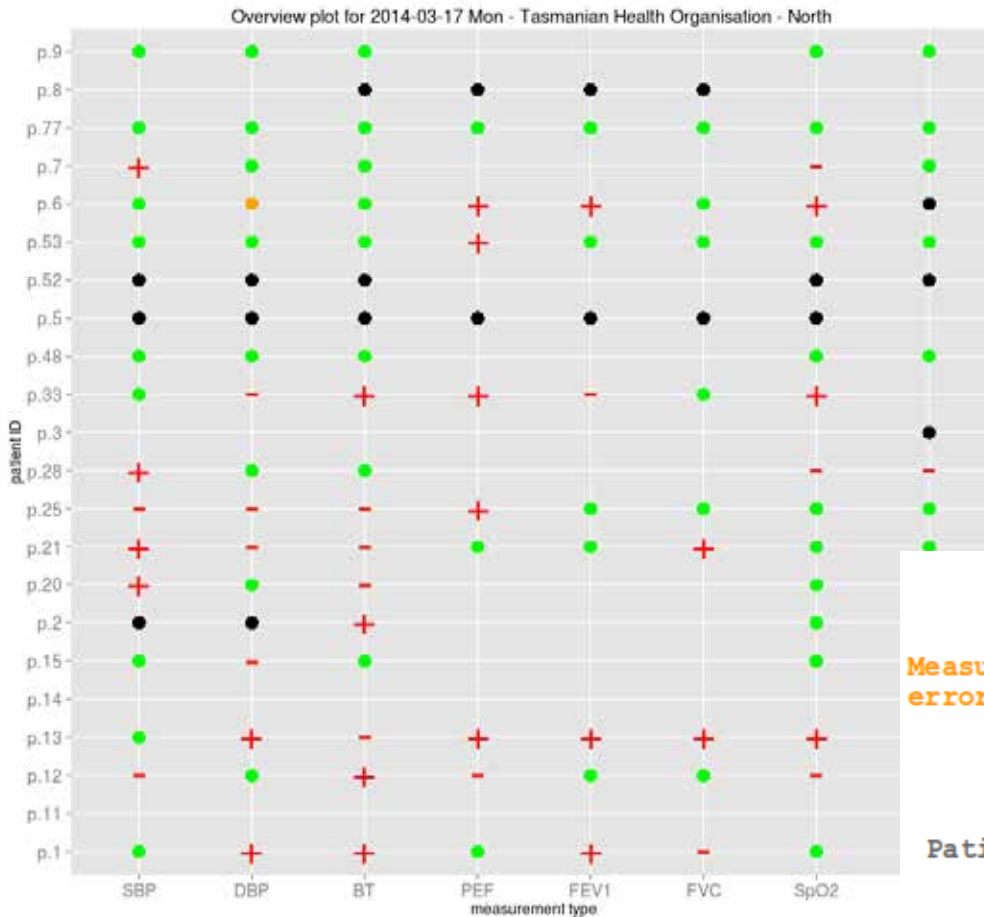
This overview plot provides the nurse care coordinator with a snap shot of what measure-patient combinations to examine (i.e., only look at those with red traffic signals because they indicate significant departures from the baseline measure).
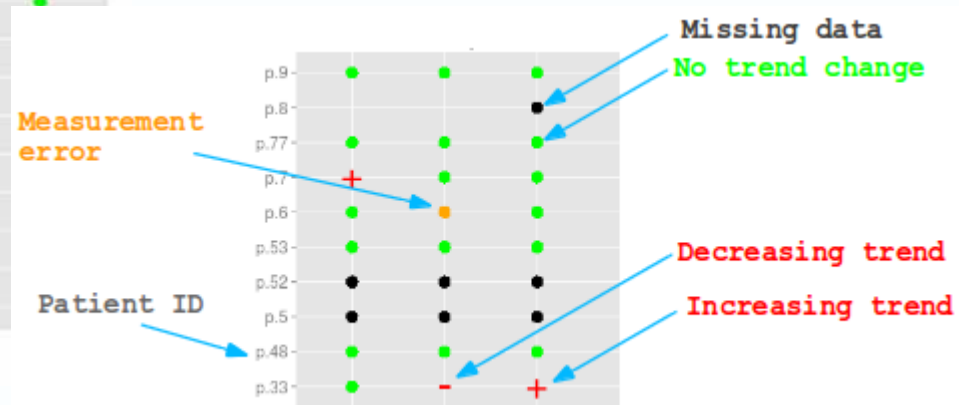
Statistical trend analysis
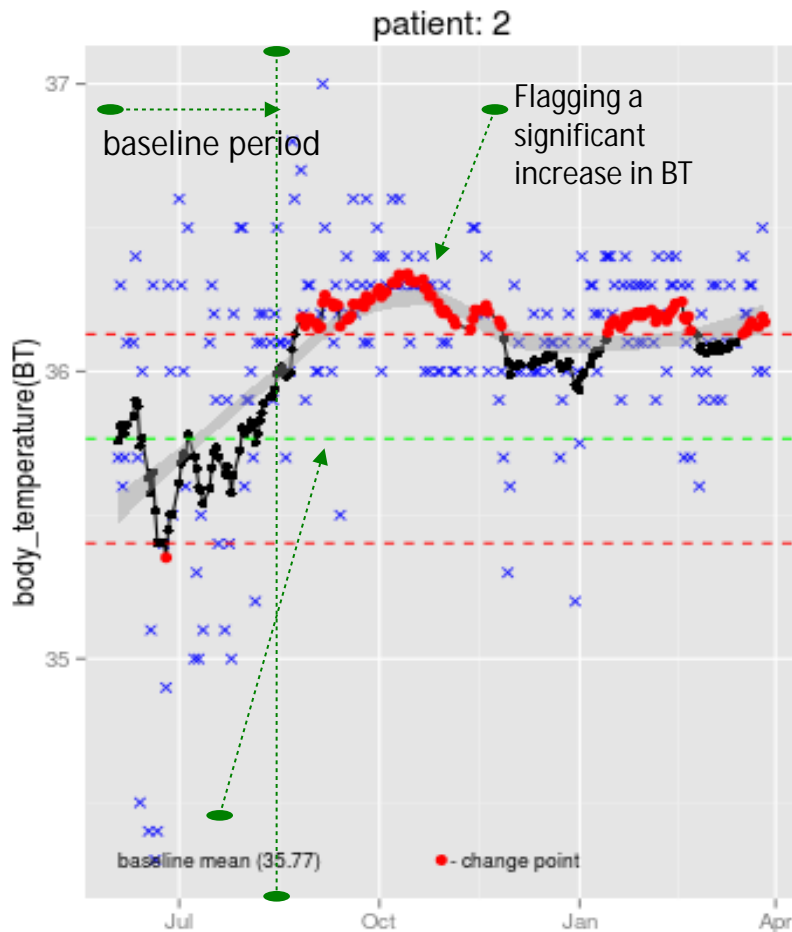
The **green line** on the plot indicates the average measure during the baseline period (baseline is taken as the first month in the report).

