Norsk Regnesentral
NORWEGIAN COMPUTING CENTER

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

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

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Norwegian Computing Center

ASSET project workshop, Finse, Norway

27. Feb. 2014

Contents

- The Quantified Self
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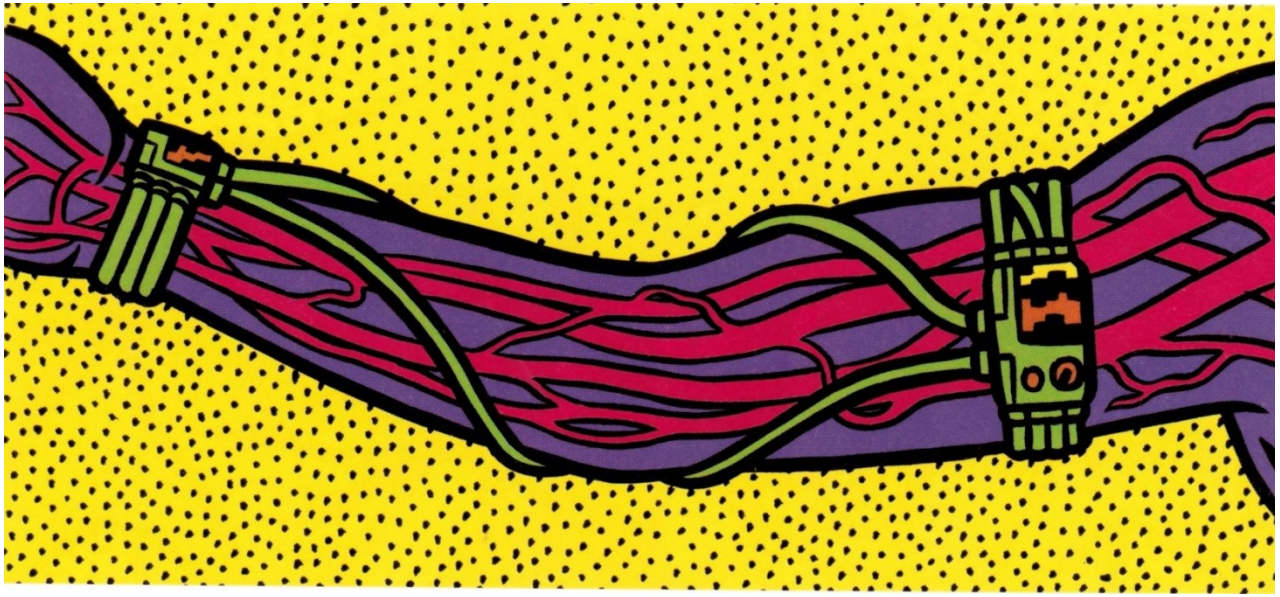
- Evaluation & Sumary

Quantified self – a new concept?



