The disruptive power of gathering your own data
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3-7-2015
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• As a result of self monitoring
  – Increased autonomy
  – New patient-GP interaction
  – Lowering of medicine intake!
QS Community

- Founded in 2007 by Gary Wolf and Kevin Kelly
- 2010: TED talk by Gary Wolf
- 2011: First international conference California
- May 2015: 206 groups in 38 countries
- Almost 50 k people active worldwide
Personal Meaning to Personal Data

Quantified Self
Netwerk Organisation

• To encourage a healthy lifestyle through technology, science and fun.
• Focus on ‘the big five for healthy life’
  – Physical activity & sports
  – Food
  – Sleep
  – Stress & relaxation
  – Social interaction
• Availability, Creativity, Validity and Efficacy
• Applied research, higher education & new business development
Healthy Ageing

Ageing is an ongoing process. "Ageing starts at fertilization."
All about data…

A huge amount of personal data…

And a lot of stakeholders.

Self-tracking; for personal reason

Self-tracking; at request of health care provider

Bring Data

Adapted from: www.nictiz.nl
Sharing data

Individual data
(n=1)

Quantified Self
Useful to you

Quantified Us

Quantified Other
Useful to others

Citizen Science

Group data
(n>1)

http://www.digitalezorggids.nl/blog/quantified-self-quantified-us-quantified-other
Patients like me

Kidnee
Female, 36 years
Atlanta, GA

Timeline
- Kidney Transplant: Sep 23, 2007

Symptoms
- Severe Symptoms:
  - None
  - Mild
  - Moderate
  - Severe

Treatments
- Purpose of Treatment:
  - Prevent organ rejection
  - Specific symptoms
  - General health
  - Other

Weight
- BMI: 25
- Healthy: 130-185 lbs
- Underweight: 100-125 lbs
- Normal: 126-149 lbs
- Overweight: 150-169 lbs
- Obese: 170 lbs and above

Blood Pressure
- Top (Systolic): 0-129
- Bottom (Diastolic): 0-89

Labs & Tests
- Outside normal
- Lab test normal

Kidney Transplant
- Kidney-related Conditions:
  - Hypertension
  - Post-infectious glomerulonephritis
- Transplant: 09/23
- First listed: 05/01

Prescription Drug
- Anti-rejection:
  - CellCept
  - Tacrolimus
  - Mycophenolate
  - Azathioprine
- Antibiotics:
  - Cefazolin
  - Vancomycin

Last weight: 172 lbs
Last update: May 23, 2015
Last visit: May 16, 2015

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Quantified Us
Points of interest and debate

• Quality of the data  
  (validity and reliability)

• Data sharing  
  (usability and interoperability)

• Privacy, safety, legality and incentives  
  (data access and control)
Thea Kooiman

Oefentherapeut / Bewegingswetenschapper

Onderzoeker Lectoraat Healthy Ageing, Allied health care and Nursing.
Reliability and Validity of ten consumer activity trackers.

1 = Fitbit Zip
2 = Misfit Shine
3 = Nike+Fuelband
4 = Omron
5 = Withings Pulse
6 = Fitbit Flex
7 = Digiwalker SW-200
8 = Lumoback
9 = Jawbone Up
10 = Moves app

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Results – Lab condition

Mean number of steps walked (95 % CI), measured in the Lab condition.
Conclusion

- All trackers showed good reliability, except for the Omron, Nike+Fuelband and Moves app.

- In the lab situation, the Fitbit Zip, Lumoback, Withings Pulse, Misfit Shine and Jawbone Up showed the highest validity.

- Nike+ Fuelband and Moves app: low validity

- In the field situation, the Fitbit Zip showed the best validity.
"At last we’ve reached a consensus! This meeting is boring!"
The day before tomorrow

- Preventive and predictive
- Personalised
- Participatory

Source: www.p4mi.org