The region between the **red dashed lines** indicates where **trend plot** lines should remain if it is not significantly different from the baseline distribution of measures**.**
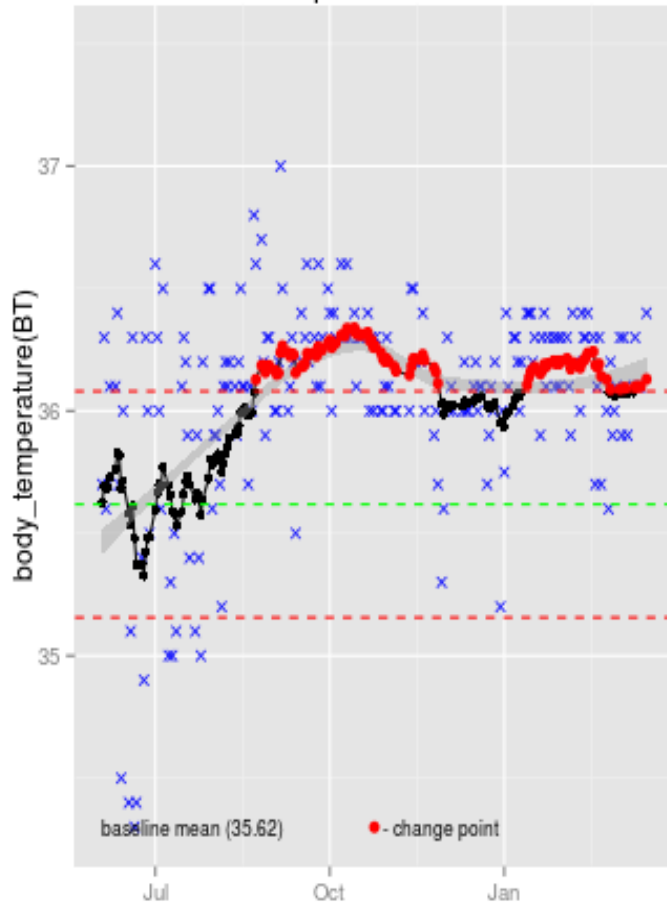
The **trend** in the average BT values is the black line which is the moving average of the measured values.

The **grey region** indicates the confidence interval for the smoothed estimate of the local trend. If the black line trend remains within the grey shaded region then the trend is more believable.
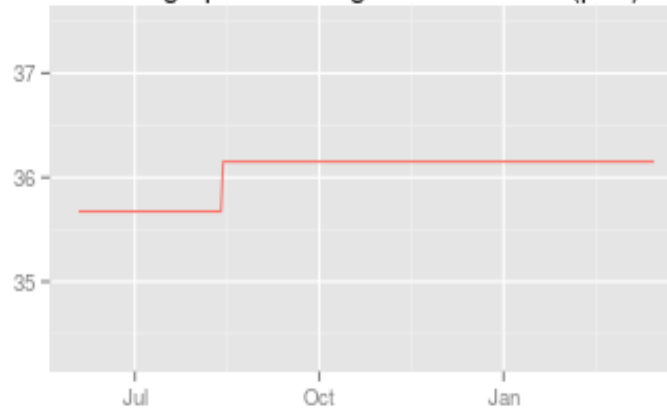
If the grey region lies outside the region spanned by the red dashed lines then we are almost certain the patient condition from this measure differs from the baseline.

