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Citizen controlled health data lockers as *game changer*

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TNO innovation for life

HHD

Boodschapp
Lab1111
Honey Nut
Cheerios
I scan a product and the App tells me if this is the right product for me, based on my preferences:
Cheap / Healthy / Biological / Sustainable
AND IT MAY SUGGEST AN ATERNATIVE ….
I don`t need to look to the advertisements, health claims, suggestions, package,
I don`t need consumer protection, I am empowered

Quantified self

Quantified Self

A movement of citizens and ‘makers’ that aim to explore the tracking.

“Almost enerates

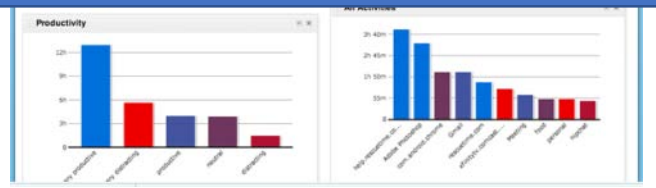
WHAT COULD WE LEARN IF

we could measure and record activities, social context, environmental context, physiological parameters, food intake, sleep across our entire lifetime? Now we have sensors for most of these..

WE CAN LEARN:

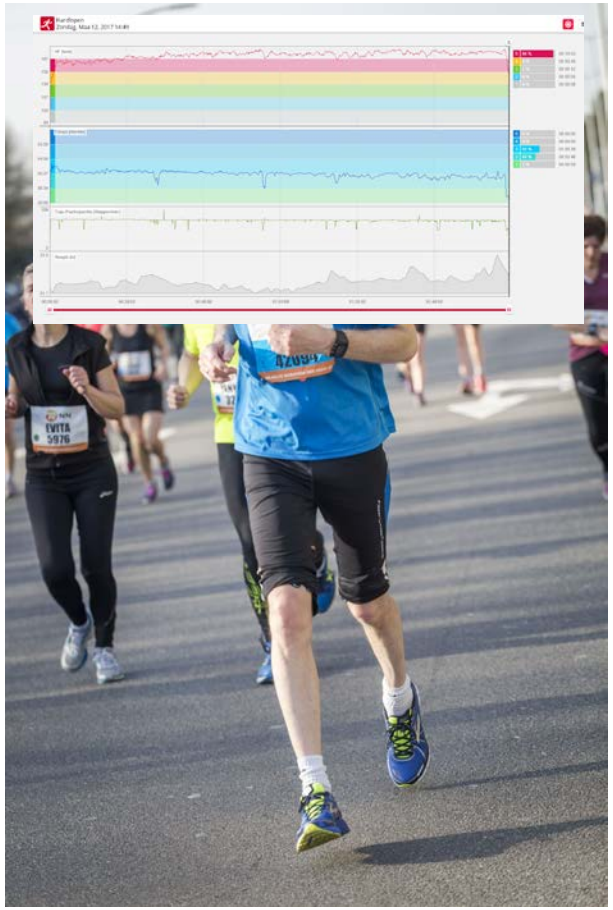
Personalized health advice based on systems view and population data