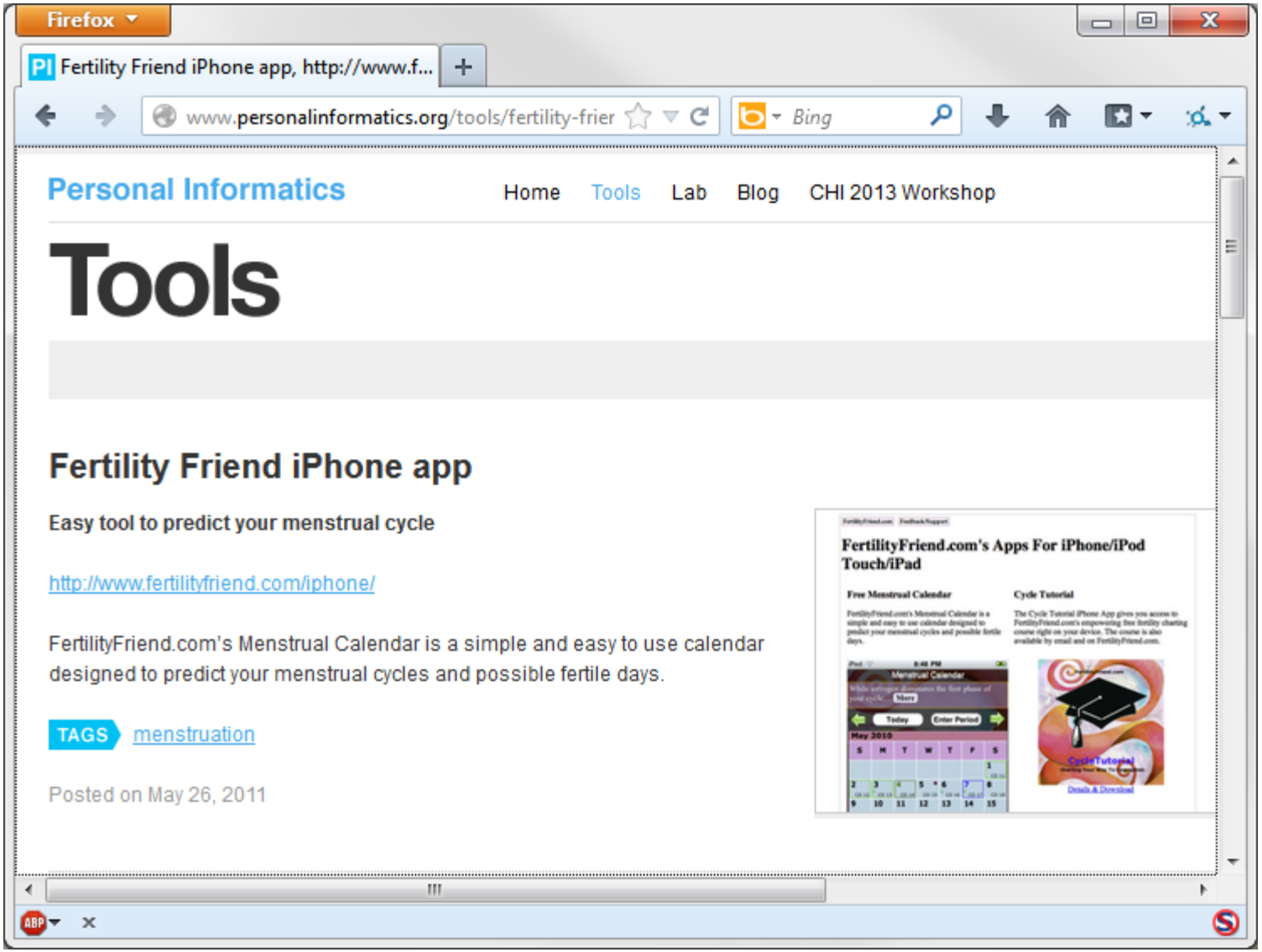
Just a new form of shared social media narcissism?