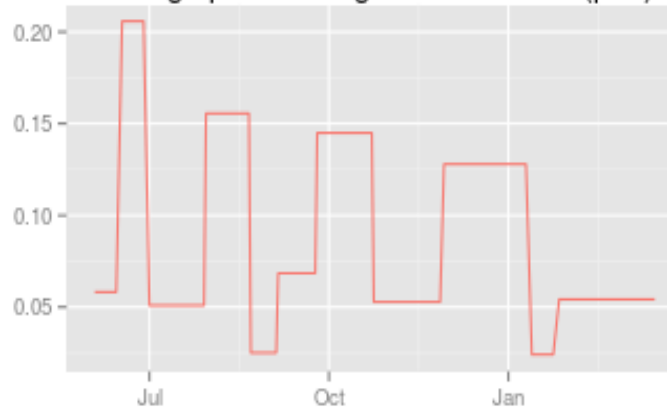# An example: Body temperature of Patient 2 until the end of March 2014

An example of step change in the trend for Body Temperature

An example of a change point & magnitude for scale plot. This shows a step change in the scale (uncertainty) of the measures

A Within Patient Overview Plot: Interpretting a patient stability of well being over the past 7 days

Parallel coordinate plot for last 7 days measurements : Patient (7)
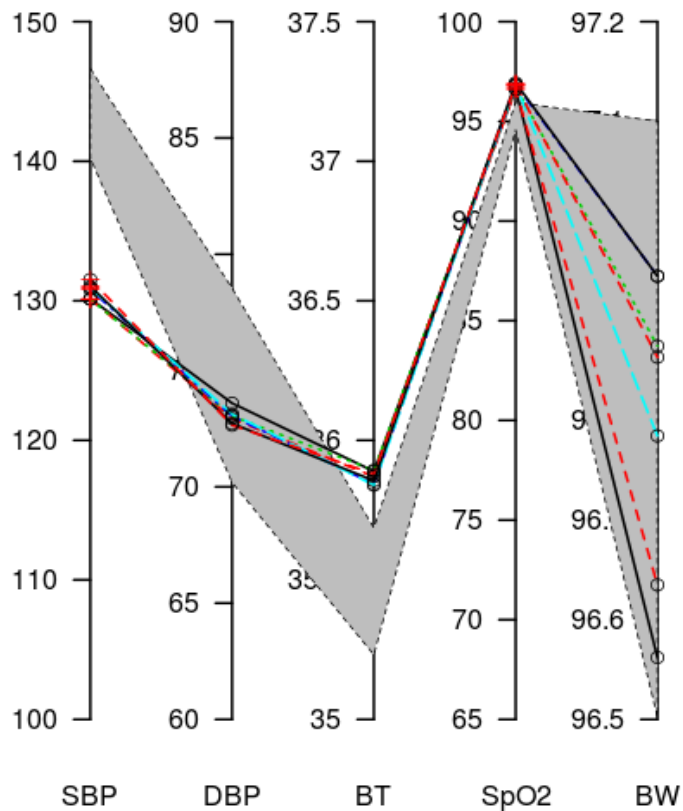
- This plot is only produced in the report for patients with three or more unusual flagged trends during the last day. It is designed to highlight patient that are either doing persistently better than baseline or unusually badly relative to baseline. The parallel coordinate plot is designed for the nurse to view the overall trends in wellness across all the measures

Global risk assessment across the whole project

- A model will be built to forecast the risk of each patient of hospitalisation for the next month based on past history of treatments, hospitalisations, medications, doctor visits, and current TMC measurements.

- This model tries to forecast risk to the next month and hence help the nurse care coordinator plan hospital prevention methods (if possible).

- At the beginning of each month the nurse care coordinator tries to design a care plan for the next months.

- Weekly updates of the model will be used to assess whether any change to the beginning of the month plan is needed based on changes in the forecast risk – given new data.

- The model will be developed using all test patients.

CSIRO

ANY QUESTIONS?

Prof. Branko Celler
CSIRO Digital Productivity Flagship
eHealth Research Program
Phone: 02 9372-4289
E-mail: **branko.celler@csiro.au**

www.csiro.au

CSIRO

AAL

Discussion Panel
Patient Role in Mobile Adaptable Healthcare:
Awareness and Accessibility
~ ironHand to support hand function ~

Roessingh
Research and Development

Gerdienke Prange-Lasonder, PhD
Roessingh Research and Development
Enschede, the Netherlands

ironHand

Roessingh Research and Development · BIOSERVO · Hocoma · nationaal ouderen fonds · Eskilstuna · terz Stiftung

---

Supporting hand function

▸ Problem definition
- Grip strength often declines with ageing
- Resulting in reduced hand function
- Difficulties performing activities independently
- Serious impact on quality of life of older adults

▸ Proposed solution: Wearable soft-robotic syste
- Combining Assistance & Exercise
  1. Assisting daily (work) activities
  2. Daily activities become training
  3. Plug in to specific training games

2

ironHand
enabling the **elderly** in **everyday life**

Assistive mode

Therapeutic mode

▸ Wearable soft-robotic glove

▸ Dedicated training environment

Iterative, user-centred design

Assistive + therapeutic effect after longterm use

Direct impact on ADL

Feasibility study

Design of prototypes

User requirements

Design adaptations

Current status ironHand project

▸ Third version in user testing for direct impact
  ◦ iH system perceived to be helpful;
    but no measurable benefit in task duration yet
  ◦ iH system desired to support + train activities at home;
    also useful at work?
▸ Next actions:
  ◦ Improvements of glove design <u>and</u> testing protocol
  ◦ Field test by elderly at home and at (volunteer) work
▸ Next questions:
  ◦ How to define where people experience biggest impact?
  ◦ How to identify where and how people can get access?

