Grounding eHealth

The need for a Human centered and Value-driven approach

Lisette van Gemert-Pijnen

The Fifth International Conference on Digital Society

eTelemed

February 23-28, 2011 - Gosier, Guadeloupe, France

Center eHealth Research & Disease Management

Guadeloupe, February 2011
Center for eHealth Research & Disease Management
Institute for Social Sciences and Technology

- to create and share knowledge about social and behavioural aspects of technology in health care
- to translate knowledge into useful guidelines and concepts for (re)designing and implementing technology in healthcare
- to intensify cooperation with international research centres and healthcare institutes
- to strengthen the relationship between research, policy and practice
- to contribute to the solution of global health problems, like ageing and chronic care, via a multidisciplinary approach (social sciences & technology)
Presentation outline

♫ Why do we need to innovate Healthcare & eHealth?
♫ Problems with the uptake of eHealth technologies
  ♫ Low Adherence to eHealth technologies
  ♫ Limited Value of eHealth technologies
♫ A new approach to ground eHealth in a digital society
♫ How it works, and Benefits
Why do we need to innovate Healthcare?

- ↑ elderly people
- ↑ healthcare associated infections (MRSA, Swine Flu etc)
- ↑ chronic diseases; comorbidity
- ↓ healthcare professionals
- ↓ budget
Digital Society
Nature of demand is changing: e-Patients want Health 2.0 solutions for sharing information

Participatory Medicine is a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners.

Welcome
Participatory Medicine is a cooperative model of health care that encourages and expects active involvement by all connected parties (patients, caregivers, healthcare professionals, etc.) as integral to the full continuum of care. The ‘participatory’ concept may also be applied to fitness, nutrition, mental health, end-of-life care, and all issues broadly related to an individual’s health.

The Society was founded to learn about and promote Participatory Medicine through writing, speaking, social networking, and other channels. Join us!
Technology can help, but what interventions do or do not work? And WHY
Problems with the uptake of eHealth technologies

- Slow diffusion
- Low acceptance
- Lack of adherence
Asynchronous and Synchronous Teleconsultation for Diabetes Care: A Systematic Literature Review

Fenne Verhoeven, Ph.D.,¹ Karin Tanja-Dijkstra, Ph.D.,² Nicol Nijland, M.Sc.,¹ Gunther Eysenbach, M.D., M.P.H.,³ and Lisette van Gemert-Pijnen, Ph.D.¹

Abstract

Aim:
A systematic literature review, covering publications from 1994 to 2009, was carried out to determine the effects of teleconsultation regarding clinical, behavioral, and care coordination outcomes of diabetes care compared to usual care. Two types of teleconsultation were distinguished: (1) asynchronous teleconsultation for monitoring and delivering feedback via email and cell phone, automated messaging systems, or other equipment without
eHealth Technologies, low impact

- Insufficient capacities
  - Lack of training, education staff
  - No integration offline-online
- Lack of project management
  - case manager, nurse, GP, specialist, patient ???
- Unclear insight in benefits (cost/benefits for whom?)
  - Bias in population (no complications)
  - Bias in publication, no report of drop outs
Technology, not human centered

- Usability problems
- Ceiling effect (ill-management; task-related eHealth systems)
- Lack of push factors (triggers for motivation, like fun, entertaining, incentives, rewards)
- Template medicine, Lack of tailor-made advice to support well-being
Research, limited power

- Lack of longitudinal studies, no focus on usage over time
- Lack of process evaluations about real-time usage
- Medical research, focus on classic trials, no evidence about HOW and WHY technology works in practice
- Technology is a black box in research > no evidence
- Underestimation of impact eHealth interventions

RCTs
eHealth, No impact?

- Patients and caregivers never used the technologies as expected
- These publications demand for a new approach to ground eHealth interventions (to increase adherence) and
- to measure the overall impact of eHealth in practice (clinical, behavioral, care coordination)
Low Adherence to eHealth technologies
Lack of Adherence, a global problem

Focus in research:
drop outs, and usage over time;
reasons for attrition; drivers for persistence

Eysenbach, 2005, the law of attrition, J Med Internet Res 7(1):1
Adherence to a web-based coach DM II, self-care Usage, Users, Drop-outs?