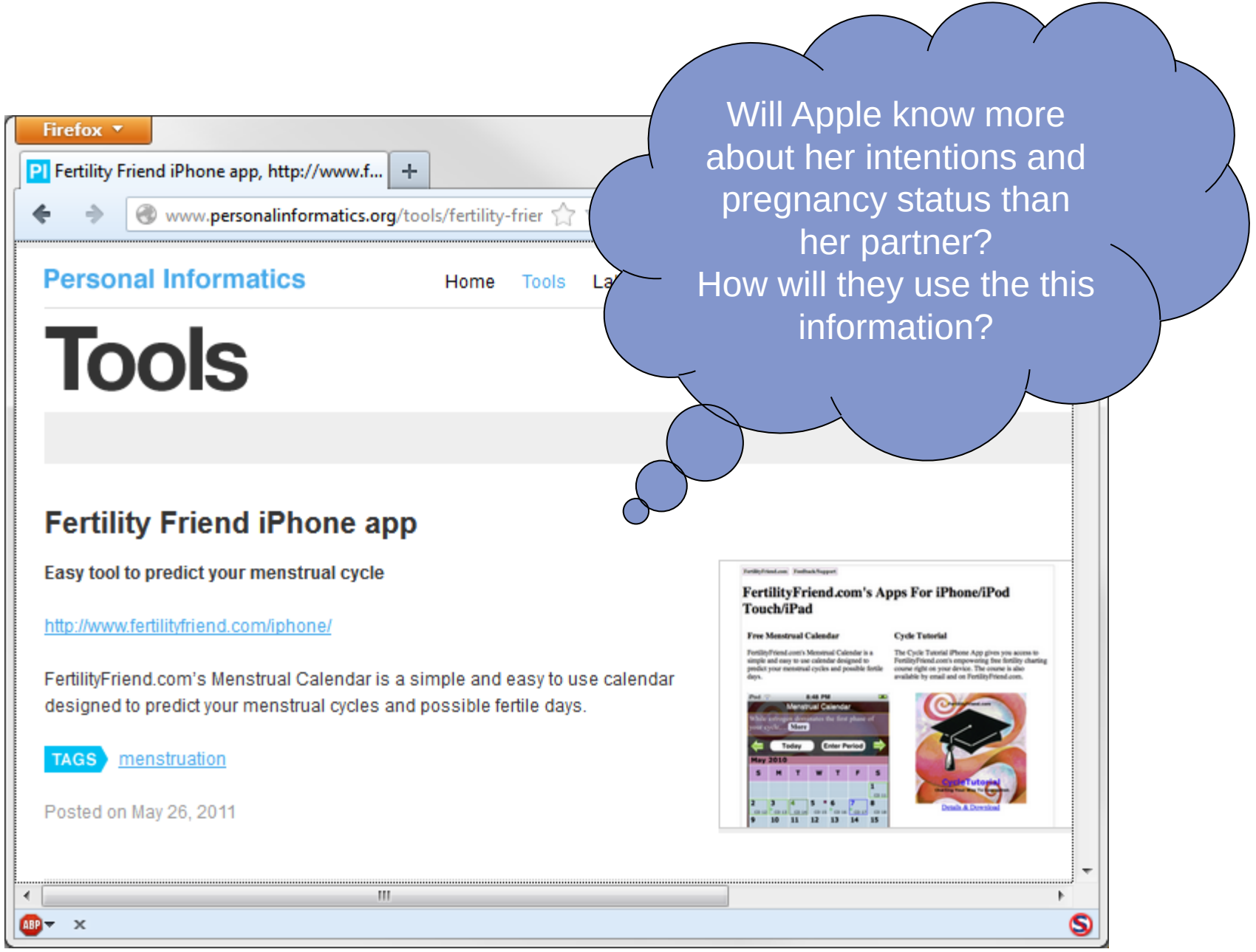
A form of identity reassurace in the times of lost traditions?

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

http://www.zeit.de/digital/internet/2013-09/big-data-han-dataismus
http://reason.com/archives/2004/08/25/transhumanism-the-most-dangero?
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


Firefox
Fertility Friend iPhone app, http://www.f...
www.personalinformatics.org/tools/fertility-frier
Bing
Personal Informatics
Home
Tools
Lab
Blog
CHI 2013 Workshop
Tools
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
FertilityFriend.com's Apps For iPhone/iPod Touch/iPad
Free Menstrual Calendar
Cycle Tutorial


Will Apple know more about her intentions and pregnancy status than her partner?
How will they use the this information?
Firefox
Fertility Friend iPhone app, http://www.f...
www.personalinformatics.org/tools/fertility-frier
Personal Informatics
Home
Tools
Tools
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.
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People sharing jogging data in public