5

Thank you.

>> Partly funded by
   AAL, ZonMW, Vinnova, SERI

Roessingh Research and Development

SEM – Soft Extra Muscles for you
BIOSERVO

Hocoma

nationaal **ouderen** fonds

Eskilstuna kommun

terz Stiftung

6

Background – Value and personalisation
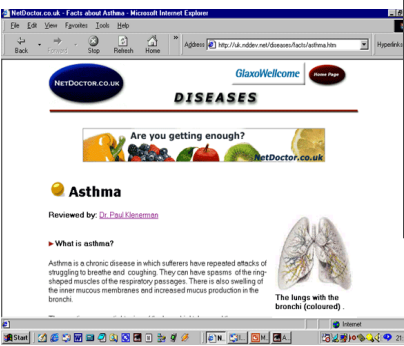
The cost is rising in accordance to severity
- preventive measures of uttermost importance

28.500 €./year

Diabetics need to be activated BEFORE they end up as difficult category 2 patients
22-dobling!

Costs per patient-year

- Informal care-givers´ time
- Patients´ time
- Non-Healthcare Resources
- Healthcare Resources

250.000
200.000
150.000
100.000
50.000
0

11% have the diagnose with minor symptoms

The vast majority of the cost is care and social costs – treatment is only a minor part

3.900 kr./year

1.300 kr./year

51% have the diagnose without significant symptoms

0   1   2   Overall

Complication status

38% have the diagnose with severe symptoms

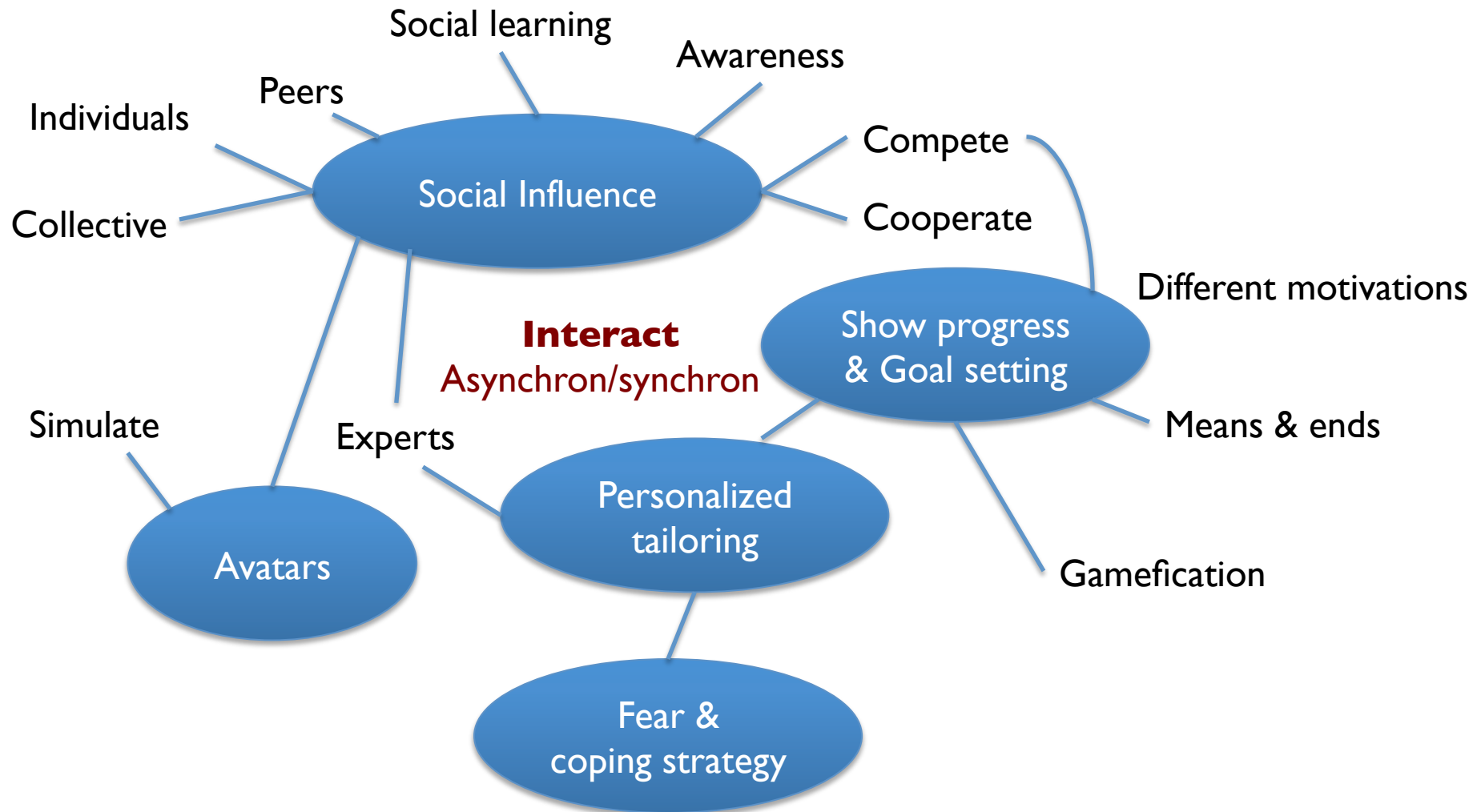| ALL PATIENTS	TOTAL	Age group			
		0-14	15-39	40-64	65+
No. of patient years, total	136,047	400	8,422	57,242	69,983
Complication state: 0	70,487	347	5,420	33,559	31,161
Complication state: 1	15,858	23	1,935	8,099	5,801
Complication state: 2	49,702	30	1,067	15,584	33,021