Integrating evidence based medicine and data driven predictions

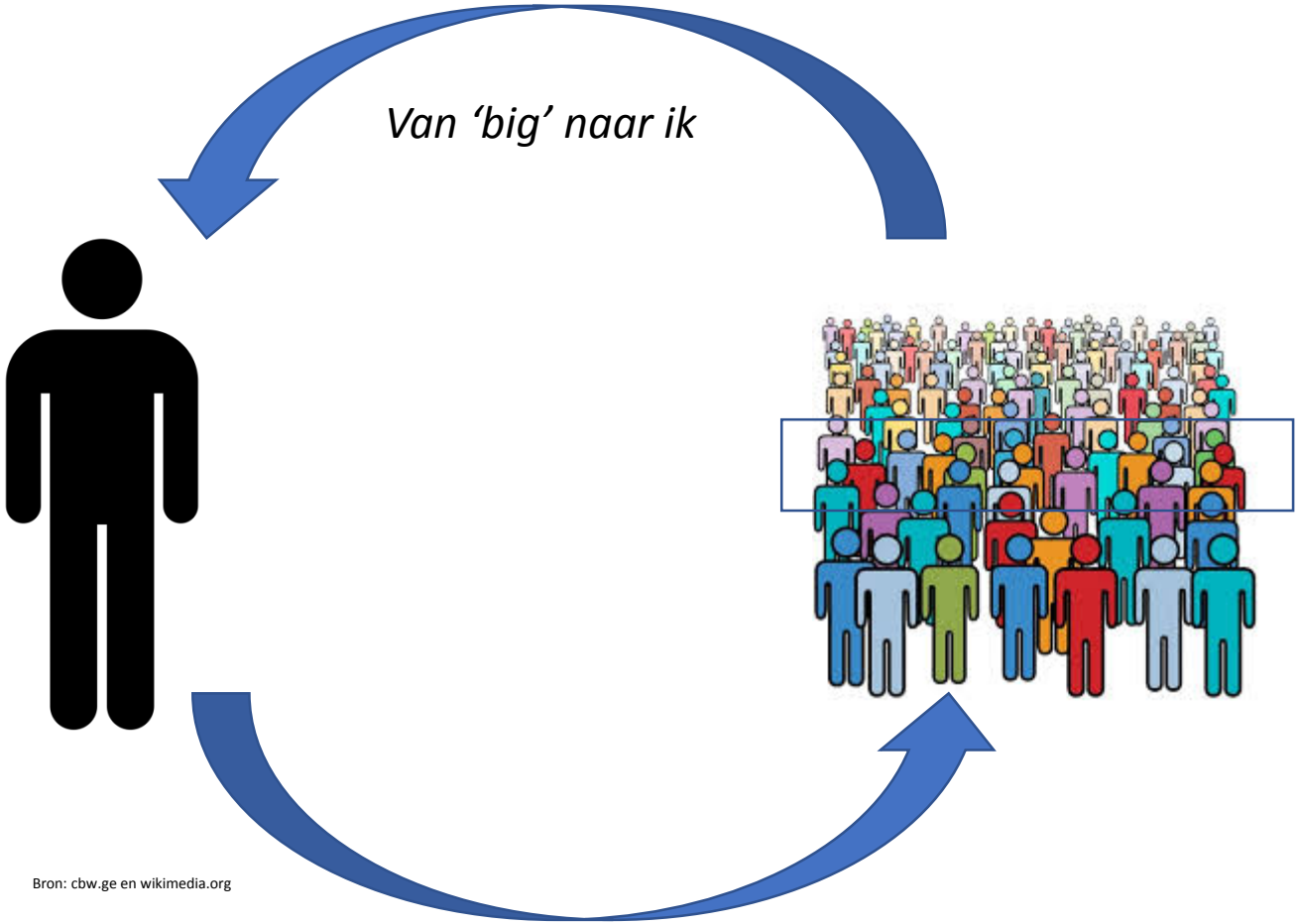


bron: RescueTime

How do you know you are on the right track?



The mutual dependence of personal and population health data



Bron: cbw.ge en wikimedia.org

Digital technology will redefine health and care

- Patient:
  - self management of health, patient science
  - Cure and prevent lifestyle diseases
- Combining the right data may lead to new insights
  - BUT Data storage is fragmented
  - BUT The GDPR limits the combination of data sets
- Challenges:
  - Provide a trusted environment, individual control on data access and sharing
  - Supporting secure and legal data analytics for combined datasets

Some barriers for data analysis

- Data is horizontally partitioned

ID	age	income	sex
1	55	70000	M
2	45	60000	F

ID	age	income	sex
3	20	25000	F
4	22	20000	M

- Distributed learning

  Personal Health Train

- Data is vertically partitioned

ID	Age	sex
1	55	M
2	45	F
3	20	F
4	22	M

ID	income
1	70000
2	60000
3	25000
4	20000

- Existing practice: Trusted 3rd party (TTP)
- Health Data Cooperative (Midata)
- Prana Data (example of secure multiparty computation)

Health care data
Different stakeholders, different interests

- Insurance: minimize cost of care
- Hospitals: Optimize processes (# successful treatments)
- Researchers: collect data for studies (# top publications)
- Tech platform companies (Google/Apple): pervasive monitoring of personal data (#users)
- Patient interest?