Different tools appear on demand: e.g. healthy living test, sport selection guide, activity scale, nutrition guide, weight manager, diet guide, mobility exercises

Monitoring
Motivation (eContact)
Mentoring
• Education
• Instruction
Usage of the web-based Diabetes coach, during 2 years

Appendix X. Overview of activity patterns in months

| Month | 1   | 2   | 3   | 4   | 5   | 6   | 7   | 8   | 9   | 10  | 11  | 12  | 13  | 14  | 15  | 16  | 17  | 18  | 19  | 20  | 21  | 22  | 23  | 24  |
|-------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|
| H     | 2   | 2   | 1   | 2   | 1   | 1   | 2   | 1   | 1   | 2   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   |
| M     | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   |
| L     | 2   | 2   | 1   | 2   | 1   | 1   | 2   | 1   | 1   | 2   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   | 1   |
|      |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |

Stop and restart
Who are the hardcore users? (reviews & evaluations usage web-based systems for self-care)

Those that might feel they have much to gain...

- Conscientiousness? (Halko & Kientz, 2010)
- Positive attitude in advance to use the application
- More healthy than they think they are
- Eager to realize goals
- Higher use of all apps a system provides
- Proactive, asking for support via eContact
- Demand for "smart" technology;
- Automatic integration of data to gain a complete picture of their condition
Discontinued users (web-based systems)

- Technology frustrates usability problems; people get lost in the system
- They have a high demand for push factors; triggers; feedback; incentives
- No obligations, free use, free choice, free of charge
- Technology does not motivate no fit into daily live
- They think their condition is under control (ceiling effect)
Value of eHealth interventions?
eHealth gives us the best means of providing accessible health care to the poorest and most vulnerable (TUTU)
Vulnerable patients → Dementia

- Safety support, care coordination *(observation)*
  - GPS track and trace
  - ADL-sensor technology (daily activities)

- Support for self-care, well-being *(inter-active)*
  - Touch screen & Video contact
  - Chitchatters (contact apps “songs from the Past”)
Handyman technologies for dementia, limited value

- GPS systems (Talk me Home tools) frightened patients and caused weird situations (following tool, disregarding traffic).
- Sensors that observe daily activities like eating, sleeping, opening the fridge provide data difficult to interpret.
Patients & carers have different needs

caregivers and family carers want technology for safety control, care planning (interest)

Patients want a view on the world outside

Patients want narrative
Technology, stories, songs, news from the past
What models underpin eHealth interventions?
Review current models, frameworks

Figure 2. Key software project success indicators in the human-organization-technology fit (HOT-fit) framework.
eHealth frameworks not advanced enough to develop technologies that make sense

- Unclear theoretical grounds, no clear visions about how technology can improve healthcare
- No empirical evidence for the benefits of using these models; Lab-models
- Focus on evaluation OR development OR implementation

No stakeholder engagement

IT is black box

No logistic
A Human centered, value driven approach
Need for holistic models to achieve technologies that are human centered, fit for context, and that have value for all stakeholders
Framework to ground eHealth interventions (2011)
Principles eHealth framework

- Holistic approach to understand the overall impact of eHealth interventions on healthcare
- Multidisciplinary project management
- Participation of stakeholders throughout development process
- Implementation no afterthought; interwoven with development
- Continuous Evaluation, no fixed-end
- Advanced methods to study process and outcomes
Contextual inquiry

Contents

1. Research activity
2. Research methods
3. Research criteria
4. Example

Research activity

Ideally, the development process of an eHealth environment in which the technology will be developed should be driven by actions that are relevant to support the technological solution to problems with the current healthcare delivery system. This means that the owners of the key problems and needs of all those involved are identified, and a clear understanding of what the contribution of technology can be, and who might benefit from the technology.

Research methods

Several research methods can be used to perform a contextual inquiry, including observations, focus groups (stakeholder meeting) [5, 8]. A focus group brings together a cross-section of stakeholders in a discussion group format. This method is useful for addressing all the points of view of different stakeholders. The general idea is that each participant can act to stimulate ideas in the other people present, and that, through a process of discussion, a collective view becomes established which is greater than the individual parts. The focus group method, which is also called group interviewing, is an excellent method to obtain a lot of information in a short time about the underlying motivations and needs of different stakeholders about a particular subject.

Research criteria

See Guideline, Contextual Inquiry.

