CAiSE'22

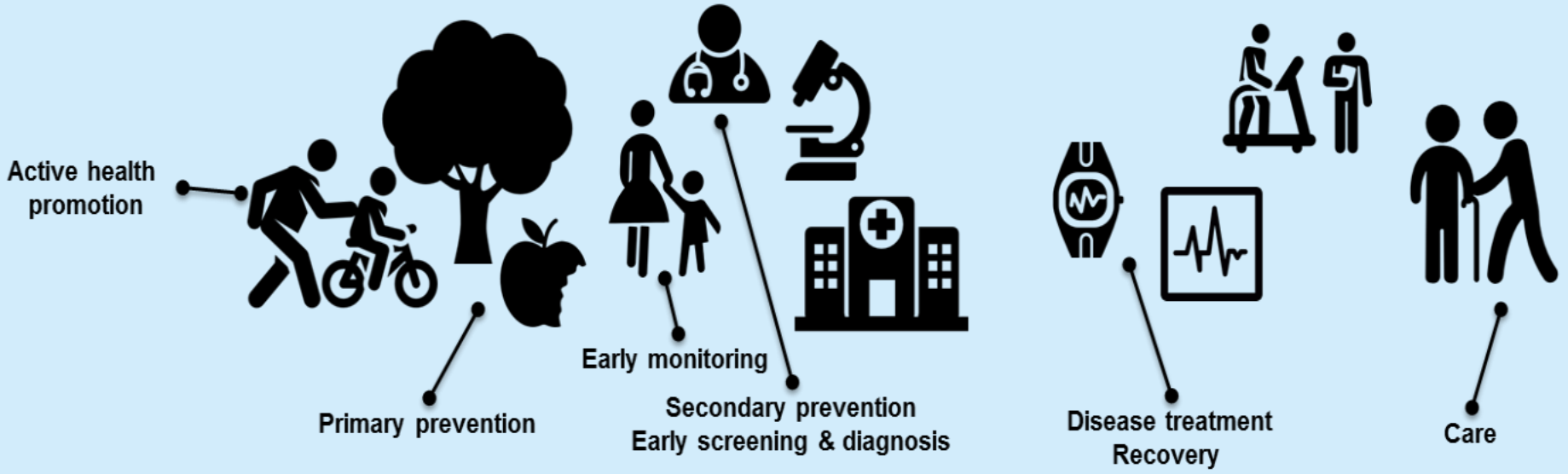
**34th International Conference on Advanced Information Systems Engineering**