THE LANCET

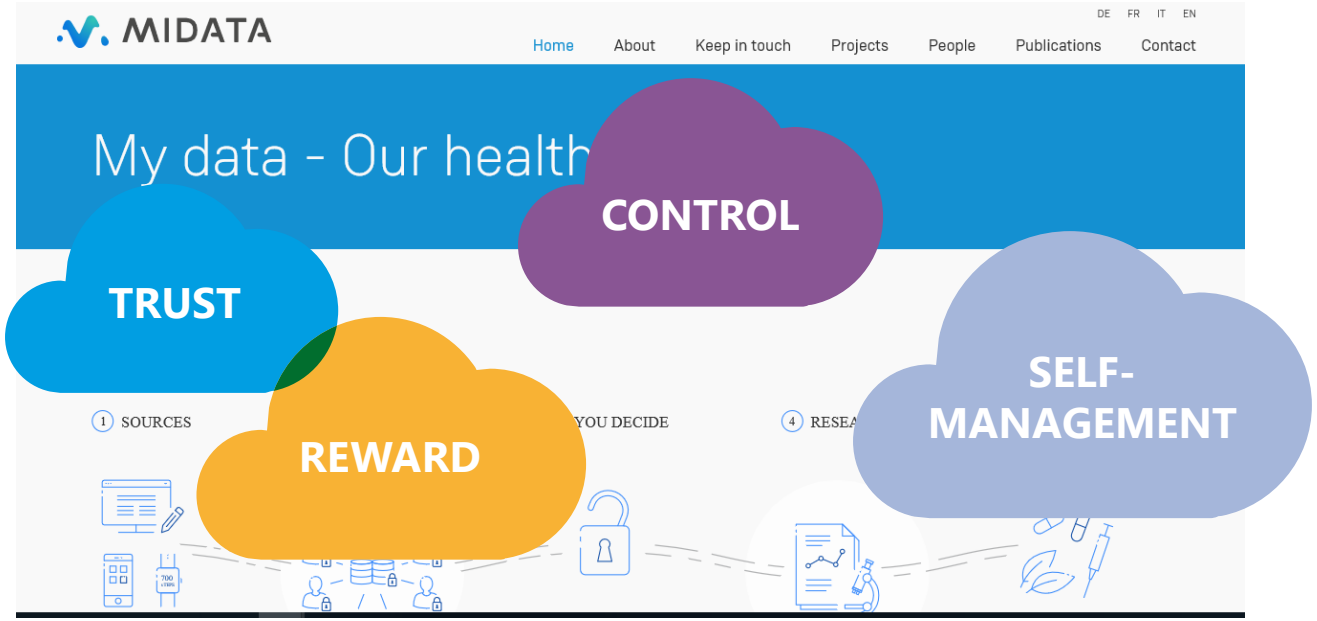
HOLLAND HEALTH DATA COOPERATIVE: THE GAMECHANGER

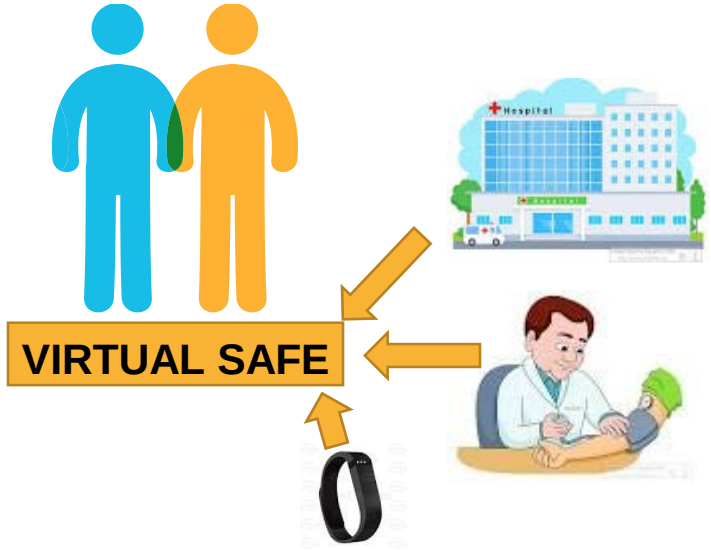
Internet companies' control of data gives them enormous power. Old ways of thinking about competition, devised in the era of oil, look outdated in what has come to be called the "data economy".

> **A new approach is needed**

ROADMAP NEXT ECONOMY

HOLLAND HEALTH DATA COOPERATIVE:





ROADMAP NEXT ECONOMY

THE GAMECHANGER

Towards a citizen driven healthcare economy:

- Citizen's together form a **Cooperative and a Community**
- The cooperative delivers the platform and governance structure
- Enables individuals to collect their data (medical and lifestyle)
- Provides services for members and delivers services to customers
- Data is controlled by citizen and patients themselves
