



# **Modern, citizen-centred data stewardship for the common good: Why do we have to go beyond the GDPR?**

Juuso Parkkinen, PhD, @ouzor  
MyData.org and Nightingale Health (Finland)  
BeyondRCT, 25 September 2018, Amsterdam

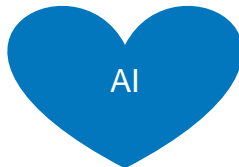


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Senior Data Scientist at **Nightingale Health**

Active member in the **MyData** and **Open Knowledge** community



## THE FUTURE OF MEDICINE:



**PREDICTIVE**  
**PERSONALIZED**  
**PREVENTIVE**  
**PARTICIPATORY**

Image adapted from <https://www.trueprocess.com/the-future-of-medicine-predictive-personalized-preventive-participatory/>

**Based on extensive health data collection and use!**

# In practice



# Growing concerns

## Healthcare Data Privacy, Security Concerns Hinder Digital Adoption

A recent survey shows that half of organizations are hesitant to adopt mobile and digital options because of healthcare data privacy and security concerns.

54%

of digital consumers are cautious about the information they share due to lack of confidence in the online security that protects their personal data.



US & WORLD / TECH / HEALTH

## 1.5 million affected by hack targeting Singapore's health data

# The business is moving

**More U.S. Hospitals Testing  
Apple's Software Than Google's**

**Google's Deep Mind artificial  
intelligence unit joins cancer fight  
with nanotechnology**

**IBM unveils Watson Health Cloud  
to reduce healthcare costs**

**Apple and IBM unveil new apps for  
nurses**

**Apple ResearchKit Now Available  
To All Medical Researchers**

**Google To Create Robotic-Assisted  
Surgical Platform with J&J**

**Who gets the value?**

# The personal data challenge

**Data protection  
& security**



**Value &  
usability**

**Can we have both?**

# MyData



**Individuals should be in  
control of their own data.**



# But why?



It is a basic **digital right**.  
Control enables **value creation**.

# MyData



The MyData approach aims at strengthening **digital human rights** while opening new opportunities for businesses to develop innovative **personal data based services** built on mutual trust.