*Healthcare Resources
Added hospitalization costs
Medication with insulin
Medication with oral antidiabetics
Medication with other drugs, added costs
Routine diabetes controls One average visit
Home monitoring One year´s activities
Physiotherapy

**Non-Healthcare Resources
Added cost for nursing home
Annual cost for nursing assistance in the home, full-time
Annual cost for nursing assistance in the home, part-time
Wheelchair
Stocks
Protese crus
Protese femur

Kilde: Green A, Emneus M, Christiansen T, Bjørk S, Kristensen JK: The social impact of diabetes mellitus and diabetes care. Report 3: Type 2 diabetes in Denmark year 2001. SDU Health Economic Papers 2006

Persuasive techniques in Behavioral Change Support Systems

Social learning

Awareness

Peers

Individuals

Compete

Collective

Social Influence

Cooperate

Different motivations

Interact
Asynchron/synchron

**Show progress
& Goal setting**

Simulate

Experts

Means & ends

**Personalized
tailoring**

Avatars

Gamefication

**Fear &
coping strategy**

Themes

1. Incitement/facilitators
   1. The honest and trustworthy relationship to the health professional
   2. Monitoring the behavioral change with nudging from a referent person
   3. Goal setting
   4. Support from partner
   5. Life events in close family
2. Impediments/barriers
   1. Self-inflicted obstacles
   2. Experience of lack of self-efficacy
   3. Keeping up appearances
3. Role of peers
   1. Experience of honest and trustworthy forums
   2. Need of acknowledgement from referent others

Components for lifestyle change in e-health related to main sociocognitive determinants

| E-Helath Components	PSYHOSOCIAL DETERMINANTS OF HEALTH BEHAVIOR							
	SELF-EFFI-CACY	OUTCOME EXPECTATIONS			GOALS		IMPEDIMENTS	
		Physical	Social	Self-Evaluative	Proximal	Distal	Personal & situational	Health System
Content at the Right Time	2.1	1.2			1.1	3.2	(1.1)	
Health Monitoring	2.1	2.1		2.3	1.2 1.3		(2.1)	
Community	3.1	3.2	3.2	3.1 3.2	1.2 1.3	3.2	2.1	3.2
One to one Care	1.1	2.1			1.2	1.3	2.1	2.2
Connectivity	1.1	2.1			1.2	1.3	2.1	2.2

Discussion

- Even though the numbers are small in the pilot study a weight loss of **7,0 kg over a period of 20 months** is comparable with other conventional treatments

- The **lack of drop** outs was remarkable (but it is seen in other Danish studies in general practice).

- Cost effectiveness seems to be good **about 25 euro per kg lost** and a probably a similar amount to keep the weight down.

- We need to learn more about the **perception of the different aspects of online treatment** from both patients and health professionals

- We don't know **who** benefits from online treatment and how their **perception of their health risk** affects the result

STRENGT FORTROLIGT

6   26/04/16
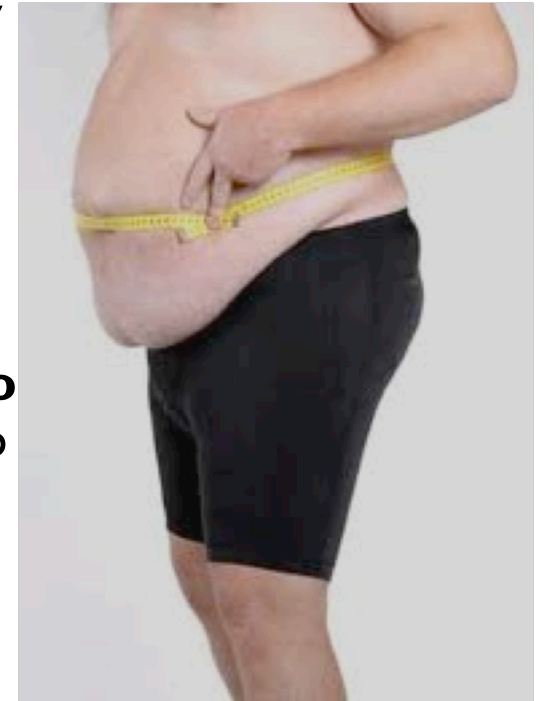
Barriers

- Implementing internet treatment needs local adjustment and handling with respect to the **local value chain**

- It is of great importance that systems are **well integrated** into the local electronic patient journal and does **not result in extra work** for the GPs and their regular staff

- The major barriers we met seems to be the **doctors reluctance to new technology** and **the patients failure to use the IT platform (2008-2016)**
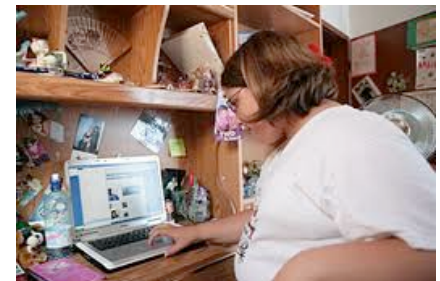
How does the **BCSS** platform - **LIVA** – work today?

