



Patient generated information, the
quantified self and consequences for
healthcare

2016-03-16

V1.0

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Conflict of interests



- Joakim Söderberg
 - Presentation contains data from an adherence program sponsored by Sanofi Aventis
 - Presentation contains data from a decision support system owned by Karolinska Hospital, Stockholm
 - Presentation contains description of a decision support system owned by Östergötland County Council with functionality sponsored by AbbVie and Telia

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Questions



- Are we ready to start using data from quantify self like concepts in our daily worklife?
- Are the legal aspects to do so in place?
- Will quantify self like concepts be an important part of your work within five years time?

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Quantified self according to Wikipedia



The Quantified Self is a movement to incorporate technology into data acquisition on aspects of a person's daily life in terms of inputs (e.g. food consumed, quality of surrounding air), states (e.g. mood, arousal, blood oxygen levels), and performance (mental and physical). Such self-monitoring and self-sensing, which combines wearable sensors (EEG, ECG, video, etc.) and wearable computing, is also known as lifelogging. Other names for using self-tracking data to improve daily functioning are "self-tracking", "auto-analytics", "body hacking", "self-quantifying", "self-surveillance", and "Personal Informatics". In short, quantified self is self-knowledge through self-tracking with technology.

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Star Trek Tricorder



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Real life 2016 in a hospital near you



UNIVERSAL CHILD HEALTH RECORD

Section 1: Patient Information (Name, Date of Birth, Sex, etc.)

Section 2: Medical History (Allergies, Previous Illnesses, etc.)

Section 3: Physical Examination (Vital Signs, Head, Neck, Chest, etc.)

Section 4: Laboratory Results (Blood Tests, Urine Tests, etc.)

Section 5: Immunization Record (Vaccination Dates, etc.)

Section 6: Developmental Milestones (Gross Motor Skills, Fine Motor Skills, etc.)

Section 7: Social History (Family, School, etc.)

Section 8: Physician's Notes (Diagnosis, Treatment, etc.)

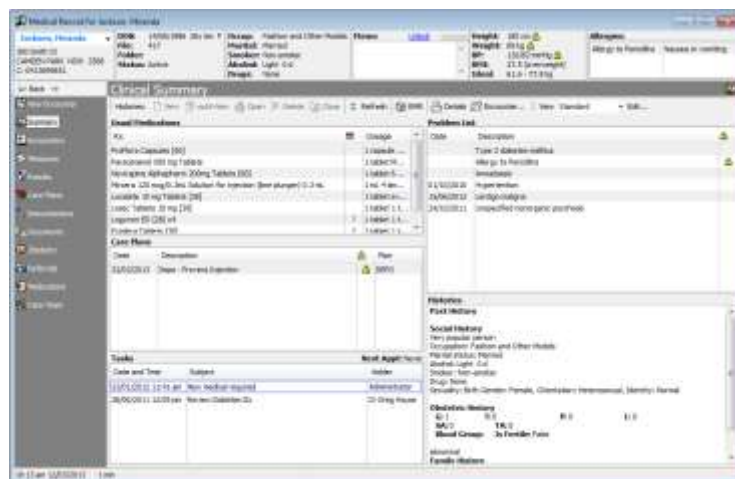
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Real life 2016 in a hospital near you



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Real life 2016 in a hospital near you



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Coexisting realities



Society at large



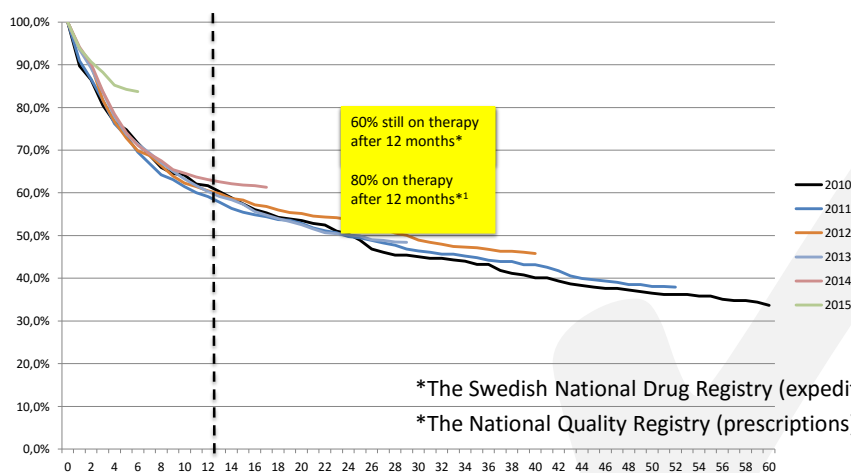
Healthcare



You

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Are we using the information we have?