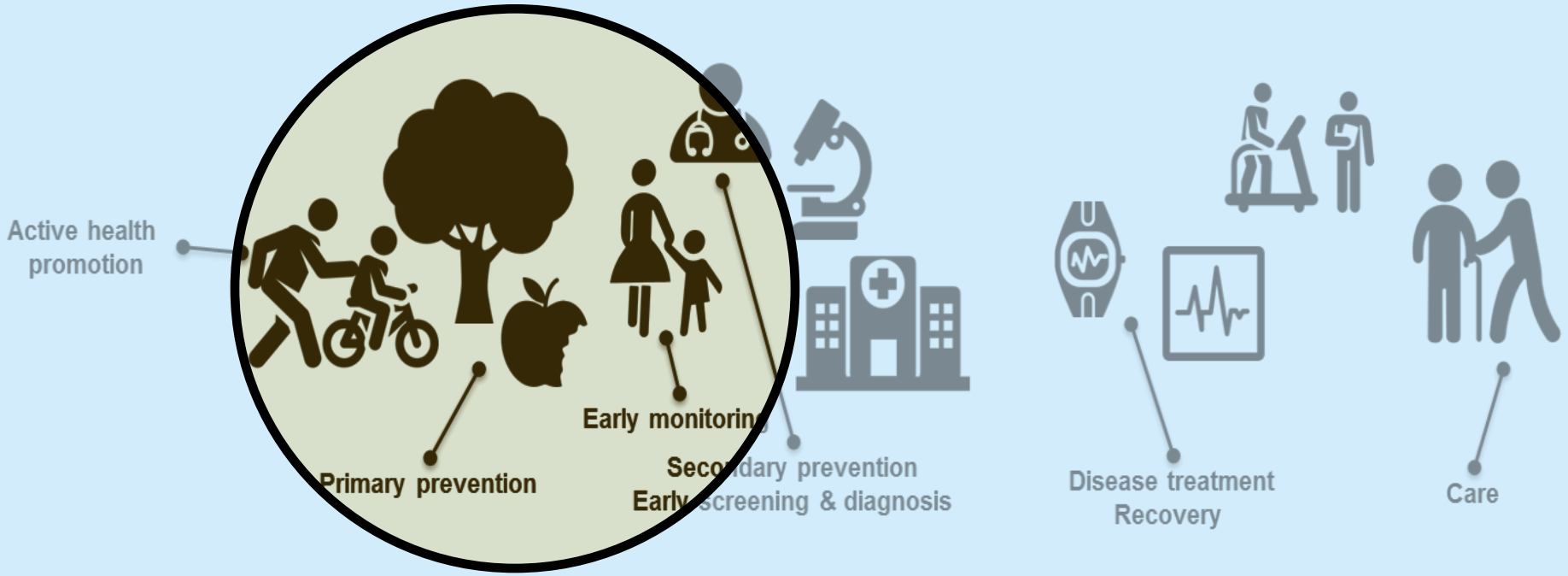
06/06/2022 - 10/06/2022, LEUVEN 2022

JUNE 9: 09:30 - 10:30
MTC - LARGE AULA

# A CITIZEN-DRIVEN ECOSYSTEM FOR PERSONAL HEALTH DATA

Jef Hooyberghs, VITO - UHasselt


Active health promotion
Primary prevention
Early monitoring
Secondary prevention
Early screening & diagnosis
Disease treatment
Recovery
Care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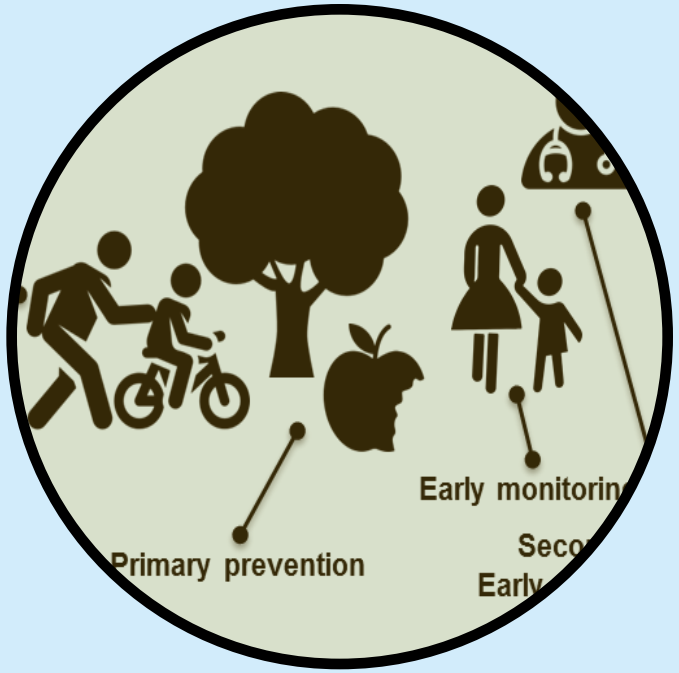