Public data on RunKeeper.com

http://flowingdata.com/2014/02/05/where-people-run/

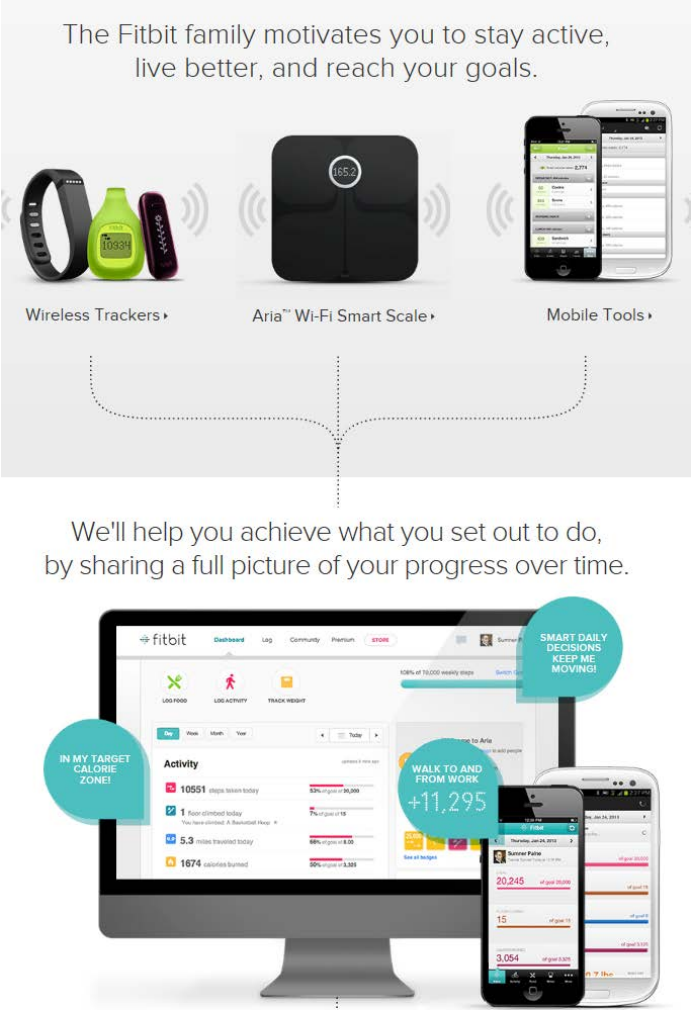
People sharing joggin

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

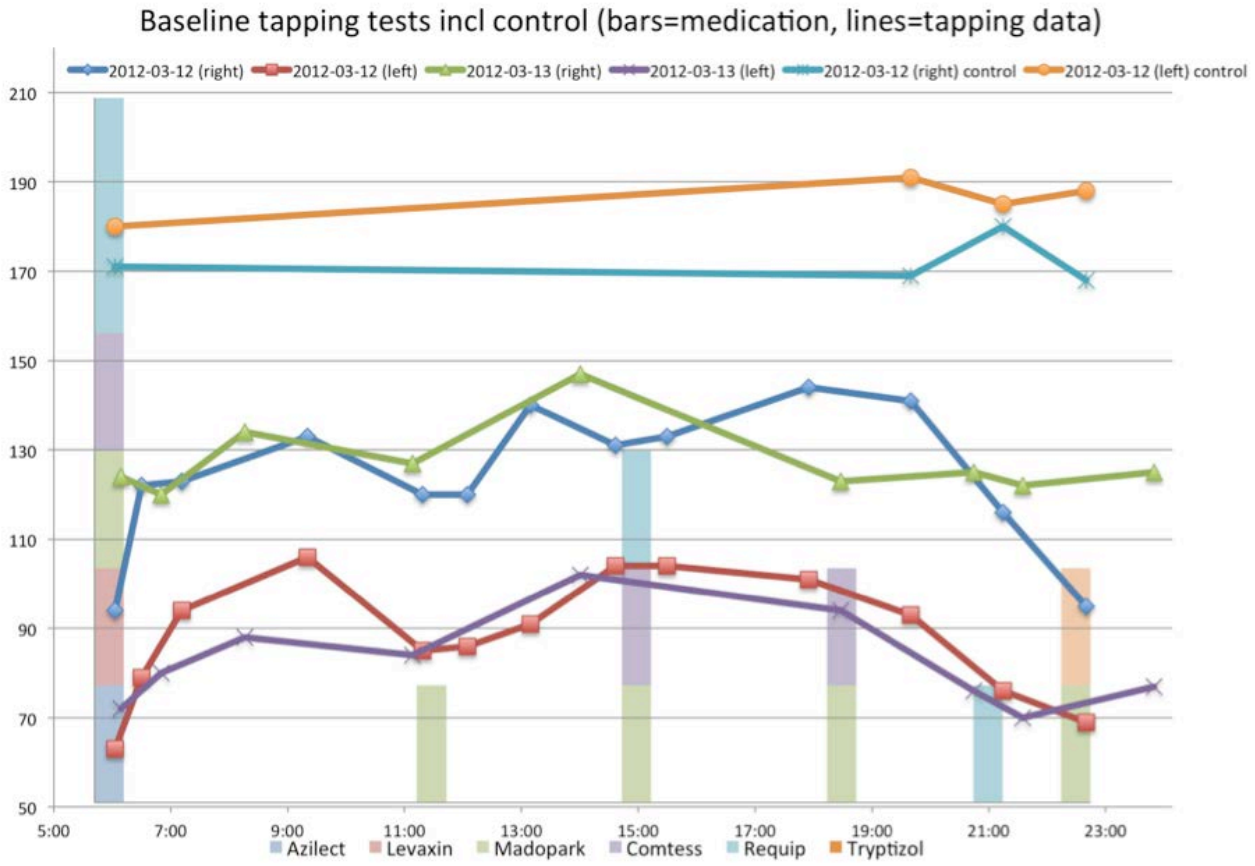


Logged Activities — Tue, Feb 2 — Select

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