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RealQ[®] **InfCare HIV** [demo] • Logged in as: Stephen Bollenberg [Sign out] Health Solutions

Home » Find studies » Find data » Patient data between member » Administration » **Study summary** » Search tool » Export »

Summary - all care units

Filter: **Study** **Site** **Demographics** **100000**

Filter	Count	Percentage
Total number of active patients ¹	1379 patients	
Number of new/returning Data Patients	Proportion: 52.6 % (218 of 1379 patients) 56.1 % (143 of 1179 patients)	
Patients with a first positive HIV serology	Share: 157 patients	
Reported patients with a new HIV diagnosis	Share: 3 patients	
Unexposed patients	Share: 33 patients	
Never patients	Proportion: 13.4 % (143 of 1379 patients)	
Treated patients	Proportion: 96.3 % (1331 of 1379 patients)	
Patients with a "drug holiday"	Proportion: 1.7 % (22 of 1278 patients)	
Patients who have been treated at least 0 months, $RNA < 10^3$	Proportion: 86.8 % (345 of 858 patients)	
Patients who have been treated at least 0 months, $RNA 99-199$	Proportion: 6.3 % (113 of 858 patients)	
Patients who have been treated at least 0 months, $RNA > 200$	Proportion: 7.1 % (81 of 858 patients)	
Patients who have been treated at least 0 months, $CD4 < 350$	Proportion: 1.6 % (16 of 858 patients)	

Are we using the information we have?



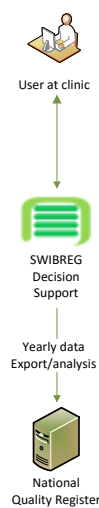
- No!

Patient Management System Evolution (IBD), 1



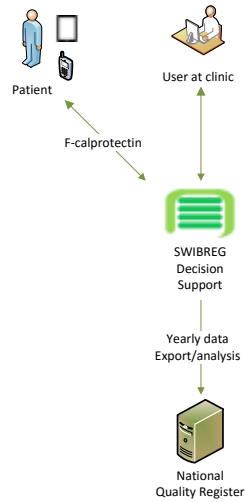
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Patient Management System Evolution (IBD), 2



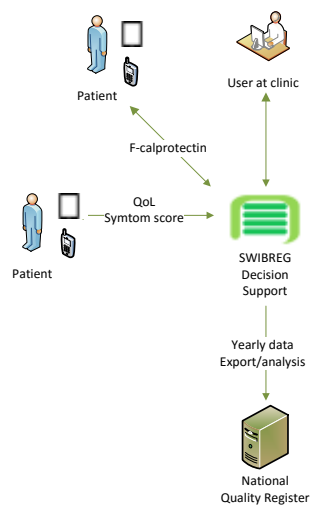
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Patient Management System Evolution (IBD), 3



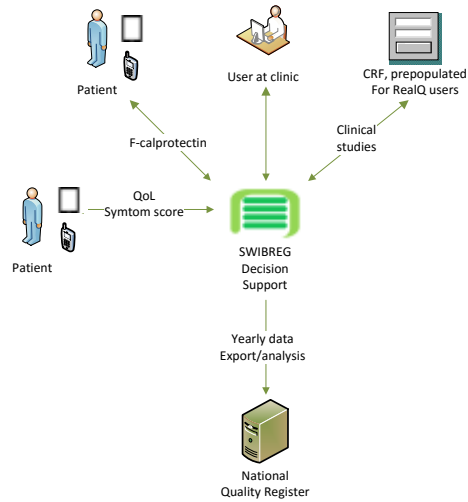
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Patient Management System Evolution (IBD), 4



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Patient Management System Evolution (IBD), 5



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Legal Evolution



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Legal Evolution, 2



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Legal Evolution, 3



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Legal Evolution, 4



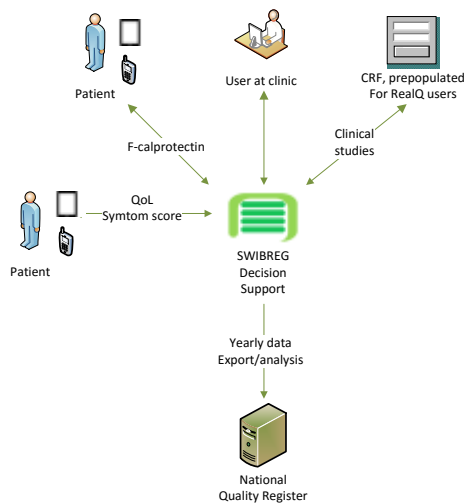
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Legal Evolution, 5



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Patient Management System Evolution (IBD), 5



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Sara Riggare



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Sara Riggare



"I see my neurologist twice a year, about half an hour every time. That's one hour per year in healthcare for my Parkinson's disease. During the same year I spend 8,765 hours in selfcare, applying my knowledge and experience together with what I get from my neurologist to manage a difficult condition as best I can"

<http://www.riggare.se/>

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Coexisting realities



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Wikipedia again



Identity politics are political arguments that focus upon the interest and perspectives of groups with which people identify. Identity politics includes the ways in which people's politics may be shaped by aspects of their identity through loosely correlated social organizations. Examples include social organizations based on race, class, religion, gender, gender identity, ethnicity, ideology, nation, sexual orientation, culture, information preference, history, musical or literary preference, medical conditions, professions or hobbies. Not all members of any given group are necessarily involved in identity politics.

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Wikipedia again



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Conclusions



- Quantified self and patient generated data are here to stay
- Technical development will facilitate and improve
- The medical infrastructure is not ready
- The medical professions are not ready

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Future



- A relatively long problematic period
- Hierarchical authoritarian healthcare culture meets strong individualists with high belief in their knowledge and their data
- Not all patients are Sara but the identity politics leads to that many believe that they are

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Almost last slide, what do we need to do?



- Don't focus on technology
 - It will take care of itself
- On a society level, adapt to the new reality
 - Legal aspects
 - Integrity aspects
- On a professional level
 - Education on all levels
 - Attitudes and hard decisions

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