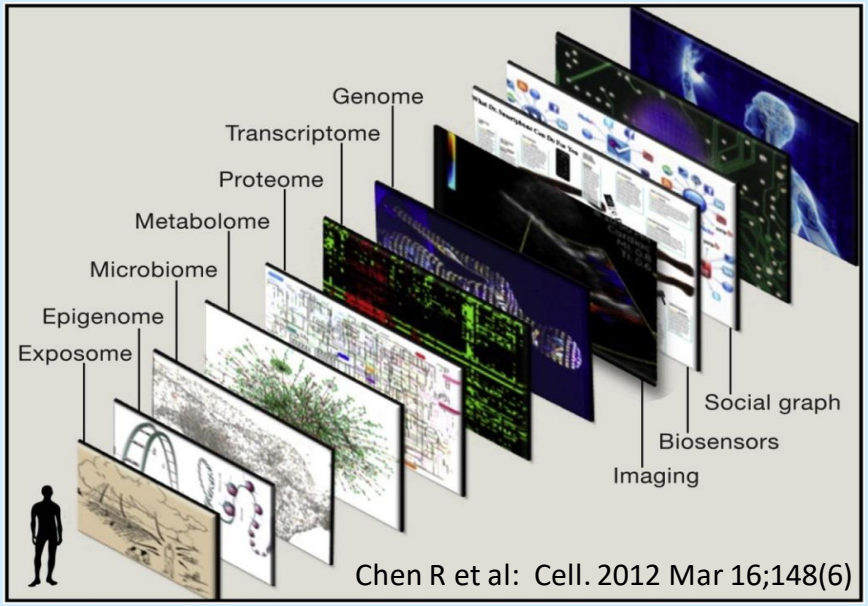


# INTEGRATIVE PERSONAL OMICS PROFILE

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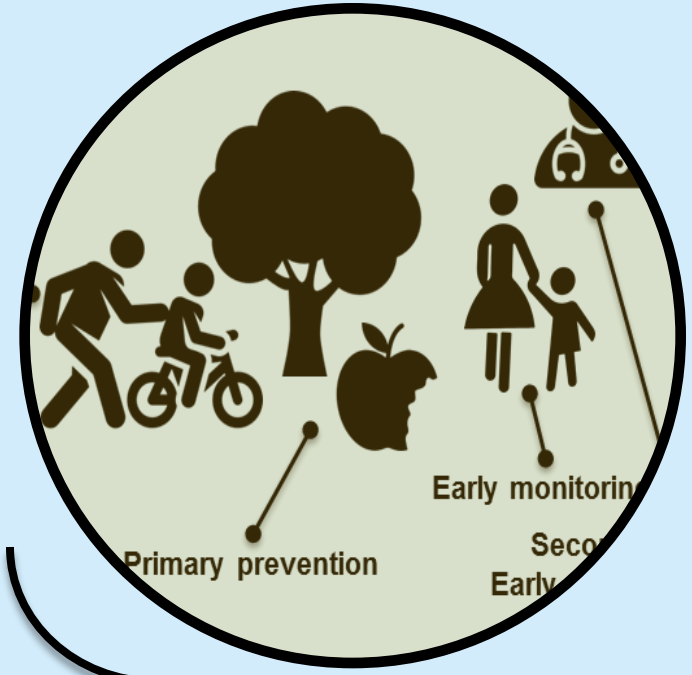
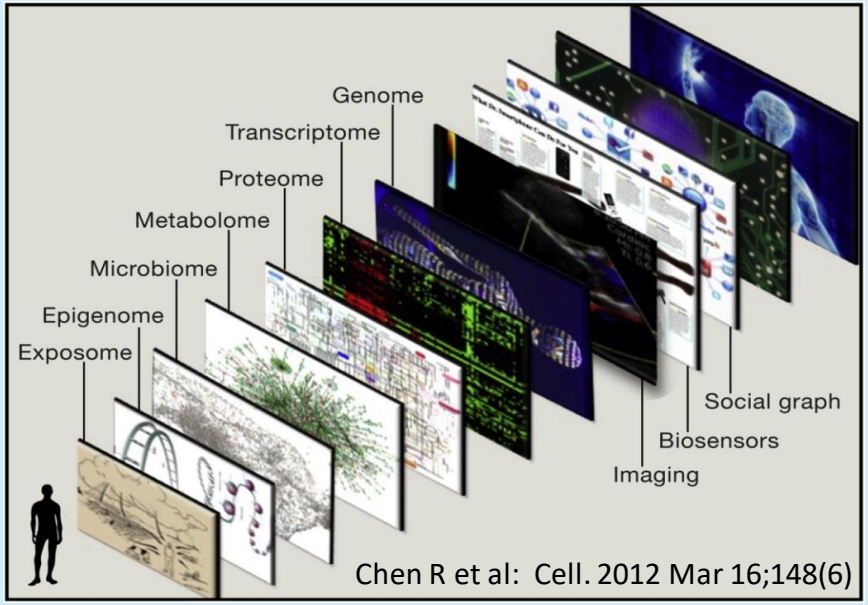