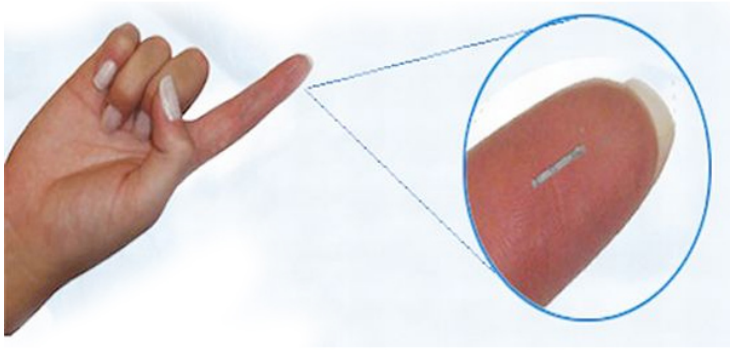
Fitbit.com, July 2011: Calorie & activity tracker site open to Google search by mistake

Medication dosage optimization



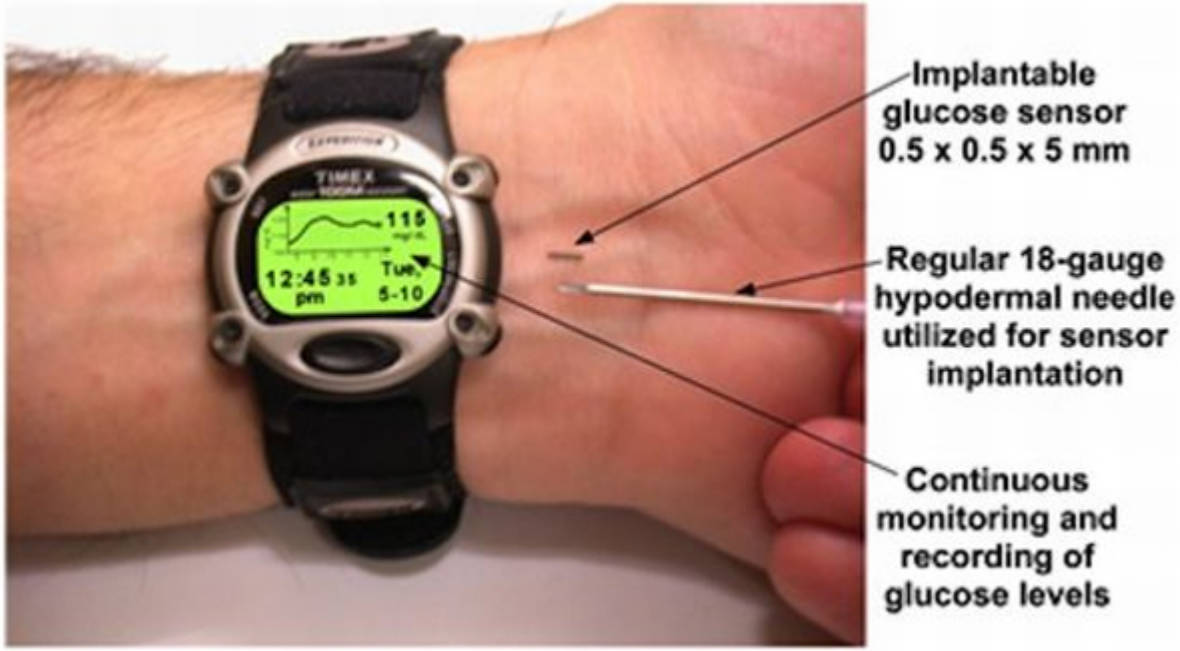
http://quantifiedself.com/2013/02/qs-europe-2013-conference-preview-sara-riggare/