- Rely on their cooperative for support

BENEFITS HOLLAND HEALTH DATA COOPERATIVE

Benefits for: citizens and patients

- A new finance model
- Gives citizens some reward for use of their data
- Citizen will get to know relevant and possible useful services and products
- Trusted alternative for commercial health data services
- Starts in the region of Rotterdam

ROADMAP NEXT ECONOMY

BENEFITS HOLLAND HEALTH DATA COOPERATIVE

Benefits for: business

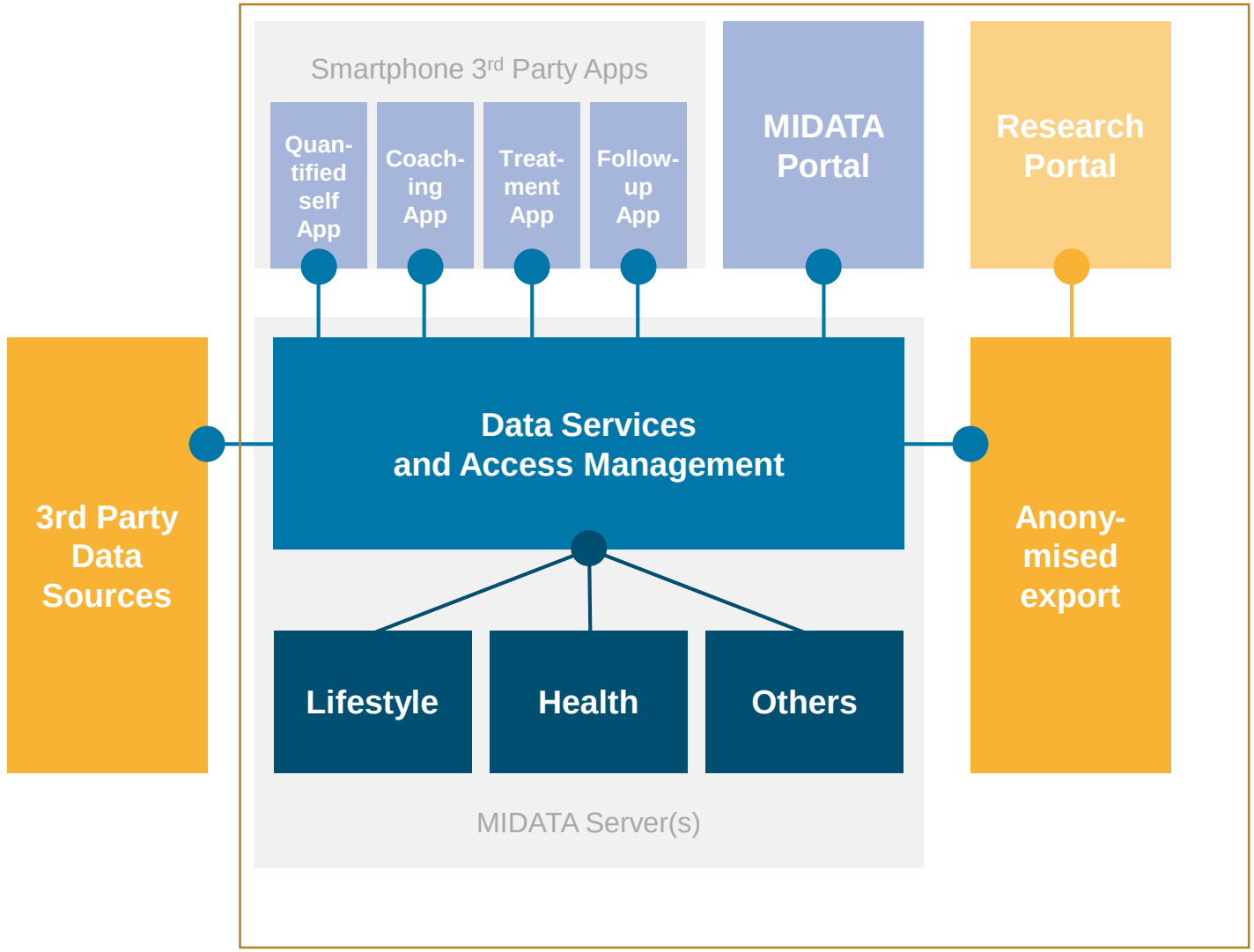
- Open and accessible health data with citizens approval
- Transparant for the community
- Testing and personalization possibilities for companies and research organisations
- Validation of new commercial health concepts with targeted individuals and groups
- Acces to relevant personal data
- Development of new ICT services and research