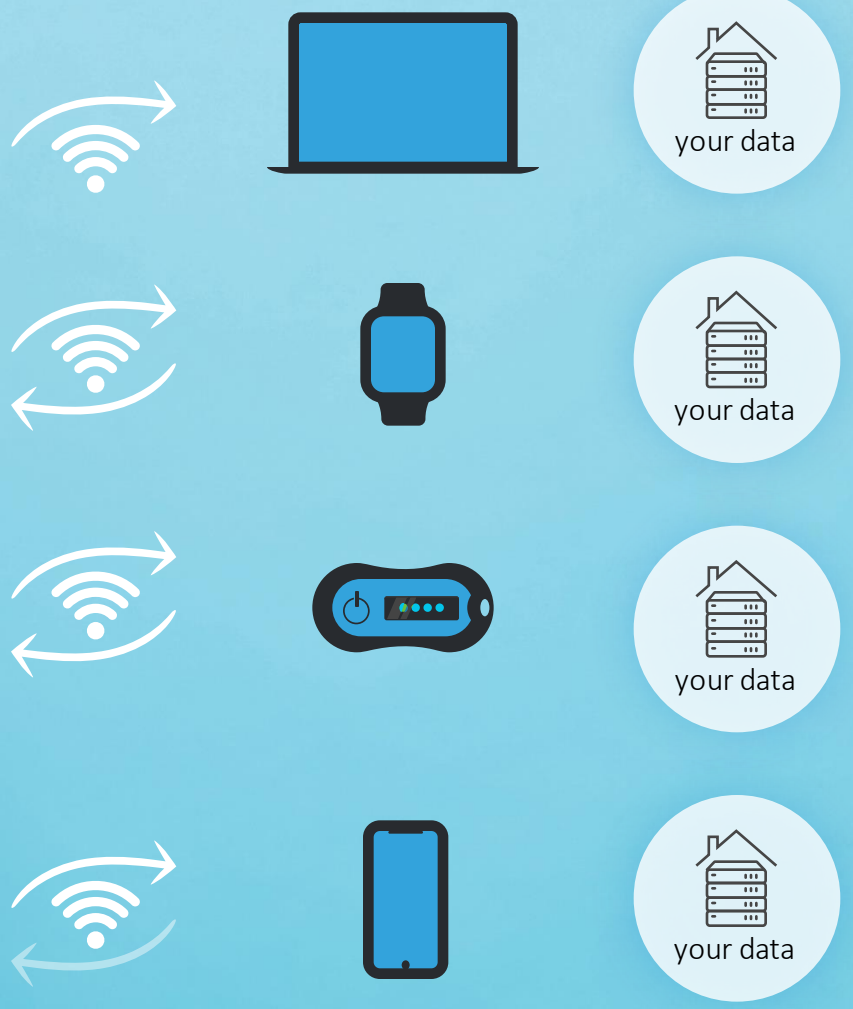

# DATA DRIVEN PREVENTION

HIGHLY DIVERSE SET OF DATA

INDIVIDUAL DATA