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.

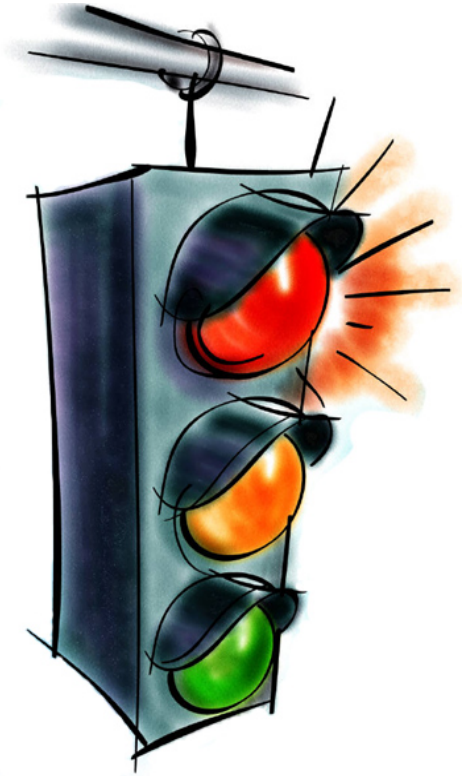
J Diabetes Sci Technol. 2008 May; 2(3): 530–532.
Published online 2008 May.
Diabetes and Eating Disorders, Ann E. Goebel-Fabbri, Ph.D.



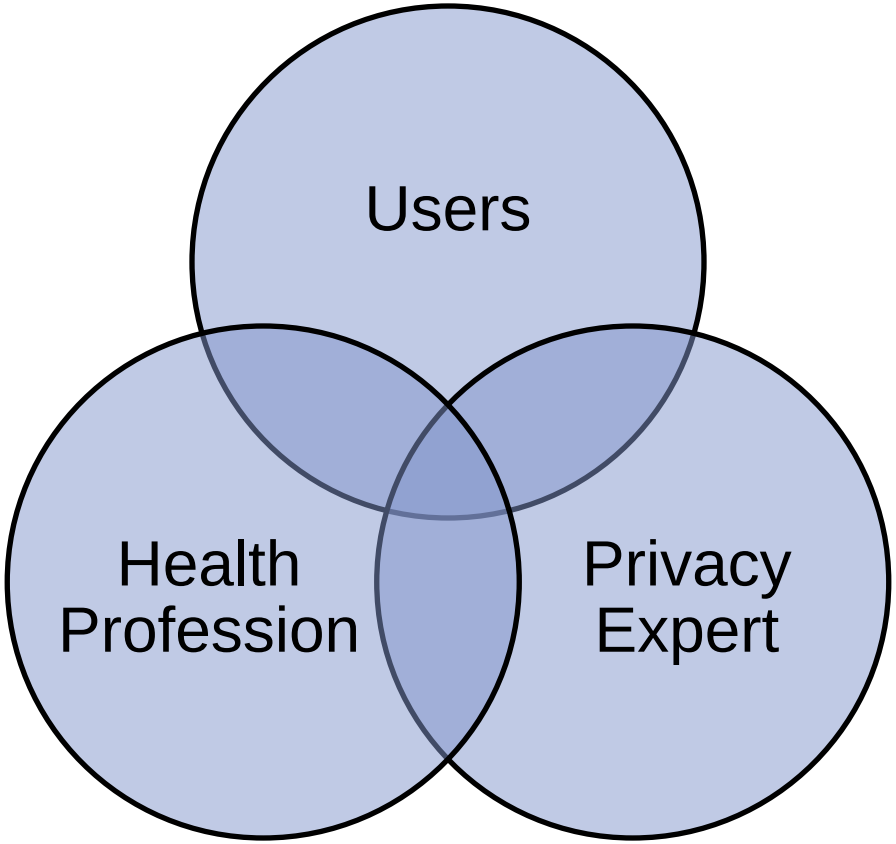
http://www.geeky-gadgets.com/glucowizzard-implant-sensors-monitors-blood-glucose-levels-03-03-2010/