Content at the Right Time
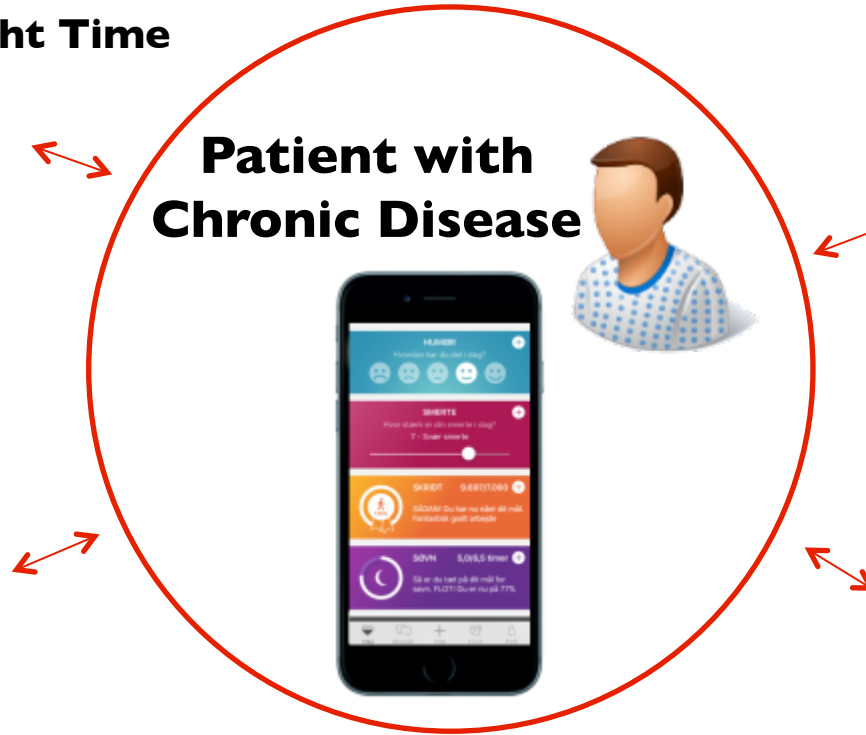
Connectivity General practice

Patient with Chronic Disease

One to one CARE By a Health Coach

Health Monitorering and Plans

Community Virtual interaction

Thank you! Questions?

Contact:

Carl J. Brandt, MD, GP.

Research Unit for General Practice, Institute of Public Health, University of Southern Denmark

cbrandt@health.sdu.dk

Tel: +45 2014 1566

Patient Role in Mobile Adaptable Healthcare: Awareness and Accessibility

Privacy Aspects

by Iryna Lishchuk, LL.M.
Leibniz Universität Hannover

Mobile Healthcare: Status Quo

Mobile Health Applications and Wearables:

- More than 97.000 mHealth apps in categories „Fitness and Health" and „Medicine"

- 2013 approx. 10 million, 2014 approx. 22 million wearables

- 2018 appr. 68 million smart watches and appr. 50 million smart bands

Popularity:

- Top 10 mHealth apps generate up to 4 million free and 300.000 paid downloads per day

Target:

- About 70% are for fitness and health oriented consumers

- About 30% are for representatives of medical profession*

Research2Guidane(2013), „The mobile health market report 2013-2017: the commercialization of mHealth apps", http://research2guidance.com/product/mobile-health-market-report-2013-2017

Patient as a User

Fields of application:

- Self tracking
- Monitoring of vital functions/disease
- Medical diagnosis
- Administration of medicinal products
- Provision of healthcare in far-to-reach regions

Status of data protection framework:

- More than 60% of wearable offers have no privacy policy (!)
- High quality healthApps, complying with purpose related data procession are rather an exception, than a rule
- In average, data is passed to third parties for commercial purposes
- The users generally obtain no knowledge (and have not agreed) to this (!)*

* Symantec Corp., How safe is your quantified self? Tracking, monitoring and wearable tech, http://www.symantec.com/content/en/us/enterprise/media/security_response/whitepapers/how-safe-is-your-quantified-self.pdf

Wearable Data in Data Protection

- **Collected data:**
- data reflecting body behavior, e.g., physical activity, temperature, pulse, energy taken, energy spent, etc.
- **Personal data:**
- *Article 2 (a) Data Protection Directive 95/46/EC (DPD)**
  - information relating to an identified or identifiable natural person ('data subject'), e.g. by one or more factors specific to his physical, physiological, mental ... identity;
- **Data concerning health:**
- *Article 8.1 Data Protection Directive 95/46/EC (DPD)**
  - Processing of data concerning health is prohibited, unless exceptions apply

* *The General Data Protection Regulation (GDPR) superseding the Data Protection Directive is on the way: http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CONSIL:ST_5419_2016_INIT&from=EN*

Defining Health Data

- **Health Data, Article 4 (15), Recital 35 GDPR:**

"*all data pertaining to the health status of a data subject which reveal information relating to the past, current or future physical or mental health status …. This includes information:*

- *collected in the course of the registration for, or the provision of, health care services…;*
- *derived from the testing or examination of a body part or bodily substance, including from genetic data and biological samples;*
- *on, for example, a disease, disability, disease risk, medical history, clinical treatment or the physiological or biomedical state of the data subject independent of its source, for example from a physician or other health professional, a hospital, a medical device or an in vitro diagnostic test.*"