LONGITUDINAL DATA

vito




# CURRENT ECOSYSTEM = APPLICATION-CENTRIC

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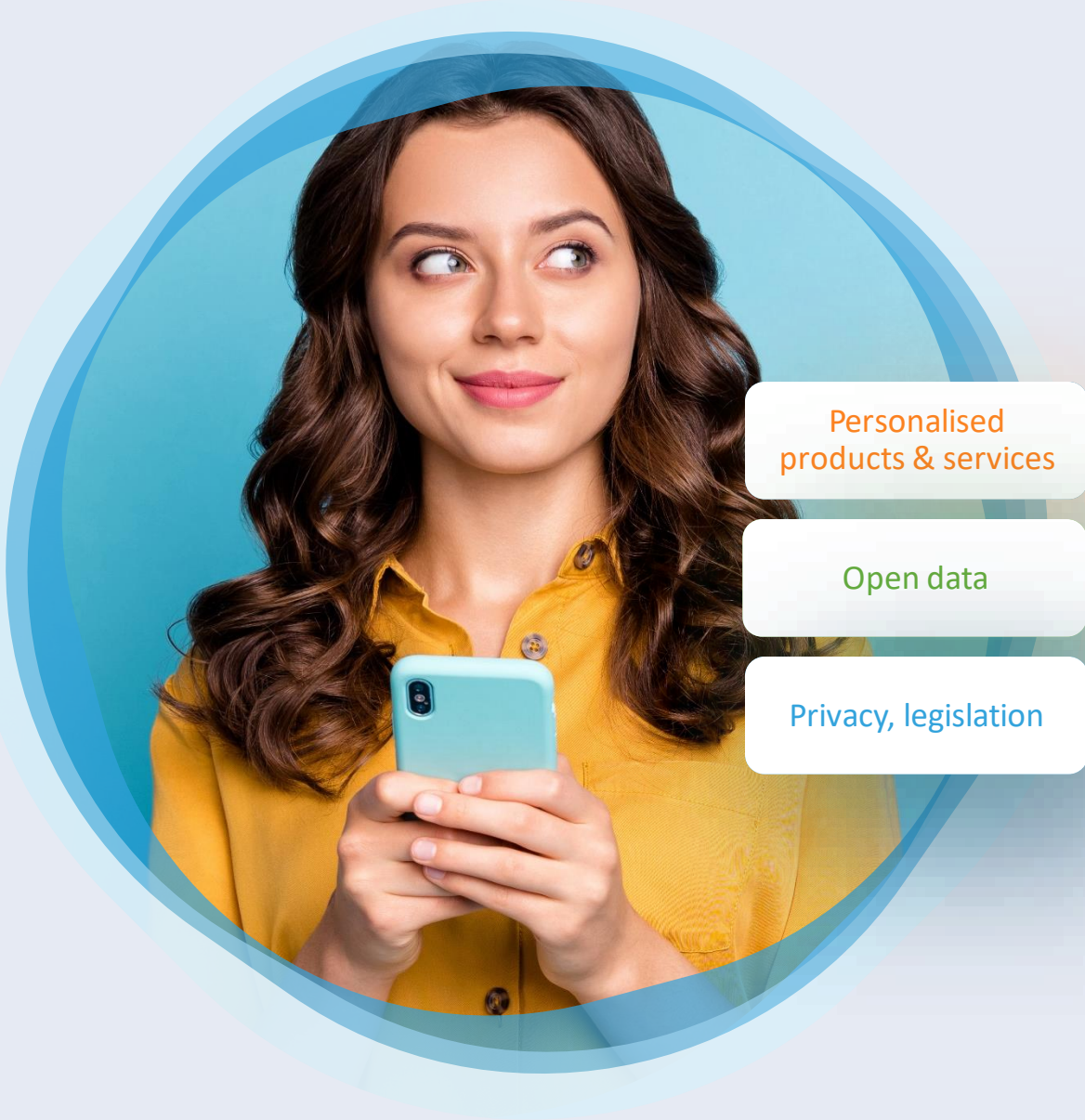
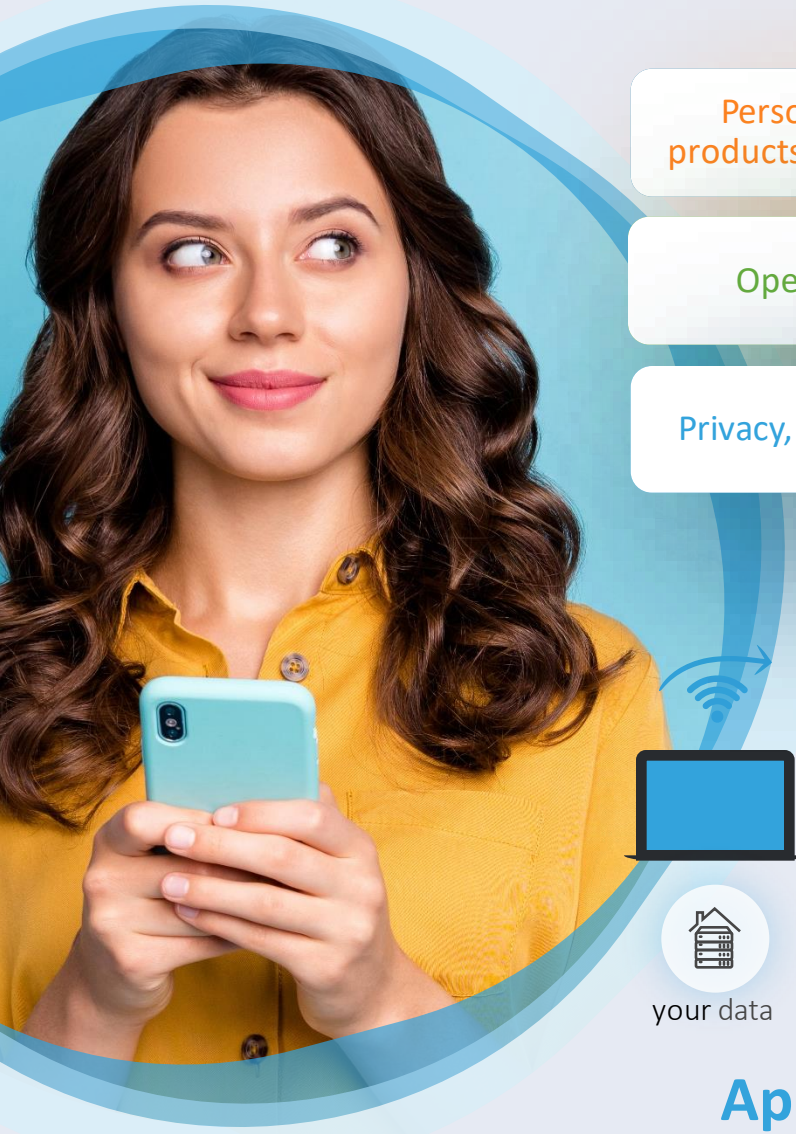