HDC: VIRTUAL PLATFORM & COMMUNITY

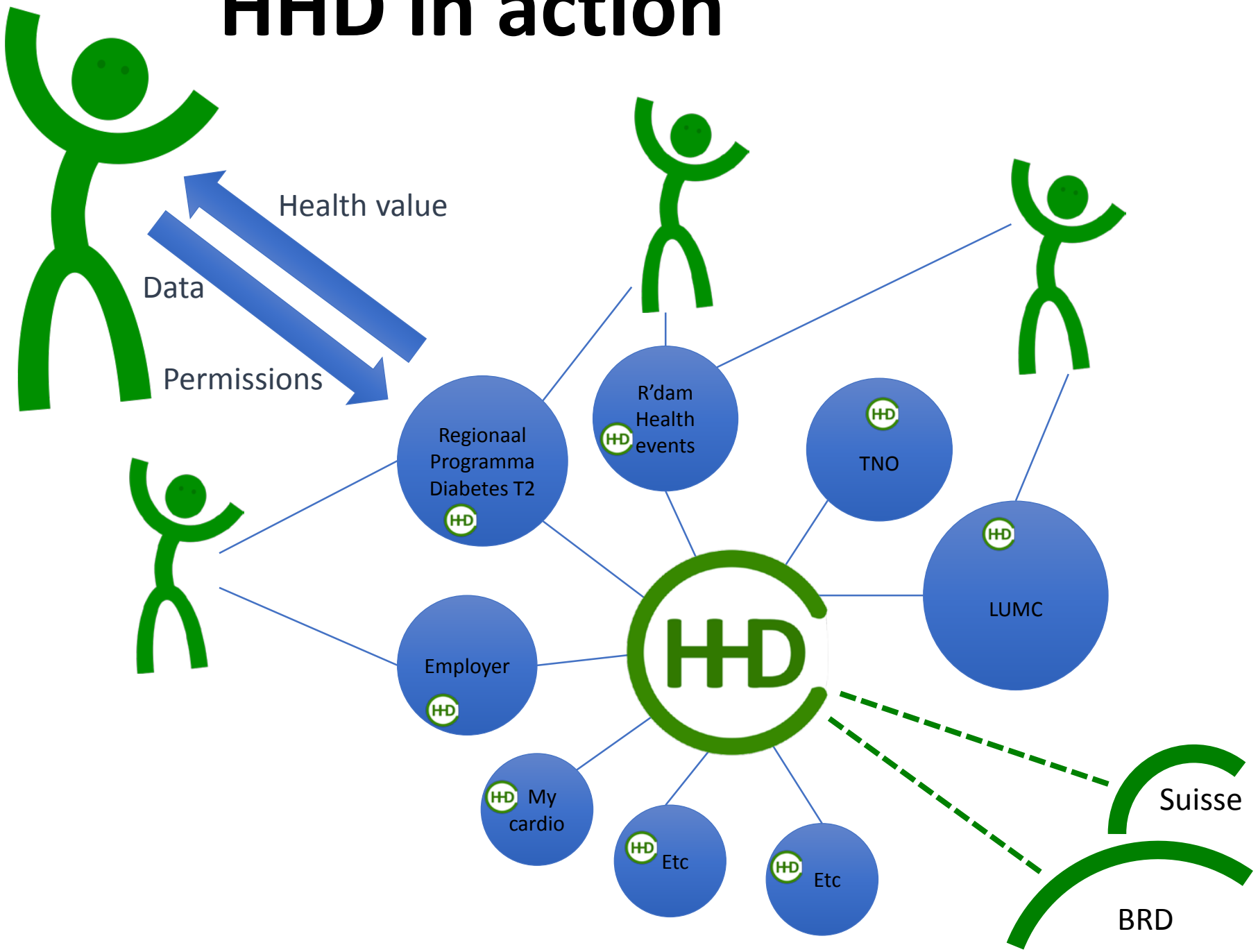
ROADMAP NEXT ECONOMY

GOALS START UP PHASE HOLLAND HDC

1. Attract members, i.c. citizens and patients, via use cases
2. Collect data via members and partners
3. Contract new partners and research organisations
4. Develop initial personalized services for members and potential partners
5. Operating the ICT MiData platform and governance structure.