# Three Models

## API Ecosystem



## Platform Model



## MyData Model



# Individual as:

**Connection point:** data from one person can be connected

**Control point:** Individual decides who uses her data and how by giving **consents**



Lots of data usage



Organisations decide



People decide

Less usage of  
personal data



Old paper times



Comply with the GDPR

Weak  
Data Protection

Strong  
Data Protection

# MyData movement

## ALTERNATIVE VISION



## GUIDING PRINCIPLES

- 1 Human Centric
- 2 Usability of Data
- 3 Open Business Environment

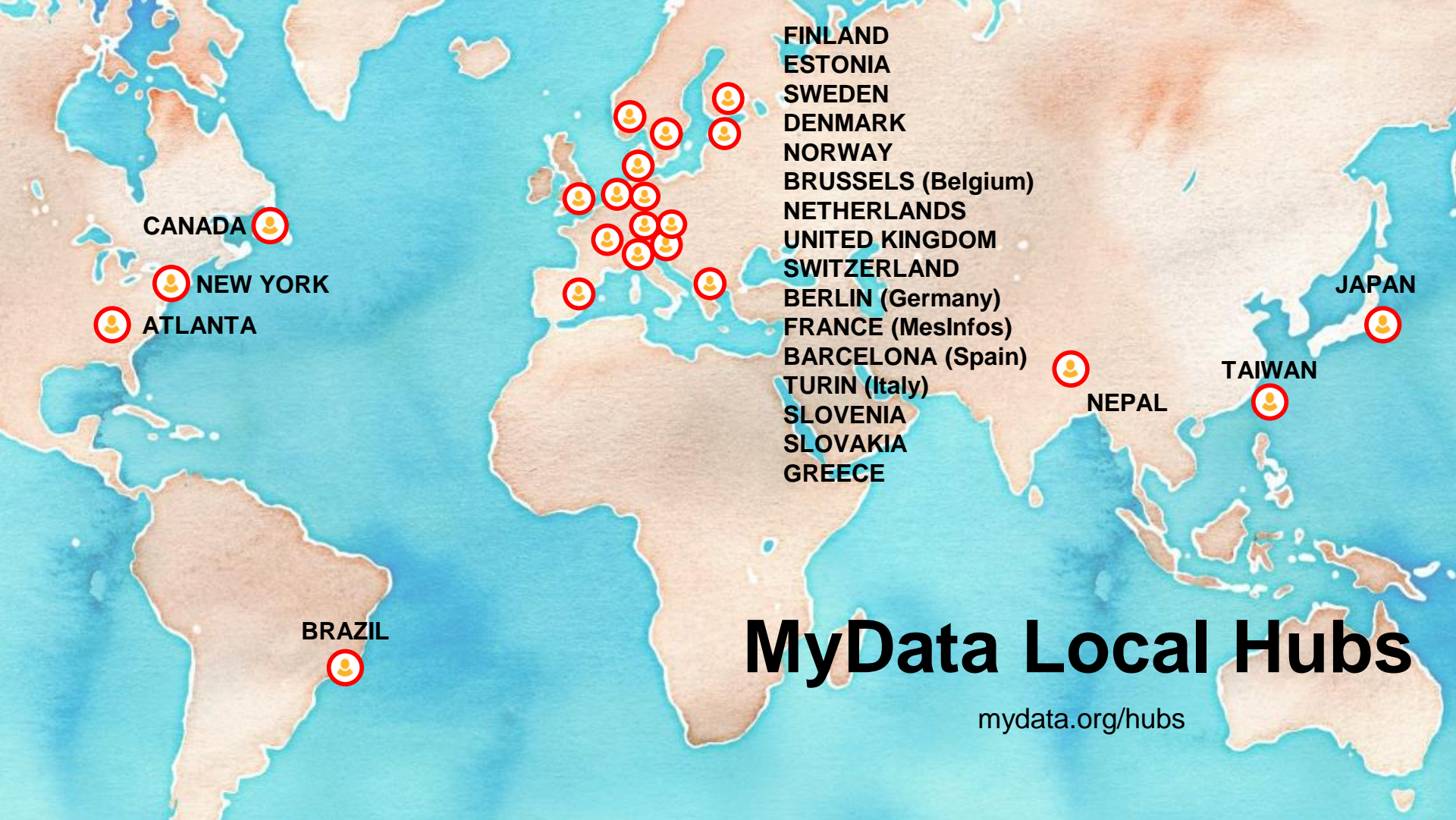
## MEETINGS & CONFERENCES

**MyData**  
2018  
Aug 29–31  
*From vision to action  
– future is now*

## GLOBAL NETWORK

MyData global  
organisation  
founding  
meeting on  
October 11<sup>th</sup>





CANADA

NEW YORK

ATLANTA

BRAZIL

FINLAND  
ESTONIA  
SWEDEN  
DENMARK  
NORWAY  
BRUSSELS (Belgium)  
NETHERLANDS  
UNITED KINGDOM  
SWITZERLAND  
BERLIN (Germany)  
FRANCE (MesInfos)  
BARCELONA (Spain)  
TURIN (Italy)  
SLOVENIA  
SLOVAKIA  
GREECE

NEPAL

TAIWAN

JAPAN

# MyData Local Hubs

[mydata.org/hubs](https://mydata.org/hubs)

# Practical examples

Arkkeo

mylife  
digital

.v. MIDATA



^mydex

healthbank

sovrin  
identity for all



personal<sup>™</sup>  
digi.me

IOTA

Cozy Cloud



fair & smart

datamixer  
DATA DRIVEN HAPPINESS

Qiy digital me

CONTEXTSPACE

SYNERGETICS  
COMPETENCY DRIVEN KNOWLEDGE

powr of you



# My data - Our health

## Our Health

① SOURCES



② MIDATA



③ YOU DECIDE



④ RESEARCH



⑤ NEW TREATMENTS



MIDATA enables you to gather all your different health-relevant and other personal data (1) in one secure place (2).

You can decide (3) to share data with friends or physicians or to participate in research by providing access to subsets of your data (4).

In that way you contribute to the development of new treatments for OUR HEALTH (5).

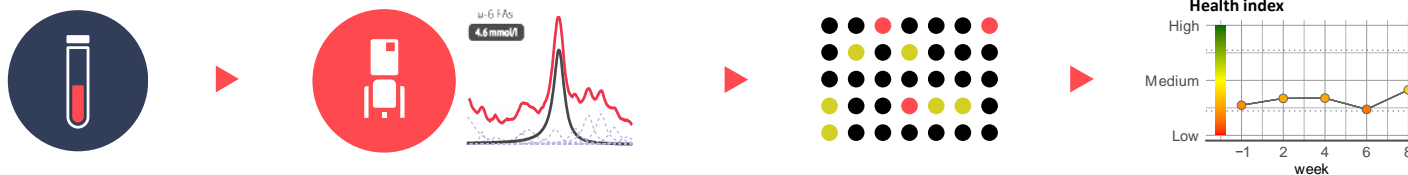


## PURPOSE OF **Holland Health Data Cooperative**

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- ✓ You manage the key to your data
- ✓ The cooperative will take care of the collective utilization of that data for you in the interest of you
- ✓ The proceeds will be reinvested in a new health economy: an economy that has an interest in your health instead of your illness

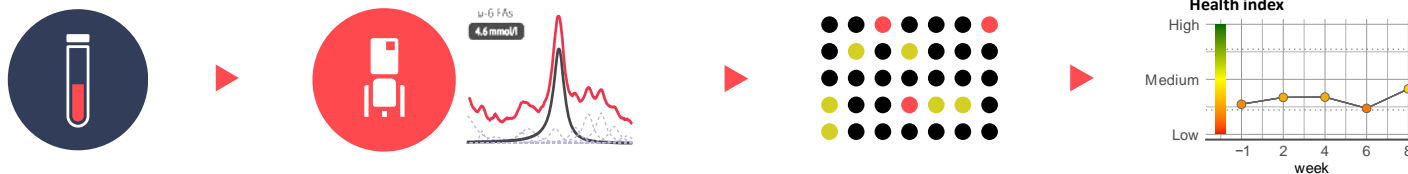
# Nightingale Health – solving the global burden of chronic diseases



Nightingale has built a **blood testing technology** that helps us **forecast our health in chronic diseases**.

We **measure, analyse and refine essential health data** to enable **preventive & personalized healthcare**.

# Nightingale Health – solving the global burden of chronic diseases



UK Biobank  
@uk\_biobank

Follow

Nightingale Health @NgaleHealth to analyse the biomarker profiles of all 500,000 participants [ukbiobank.ac.uk/2018/06/nighti](https://ukbiobank.ac.uk/2018/06/nighti)

How about  
the Biobank of  
the World?

## Recap

To enable **human-centric, personal data** –driven future of healthcare, we need

- privacy and data protection.
- **value from collective use of personal data.**

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**MyData.org**