



Ministry of Health, Welfare and Sport

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What trade-off?

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*Ministry of Health, Welfare and
Sport*

The Netherlands

#pinksocks



A patient and caregiver included movement to improve health care

A man with short brown hair and a prosthetic right arm is seated in a black office chair. He is wearing a white t-shirt under a light-colored, textured blazer. A small black lapel microphone is clipped to his shirt. He is looking slightly to his right with a thoughtful expression. The background is a solid dark blue-grey color.

We moeten ermee dansen.
Dan wordt het opgelost.



eHealth = regular healthcare

From the waiting room to the living room

Cold technology for warm care

Low-tech, high impact

Everybody CEO of their own health



Dutch ambitions on eHealth

1. By 2019 80% of the chronically ill have **direct electronic access to some of their medical data**, such as medication data, vital functions and test results, and is able to use this data in mobile apps or internet applications.
2. Of the chronically ill (diabetes, COPD) and vulnerable elderly 75% who are willing and able can **take their own measurements** by 2019, mostly in combination with remote monitoring by a professional.
3. By 2019 everyone in need of care at home will be able to **communicate by video with their care professional remotely 24 hours a day**. Also, smart home technology will be used to support home care.



Flourishing ecosystem



Health deals

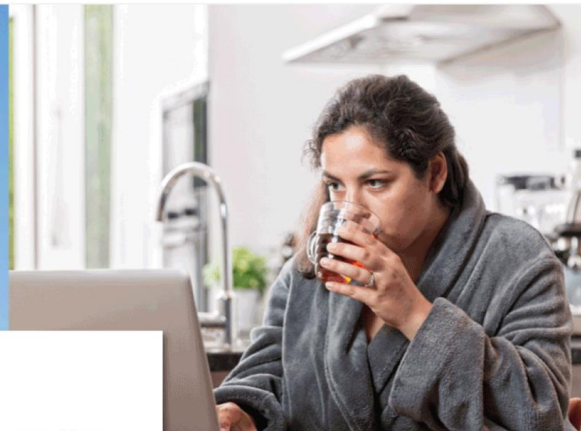
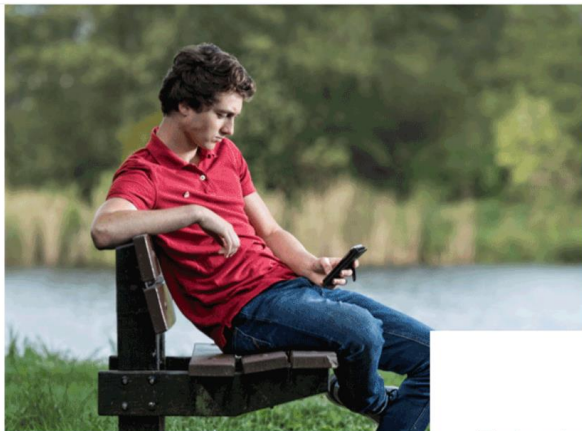
Decision support for oncology
Chronic pain management
Academy The Village “Het Dorp”





ehealthWEEK2017

21 T/M 27 JANUARI

[HOME](#)[ACTIVITEITEN](#)[NIEUWS](#)[PARTNERS](#)[PATIENTS INCLUDED](#)[OVER](#)

e-healthweek 2017

Technologie vindt steeds beter zijn weg naar de woonkamer. Hoe maak je zinvol gebruik van de technologische mogelijkheden, of je nu zorg ontvangt of verleent? Tijdens de e-healthweek 2017 hebben meer dan 200 partners diverse activiteiten georganiseerd om te laten zien wat e-health is en hoe e-health werkt.