6. Validated business case

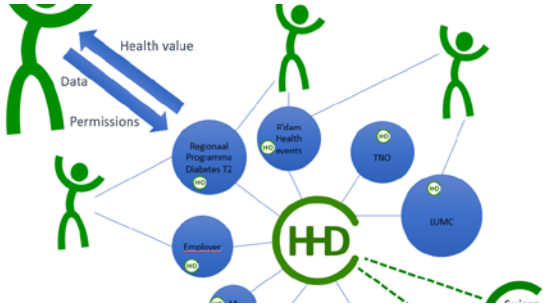


HHD in action

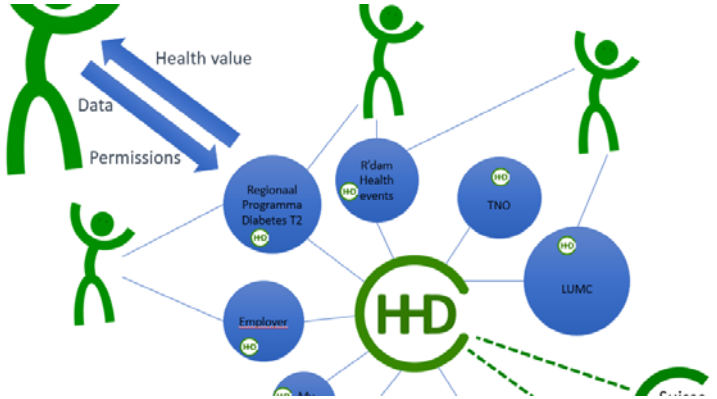


Status Holland Health Data Cooperative

- Cooperative founded in November 2017
- Software platform Midata will be tested in Q1 2018
- Ethical board in preparation
- First pilots expected Q2 2018
- Medical Delta employees as a pilot population