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



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 temination when issues arise
  - Potentially unreliable technology
  - Creates privacy issues
  - Wrong allocation of budgets to hi-tech with short history

Quote: http://www.psychologytoday.com/blog/eating-disorders-news/201402/self-monitoring-apps-recovery-record-or-rise

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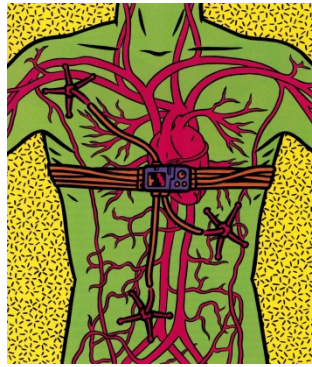
Jessica Raymond, founder of *Rise Up: Overcome Your Eating Disorder*, is an *oceanographer* by profession with a passion to help others recover as she herself has. Jessica found that daily self-monitoring help her be accountable to herself and her providers. She created *Rise Up*, a free app available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

Quote: http://www.psychologytoday.com/blog/eating-disorders-news/201402/self-monitoring-apps-recovery-record-or-rise

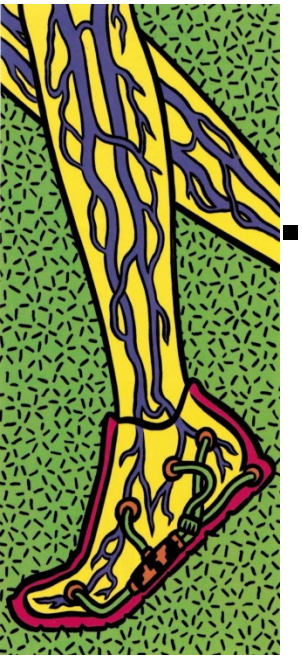
User perspective

- Self-Metering
  - Playfull
  - User control
  - Demonstratable
  - Reactive
  - Reinforcing
  - Self-assesment and comparision
  - Make you look cool and tech savy
  - «Fix it now»
- Health systems
  - Use regulated
  - Purposeful
  - Tiring security infrastructure
  - Complicated data
  - Hard to explain
  - Make you look sick
  - Makes feel dependend 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 regualtion 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.