Non-Health Data v. Health Data

Amison New Smart Wrist Band

Non-health data in the meaning of DPD:

- Data enabling no reasonable conclusions about the person´s health

- **Example 1: Step counter**
  - Counting steps in a single walk
  - Not storing the data
  - Not combining the data from and about the same person from the same device and other sources
  - Is not used in the medical context, e.g. by providing health care services, doing medical research, etc.
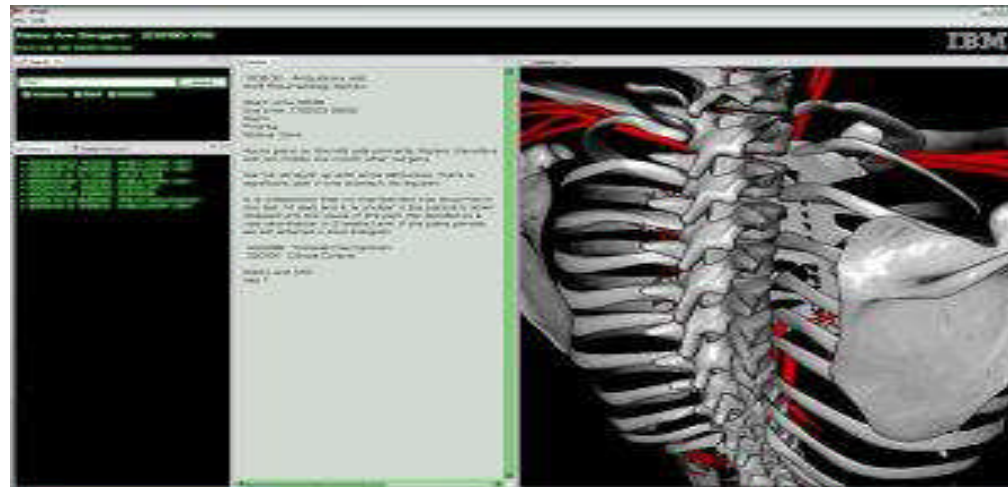
Health data:

- Data enabling conclusions about the health of the data subject

- **Example:** MyHealth Avatar

- an avatar - a 3D representation of the human body - to allow End Users (e.g. patients, doctors) to visualize patient medical records in a new way

www. myhealthavatar.eu

Non-Health Data v. Health Data

Non-health → health data:

- Non health data used to draw conclusions about the health

- analysis of social media to detect whether people may suffer from a depression

- "Sad" messages do not have to be treated as health data by generalist social networks

- Systematic analysis of such messages for the purpose of diagnosis/health risk prevention or medical research

© Facebook.   →
Processing of personal data

Legitimation of Data Procession

- **Article 8 DPD:**

  - The processing of data concerning health is prohibited … unless exceptions apply…

- **Exceptions relevant to mobile healthcare:**

  - **Art. 8 (3) DPD:**

  - Procession for the purposes of preventive medicine, medical diagnosis, the provision of care or treatment or the management of health-care services + medical secrecy rules

  - **Art. 8 (2) (a) DPD:**

  - Explicit and informed consent of the data subject

Obligations against the user

The service provider (acting as data controller) must:

- **inform users:**
    - Whether the data are protected by medical secrecy rules
    - Whether the data will be combined with other data from the device/other sources and consequences of such combination
    - Purposes of further processing
    - To what third parties data will/may be transferred
- **make information accessible** to the user before installing the app/buying the device/service
- **define** compatible and legitimate **purposes** of data processing
- **apply** appropriate **anonymization and security measures***

* Art. 29 Data Protection Working Party

THANK YOU!
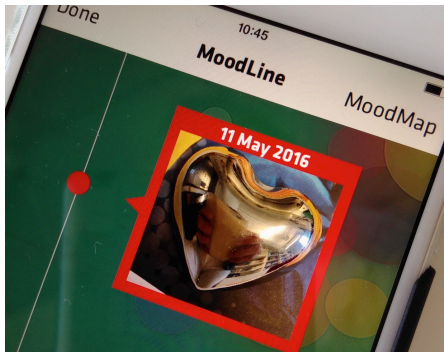
Patient Role in Mobile Adaptable Healthcare

Awareness and Accessibility

Maja van der Velden

Associate Professor

Design of Information Systems
Department of Informatics
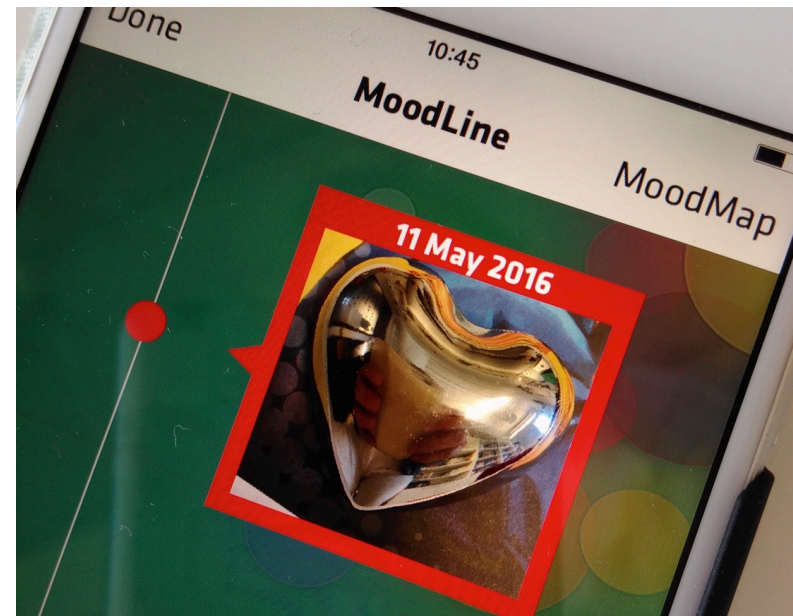University of Oslo

