The metered self vs. managed healthcare IoT - a reality check

Are managed sensor networks in healthcare threatened by the quantified self wave?

Dr. Lothar Fritsch

Norwegian Computing Center

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Quantified self – a new concept?

Just a new form of shared social media narcissism?

A form of identity reassurance in the times of lost traditions?

«Dataism» or «Transhumanism» or «datasexuality»?

http://spectrum.ieee.org/at-work/test-and-measurement/meet-the-datasexual

Body imagery by Krisitan Hammerstad, Magasinet Plot nr. 18, Feb/Mar 2014, «Ny-narsissistene», pp.78, ISSN 1892-4417
Fertility Friend iPhone app

Easy tool to predict your menstrual cycle

http://www.fertilityfriend.com/iphone/

FertilityFriend.com’s Menstrual Calendar is a simple and easy to use calendar designed to predict your menstrual cycles and possible fertile days.

TAGS: menstruation

Posted on May 26, 2011
Will Apple know more about her intentions and pregnancy status than her partner? How will they use this information?
People sharing jogging data in public

Public data on RunKeeper.com

http://flowingdata.com/2014/02/05/where-people-run/
People sharing jogging data in public

Will people share their vital data or rehabilitation exercise on social media with do-it-yourself privacy by default?

Public data on RunKeeper.com

http://flowingdata.com/2014/02/05/where-people-run/
Dieting, health or goal journals

The Fitbit family motivates you to stay active, live better, and reach your goals.

Wireless Trackers • Aria™ Wi-Fi Smart Scale • Mobile Tools •

We'll help you achieve what you set out to do, by sharing a full picture of your progress over time.

Logged Activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Distance</th>
<th>Duration</th>
<th>Cals</th>
<th>Fav</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aerobic step</td>
<td>N/A</td>
<td>45 minutes</td>
<td>355</td>
<td></td>
</tr>
<tr>
<td>6 - 8 inch step</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual Activity, Passive, light effort, kissing, hugging</td>
<td>N/A</td>
<td>10 minutes</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Sexual Activity, Active, vigorous effort</td>
<td>N/A</td>
<td>15 minutes</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Sitting quietly and watching television</td>
<td>N/A</td>
<td>1 hour</td>
<td>56</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>N/A</td>
<td>2 hours 10 minutes</td>
<td>441</td>
<td></td>
</tr>
</tbody>
</table>

Fitbit.com, July 2011: Calorie & activity tracker site open to Google search by mistake
Medication dosage optimization

Baseline tapping tests incl control (bars=medication, lines=tapping data)

http://quantifiedself.com/2013/02 qs-europe-2013-conference-preview-sara-riggare/
Blod sugar live status monitoring

Additionally, it may be that access to such detailed information about blood glucose patterns will be misused by women intent on using hyperglycemia for caloric purging.


Diabetes and Eating Disorders, Ann E. Goebel-Fabbri, Ph.D.
When crisis data hits the public

- User with lots of data hae a tendency to share data in personal crisis situation, e.g. by posting journals
- Serious problem for medical privacy
- The Norwegian Cancer Society (Kreftforeningen) has developed a guidebook and «traffic light» system for social media use for its volunteers.
  - No discussion of personal medical issues in social media
  - People who are emotional get called
Stakeholder perspectives

Users

Health Profession

Privacy Expert
Health professional perspective

► Self-Metering
  - Thin scientific grounds in theory
  - Data interpretation by amateurs
  - Focus on wrong issues
  - Might do damage
  - Unreliable configuration, function and use
  - Hard to manage in a hospital setting with privacy & quality requirements

► Health systems
  - Used for proven therapy
  - Data interpreted by professionals
  - Modification or termination when issues arise
  - Potentially unreliable technology
  - Creates privacy issues
  - Wrong allocation of budgets to hi-tech with short history

Health professional perspective

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Jessica Raymond, founder of Rise Up: Overcome Your Eating Disorder, is an oceanographer by profession with a passion to help others recover as she herself has. Jessica found that daily self-monitoring help her be accountable to herself and her providers. She created Rise Up, a free app available on iTunes.

User perspective

► Self-Metering
  ▪ Playfull
  ▪ User control
  ▪ Demonstratable
  ▪ Reactive
  ▪ Reinforcing
  ▪ Self-assessment and comparison
  ▪ Make you look cool and tech savvy
  ▪ «Fix it now»

► Health systems
  ▪ Use regulated
  ▪ Purposeful
  ▪ Tiring security infrastructure
  ▪ Complicated data
  ▪ Hard to explain
  ▪ Make you look sick
  ▪ Makes feel dependent on doctor
Privacy perspective

► Self-Metering
  - «free» services accumulate and sell information
  - Unknown quality of security and privacy measures, staff reliability or protection from espionage
  - Data export into other legislation

► Health systems
  - Under national data protection supervision, often with specific laws
  - Standards for security and privacy
  - Qualified personell (in IT, at least)
  - But: Ignorant and pragmatic health personell
Roles and responsibilities

► Self-Metering

- Default policies set by vendors and service providers
- Encourage sharing
- Fluffy privacy guarantees
- User decides, mostly «share or no service» options. Social media policies
- Data sharing with companies and advertisers
- Pay a fee for more privacy

► Health systems

- Regulated roles concerning data access and technical maintenance
- Strong data protection
- Strong availability focus
- Various roles in medical and care scenarios
- Data not always accessible to patients
Evaluation (I)

► Self-metering equipment is used in ad-hoc ways, often with little (medical) scientific verification of the claimed benefits

► Those technologies are very appealing to users due to the perceived empowerment (see E.Rogers, Diffusion of Innovations)

► Self-metering as of today puts all the burden of security and privacy evaluation on the end user. Most systems operate outside the European regulation frameworks for e-health or data protection

► Some applications are beneficial to users already

► Most health apps are used for a few weeks only.
Evaluation (II)

- Managed e-health systems can provide better managed security for users (if done right)
- Managed e-health systems can ensure a silo approach to health data
- In contract, self-metering social media are part of the prosumer economy turning patient’s data into commodities for commercialization [1]
  - However, a public health database actually gets commodified by the research hospitals and their industry project partners.

Lupton, Deborah: The Commodification of Patient Opinion: the Digital Patient Experience Economy in the Age of Big Data; Sydney Health & Social Group Working Papers 3; 4-May-2013; http://hdl.handle.net/2123/9063
“The use of m-health in health promotion extends the temporal nature of health surveillance, and allows for further refinements of the categorising and identifying of ‘risk factors’ and ‘at-risk groups’ that are then deemed eligible for targeting. Health-related data may easily and frequently be collected from users’ mobile devices each time they log on to the relevant app. Such devices thus offer an unprecedented opportunity to monitor and measure individuals’ health-related habits. These technologies are now becoming used not only to facilitate medical supervision and monitoring of ill bodies, but into the realm of well bodies in the attempt to prevent illness and disease.”

The ideal user

“So too, the m-health discourse in health promotion represents people as willing to take on responsibility for promoting their health using these latest technologies, to the point that they are happy to receive regular messages on their smartphone or to have their health habits and behaviours continuously monitored and assessed. This is a body/self configured as requiring, and in fact desiring, of constant digital surveillance. It conforms to the entrepreneurial, self-regulating subject that is represented as the ideal responsible citizen in neoliberal societies.”

Questions & Discussion