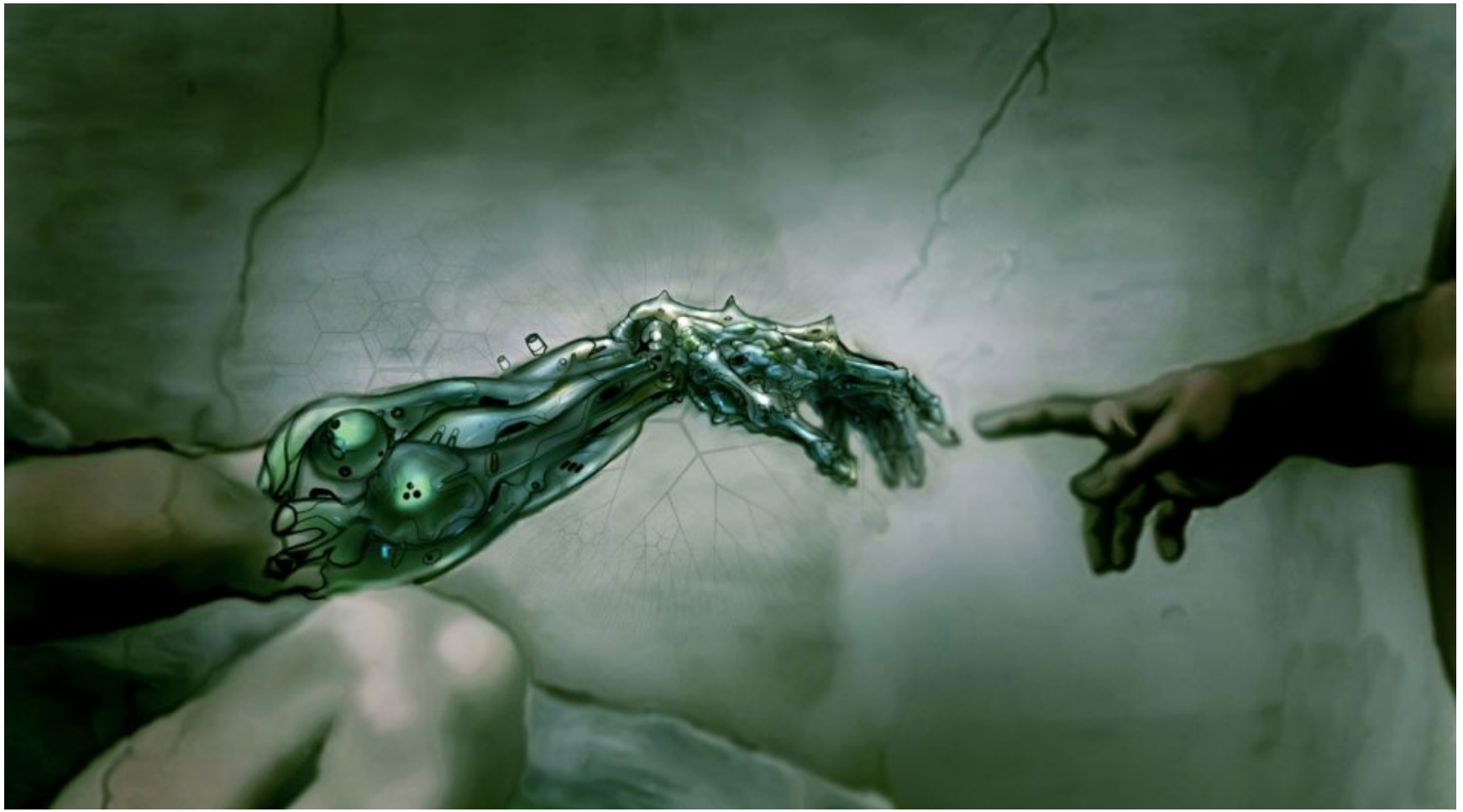
Lupton, Deborah: The Commodification of Patient Opinion: the Digital Patient Experience Economy in the Age of Big Data; Sydney Health & Social Group Working Papers 3; 4-May-2013; http://hdl.handle.net/2123/9063

“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.”

Deborah Luptona: M-health and health promotion: The digital cyborg and surveillance society; Social Theory & Health (2012) 10, 229–244. doi:10.1057/sth.2012.6; published online 27 June 2012 http://www.palgrave-journals.com/sth/journal/v10/n3/full/sth20126a.html

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."

Deborah Luptona: M-health and health promotion: The digital cyborg and surveillance society; Social Theory & Health (2012) 10, 229–244. doi:10.1057/sth.2012.6; published online 27 June 2012 http://www.palgrave-journals.com/sth/journal/v10/n3/full/sth20126a.html

Questions & Discussion