Example

Doctors should be easier to reach

General Practitioners (GPs) are unacceptably hard to reach in an emergency. This is the view of the Public Health Inspectorate [IGZ] in the Netherlands and the Dutch Federation for Patients and Consumers [NPCF]. In non-emergencies too, GPs are difficult to reach. More than one quarter of the callers cannot get through to the GPs' emergency numbers. By the end of the afternoon, this will have risen to 40% of all callers. Furthermore, many GPs do not even have an emergency number or, if they do, their patients do not know this number. This applies to more than half of the callers. And in seventeen percent of the cases where an answering machine is attached to the emergency number. IGZ and NPCF believe that GPs should answer their phone within 80 seconds of receiving an emergency call. In more than one third of all cases this does not happen. It is not much better in the case of non-emergency calls. Forty percent of the callers have to wait for more than ten minutes before they get anyone on the line. IGZ and NPCF believe that non-emergency calls should be answered within two minutes, but half of all callers have to wait longer. [url]http://nos.nl/artikel/75774-bereikbaarheid-huisartsen-meet-beter.html[/url]
How the framework works… several studies

- Chronic Care Platform eCoaching
- Teledermatology (wound care; diabetic foot)
- Infection control (www.eursafety.eu)
- Dementia & Safety and Daily activity support
- Mental Health via online Therapy
Teledermatology (wound care)

Problem identification
Actor mapping

Selection actors
Values
Functional requirements

Design requirements
Technical feasibility

Infrastructure wound care
Business logic

Assess Effects
Identification of problems

• Inadequate diagnosis and monitoring
• Lack of coordination
• Miscommunication
• Unclear financial structure
• Lack of practical guidelines

**Figure 1. Multidisciplinary network of stakeholders in the dermatology wound care**

- GP nurse practitioner
- Home care district nurse
- Home care specialized wound nurse
- Patient
- Dermatologist
- Insurer
- Technology provider

The patient should play a central role in his own healthcare process by self-care and self-monitoring.
Stakeholders’ perspectives on the values of eHealth technology

- Is there any need for a new system?
- What are the benefits, given the observed problems?
- What are the critical design factors?
- What are the conditions for implementation?
- SPACE for INNOVATION
RESULTS: Design requirements

Dermatologist: "Technology shall help with coordination of work"

(manager home care: "A patient file (EPD) especially for wound care."

Specialized wound care nurse: "It would be excellent to use a tool to consult the GP"
Health-technology-development is more than designing, engineering a good “thing” or stand alone device, it is about creating an infrastructure for communication and the organization of care.

Technology a catalyst to create an infrastructure for improving service; technology not a purpose in it self.
Answering the “What Works?” Question in Health Behavior Change

Gregory J. Norman, PhD

What are the capacities of technology to motivate, inspire?
Persuasion via social media.

- Persuasive technologies to increase adherence, SOME to trigger, to remind, to educate

- “Healthy Mouth Means Healthy Life, and Healthy sex”
IMPACT ON ADHERENCE VIA PERSUASIVE TECHNOLOGY

SoMe tech, CoDesign motivates
3 Technology that inspires and motivates to safe behavior
Co-creation of an Antibiotic Stewardship Program

Shift from protocols to a dashboard for communication

- awareness, education, cooperation, outbreak management
Implementation of an Antibiotic Stewardship Dashboard

- **Business Modelling**
- Critical factors of adherence, risks, and costs
- Establishing the business case

Shift from protocol-driven thinking to an infrastructure for better management of antibiotics
Methods To ground eHealth

To know Why and How technology can make a difference- or not- in healthcare:

- longitudinal process studies (focus on drop-outs & persistence )
- observations of real-time usage (user-profiles)
- evaluation methods to know how technology evolves over time
- experiments to put persuasion into technology (tech-profiles)
- Robust evaluation methods to measure effects; a bird’s eye view on the impact of technology on healthcare (human, legal, ethical challenges, cost-benefits)
Benefits of the Framework

CO-CREATION OF A WEB-BASED COMMUNICATION SYSTEM; 2008
I think people know too little about MRSA, which leads to much uncertainty. The website can help in here.
Benefits of the eHealth framework

- Technology no stand alone device, but a catalyst for innovations, new way of thinking how to support healthcare via technology in a Digital Society
- Better adherence to safe behavior via co-creation
- Better implementation via stakeholders’ involvement /investment
- Staff, patients can manage IT; participation=motivation
- eHealthwiki, instruments to judge the true value of eHealth interventions (overall impact)
- eHealth-education-roadmap (students & caregivers, developers)
Thanks..

Contact: dr. J (Lisette) van Gemert-Pijnen
J.vanGemert-Pijnen@utwente.nl
www.ehealthresearchcenter.nl
Leaflets CeHRes (registration desk)
EVERYTHING THESE DAYS IS DOT-COM THIS AND DOT-NET THAT! I JUST CAN'T STAND IT ANYMORE!!!