Fast track eHealth





**HEALTH
INNOVATION
SCHOOL**



**BUILDING
THE FUTURE OF
DUTCH HEALTH AND CARE**



Everybody CEO of
their own health
New treatments with
Big data and AI
Tele-health
Living at home
Longer, self sustainable
Self-measurements

Good climate

Fertile ground

National Health Info Council

Standards

Indicators

Registers

Safe communication

Core

Purchasing

infrastructure

Frameworks

Unity in language

Trusted authentication

Patient access

Sustainable health information complex

Monitoring

Enforcement




National Health Information Council: *Whole system in a room*



Four outcome goals

1. *Medication safety*: standardized patient verified medication data for exchange used everywhere by 2019
2. *Patient empowerment*: patients equal in collaboration with healthcare providers, digital copy of their data to be used in a personal health environments by 2020
3. *Exchange*: digital exchange of patient data is part of the norm for quality of care, with patient informed consent
4. *Registration*: point of care is primary source of health data, secondary use for purchasing, research, transparency, quality and governance by 2021



Sharing Patient Data from the Patient's Perspective



ENTERTAINMENT NEWS

APRIL 9, 2018 / 6:49 PM / 2 DAYS AGO

Widely-watched Dutch comedian says 'Bye Bye Facebook'

Reuters Staff

3 MIN READ



AMSTERDAM (Reuters) - A popular Dutch comedian has urged hundreds of thousands of fans to join him in saying "Bye Bye Facebook" in protest at the social networking giant's handling of private data.

Arjen Lubach, whose widely-watched satirical television show "Sunday with Lubach" has more than 400,000 followers on the social media site, said the programme would delete its Facebook account on Wednesday, joining a string of high-profile entertainers and tech executives who have urged users to do the same.



No trade-off between privacy and quality of health care

- **No trust, no data**
- **Patients are important source of data**
healthy episodes, wearables, outcome measurement, older data: consent will always be needed
- **Patients, caregivers and researchers need data to learn from and to improve personal health and healthcare delivery in general**



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Some key elements of trust in digital health

- **Trust in e-Health is based on trust in caregivers**
- **Privacy**
- **Transparency (of use, algorithms, etc.)**
- **Ethical use of data (including research, algorithms)**
- **Informed consent and control (empowerment)**
- **Data solidarity**
- **Clear personal or societal benefits**
- **CEO of one's own data (who uses it for what, what did they learn and what can I learn from that)**

A man with short brown hair and a light complexion is seated in a black wheelchair. He is wearing a white t-shirt under a light-colored, textured blazer. He has a small black lapel microphone clipped to his blazer. His right hand is raised, with fingers slightly spread, as if gesturing while speaking. He is looking slightly off-camera to his right. The background is a solid, dark blue-grey color.

Een apparaat voor thuisonderzoek zou
nuttig zijn en alles totaal veranderen.



More and more people are interested
in actively managing their health data...



Some key elements in fair use of data

- Give me my damn data and research results
- Do not talk of data ownership: if you want to own data about me I will not trust you (stewardship)
- Standardization / Interoperability (GO-FAIR)
- International standards (like HL7/FHIR)
- Open API's to existing silo's
- Tamper proof exchange of data (e.g. blockchain)
- Access to data (e.g. from devices) for doctors & patients
- As less big data collections as possible: bring research and algorithms to the data (including the PHR as source)
- Consider privacy a driver for innovation

The image features a light gray background with two thick, dark purple horizontal lines. The top line has a thin gray diagonal line extending from its left end towards the top-left corner. The bottom line has a thin gray diagonal line extending from its right end towards the bottom-right corner.

Personal Health Train

The Digital Health Society

A multi-stakeholders initiative

launched in July 2017

under the Estonian EU Presidency



The Task Forces



The Declaration



Actions & Projects



Events & workshops



**Coalition of ~~doing~~
the g**





No trade-off

- **Privacy** brings **trust**
- **Trust** brings **sharing of data**, algorithms and knowledge
- **Sharing of data** brings **ways to learn** how to improve our own health and health care in general



There is a role for governments

- **Embrace and enable opportunities to learn and improve from data (positive climate, fertile ground)**
- **Realize “crash barriers” that bring trust**
- **Think big, act small and start now**