Planned Extensions



- Develop research platform at the HHDC
  - No need to distribute the data
- Qualify for MEDMIJ standards
- Build a FAIR data station as integral functionality of the HHDC
  - Connect to the so-called Personal Health Train
  - Bring algorithm to the data
  - Secure multiparty computation

Personal health train

Sign the manifesto at:
https://www.dtls.nl/phtmanifesto/

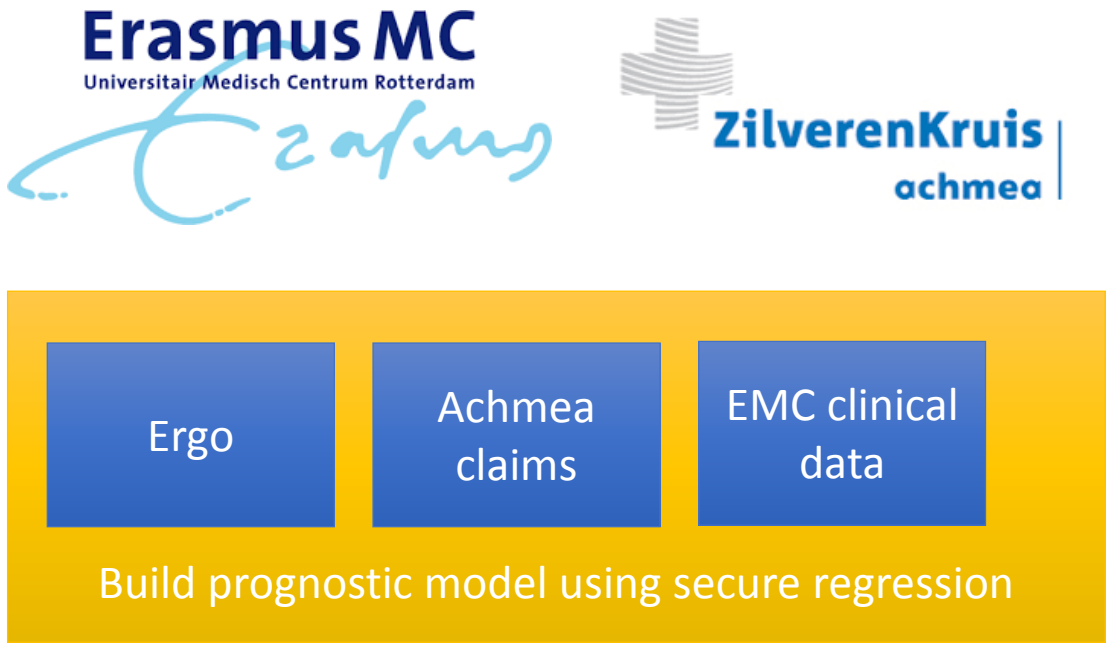
- Distributed data
- FAIR data stations
- Bring the algorithm to the data
- Approximate global analysis

- FAIR data stations include
  - Clinical repositories
  - Personal lockers (PGO)
  - Umbrella stations (e.g. HDC)

- Trains implement secure workflow for researchers and patients

H2020 BigMediLytics

- Developing “secure regression” using advanced encryption methods
- Aim: improve KPI with 20% in large scale trials
- Erasmus MC Heart Failure pilot
- KPI’s
  - Increase number of healthy years
  - Decrease number of hospital re-admissions



Develop and evaluate intervention informed by the joint longitudinal dataset (based on risk and cost analysis)

Individual person controls access to his/her data

Citizens can pull digital copies of clinical data into their locker

Integral (=defragmented) health data is quite valuable for personalized health

HDC's enable a new health economy when run as a cooperative

HDC's are a trusted infrastructure to make new data available for research, given consent

Conclusion: Health Data Cooperatives have the potential to be a game changer