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What trade-off?
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The Netherlands
A patient and caregiver included movement to improve health care
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”
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

Seed Capital eHealth

Expertise and support

Scale-up coalitions
Good climate
Fertile ground
National Health Info Council
Sustainable healthinformation complex

- Everybody CEO of their own health
- Living at home longer, self sustainable
- New treatments with Big data and AI
- Tele-health
- Self-measurements
- Core infrastructure
- Indicators
- Safe communication
- Purchasing
- Frameworks
- Patient access
- Enforcement

- Standards
- Registers
- Unity in language
- Trusted authentication
- Monitoring
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
Widely-watched Dutch comedian says 'Bye Bye Facebook' 

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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BENEFITS OF USING BITMARK DONATION APP »
STUDY DETAILS »
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)**
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
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 the willing doing the good
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