majava@ifi.uio.no

Teenage patient as designer

- Participatory Design

- Design from somewhere

- Diversity

Teenage patient as user

- Personalisation:
  - Colours
  - Images
  - Language

- Select / de-select functionalities

- Decision to use / non-use

- Privacy

Patient Role in Mobile Adaptable Healthcare: Awareness and Accessibility

Sherri Portnoy
NHS Human Services, USA

www.nhsonline.org

mHealth

- Provision of health services enabled by mobile communications

- New solutions needed to healthcare crisis

- Paradigm shift

Technology Trends Transforming Healthcare

- Electronic Health Record

- Patient Centric Devices

- Big Data Analytics and Patient Access

NHS
HUMAN SERVICES

Benefits to the Patient

- Access

- Control

- Increased quality of life

NHS
HUMAN SERVICES

Patient Role in Mobile Adaptable Healthcare: Awareness and Accessibility

Mobile health to improve care for the old and multimorbid patients

Trine S Bergmo

Norwegian Centre E-health Research

University Hospital of North Norway

Comprehensive integrated care model

- Established in Tromsø in 2014
- Consists of interdisciplinary teams (community and hospital staff)
- Works patient-centred (CCM)
- Offers coordinated, proactive and planned care and follow-up
- Provides outreach services
- Included 300 patients in 2015
- Use tablets to communicate with the providers

Experiences from Tromsø

Tablets have been used to:

- To communicate and seek advice

- Filming physiotherapy session

- Videoconferencing using WebRTC (Secure Health Network)

Specific Usage

- To store pictures of ulcers and show to specialists at the hospital

- Store films of physiotherapy sessions for progress and advise

Videoconferencing (real time)

- Emergencies (medical doctor talk directly to the patient)

- Wound/ulcer care (treatment advice between carers)

- Advise from colleagues (team members)

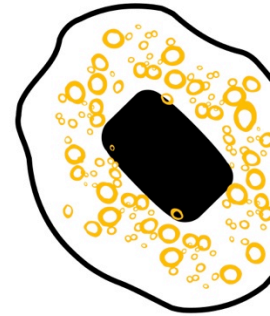- Coordination purposes between different personnel

Patient Use

No ICT competence
Used by the carers only (on behalf of the patients)
Need continuous encouragement and training
It must be easy to use (one or very few buttons)

Patient Role in Mobile Adaptable Healthcare:

Personalization, Awareness & Value

Panel

Dr. Olga Kulyk
Assistant Professor
Persuasive Health Technology Lab

eTelemed 2016, Venice

DATA-DRIVEN PERSONALIZED HEALTHCARE

- Rapid growth of health data provides new opportunities for **personalizing** and improving healthcare

- **Physical activity case:**
  - ✓ I'd like to get some coaching advice…
  - ✓ I would like to see my track record…
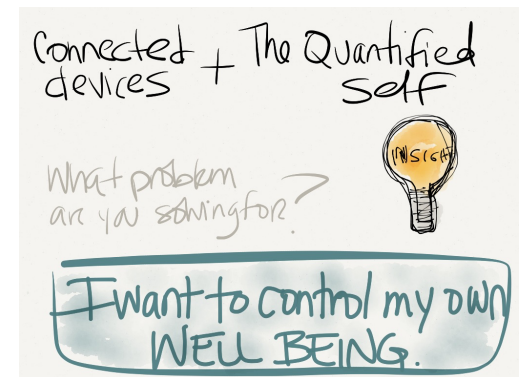
CO-

Patient-centred approach:

- **Co-creation** with **patients** & various **stakeholders**

- **Participatory** design

- **Multidisciplinary** approach

- **Training** needed for **clinicians**!

  ✓ How to optimally integrate mobile healthcare in daily medical practice?

Value of **personalized data**

- How to make make big data **meaningful** for various users?
  - ✓ **Individual** user
  - ✓ Across **group of users**

- Making patients **aware** of their own data:
  - ✓ **Personalized feedback** & **coaching**
  - ✓ **Big data analytics**: creating **value**, **visualizations** tailored to user
  - ✓ Using various **modalities** for feedback:

    speech, **text**, **ambient light** etc.
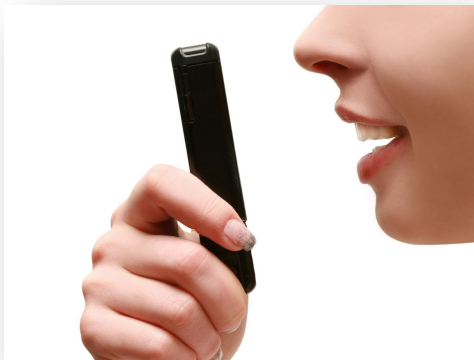
CURIOUS?

@okulyk

Contact:
o.a.kulyk@utwente.nl