I KNOW A WEB SITE THAT CAN HELP YOU...
Expert driven eHealth models
(review Van Gemert-Pijnen, Nijland et al)

Design models: ISO 13047 “Human-centered design processes for interactive systems

No HOT-Fit

No social context

IT is a black box

No instruments

No project management

No participation
Benefits of the eHealth framework

- Technology no tool or end in it self, but a catalyst for innovation
- Investments through stakeholder-engagement (commitment, trust, power)
- Participatory development (staff, patients that can manage IT)
- Human touch, High Impact via user-engagement
- eHealthwiki, instruments to judge the true value of eHealth interventions (overall impact)
Benefits, human centered and value driven framework

- Technology no tool or end in it self, but a catalyst for innovation,

- Development= creating an infrastructure for service management

- Human touch, High Impact via engagement

- eHealthwiki, instruments to judge the true value of eHealth interventions (total impact)
Why Technology has limited value..

- Supply-driven technology disregards needs and demands (frustration)
- Medical-driven technologies have a focus on ill-management apps, not on well-being and lives to live (ceiling effects; drop outs)
- Absence of adequate business models hinder up-scaling (unclear who benefits)
- Shortage of fully qualified eHealth professionals (no fit between offline-online care;)
- Lack of HOT-fit (shadow-organisation)
Persuasive technology and personalities  (Halko & Kientz, 2010)

- More or less persuadable (Big Five Personalities)
- Conscientiousness successful for tech-persuasion (realising goals)
- Extraversions hard to persuade via tech
- Openness more likely to favour competitive or authoritative tech
- Agreeableness not very successful to persuade via tech
- Neuroticism no cooperation, enjoyment of negative reinforcement

*Technology fits with personalities*
Need for participatory development

- “success in achieving change is enhanced by the active participation of members from the target user groups [...] to ensure that planners have a structure in place to engage system end-users effectively from the start.” (Kukafka, 2003)

- “There is a need for evaluation research at each stage of development and implementation, from conception to the routine operational use” (Kaufman, 2006)

- The ability of eHealth to empower consumers, support dynamic information exchanges among organizations, and “flatten” organizational hierarchies might result in a need for new organizational strategies, business models, service delivery models, and management mechanisms.” (Ganesh, 2004)
Co-creation via participation of users, stakeholders

- **Human-centered**
  - Usability theories (smart, simple)
  - Persuasive technology (motivation, empathy)
  - Health behavioral theories (self-control, adherence)

- **Value-driven**
  - Holistic model (*fit between human, technology, organization*)
  - Business modelling for value creation
  - Participation of key-stakeholders during development process
Integration of 4 levels; holistic approach eHealth

Table 1
Challenges associated with eHealth research

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Major challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design and methodology</td>
<td>Deductive vs. inductive approach</td>
</tr>
<tr>
<td></td>
<td>Randomization of subjects and/or technology</td>
</tr>
<tr>
<td></td>
<td>Clinician buy-in and commitment</td>
</tr>
<tr>
<td></td>
<td>Recruitment of subjects</td>
</tr>
<tr>
<td></td>
<td>The “digital divide” as a source of bias</td>
</tr>
<tr>
<td>Technology</td>
<td>Technical requirements related to the hardware and software</td>
</tr>
<tr>
<td></td>
<td>Infrastructure and resources needed to support the technology</td>
</tr>
<tr>
<td></td>
<td>Vendor relations and support</td>
</tr>
<tr>
<td></td>
<td>Staff, subject training</td>
</tr>
<tr>
<td></td>
<td>User satisfaction with the system and the project</td>
</tr>
<tr>
<td></td>
<td>Overall system maintenance</td>
</tr>
<tr>
<td>Environmental</td>
<td>HIPAA regulations</td>
</tr>
<tr>
<td></td>
<td>IRB requirements</td>
</tr>
<tr>
<td></td>
<td>Funding/reimbursement for services provided</td>
</tr>
<tr>
<td>Logistical</td>
<td>Roles and responsibilities of a multi-disciplinary team</td>
</tr>
<tr>
<td></td>
<td>Procedures for data collection</td>
</tr>
<tr>
<td></td>
<td>Communications</td>
</tr>
</tbody>
</table>

HIPAA, Health Insurance Portability and Accountability Act; IRB, Institutional Review Board.

K.H. Dansky et al, 2006
eHealth “a way of thinking about supporting health by technology”

- “eHealth is not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve healthcare locally, regionally, and worldwide by using information and communication technology.” (Eysenbach, 2001)
IMPACT ON ADHERENCE VIA PERSUASIVE TECHNOLOGY