| | | |
|---|---|---|
| Personalised products & services | » | Data economy |
| Open data | » | Innovation |
| Privacy, legislation | » | Protect & engage end users |

# SOCIO-ECONOMIC TRENDS

Global & European

vito



Personalised products & services → Data economy

Open data → Innovation

Privacy, legislation → Protect & engage end users

**Application-centric**

- Counteracting trends
- Ethical issues
- Oligopoly
- …

# SOCIO-ECONOMIC TRENDS

Global & European

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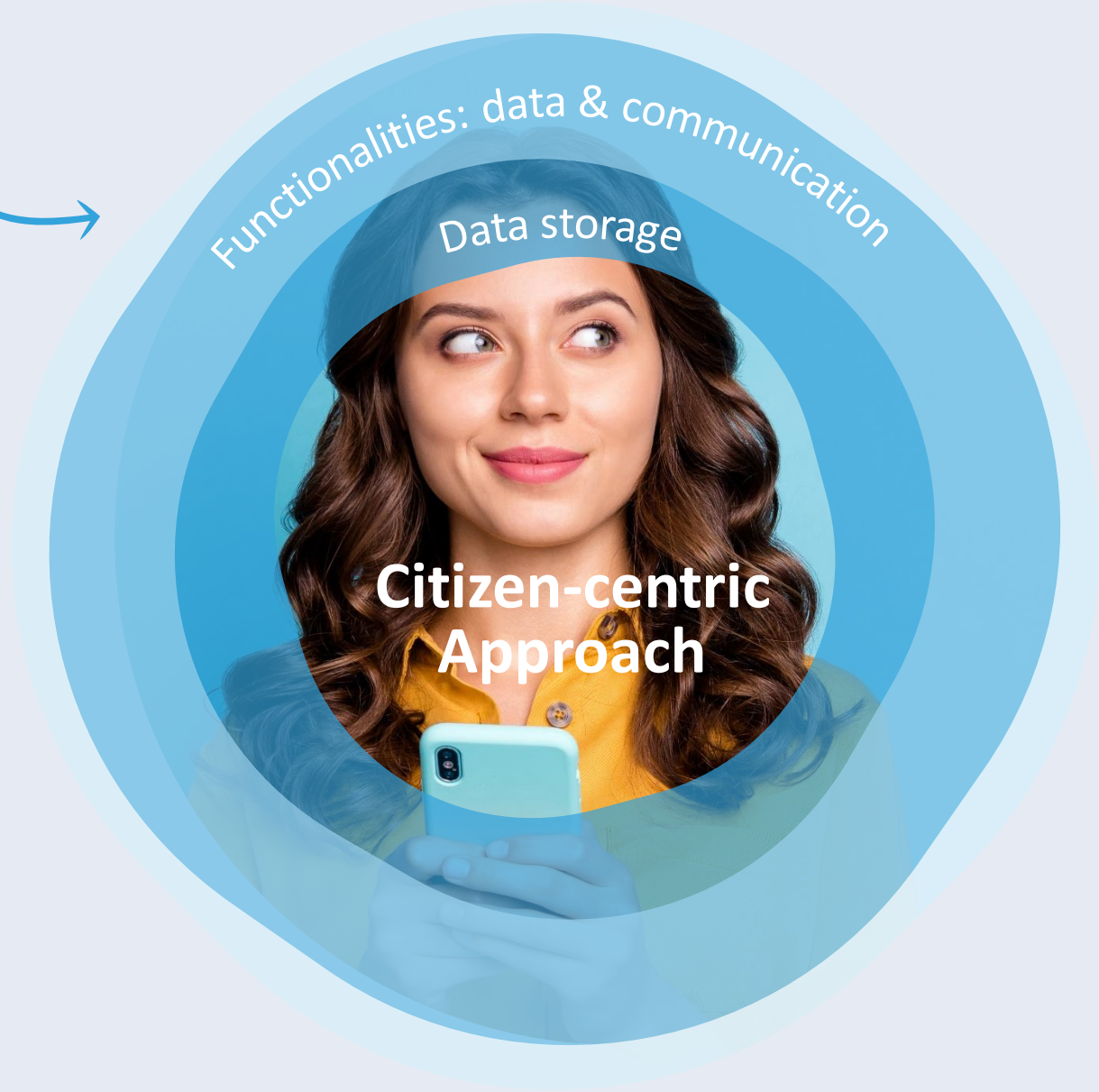
# CITIZEN-CENTRIC ECOSYSTEM

vito

Creation and capture of personal health data




# CITIZEN-CENTRIC ECOSYSTEM

vito

Creation and capture of personal health data

Functionalities: data & communication

Data storage

Citizen-centric Approach

CONSENT

R&D innovation

- Academia
- Civil Society
- Public authorities
- Industry

# CITIZEN-CENTRIC ECOSYSTEM

vito

Creation and capture of personal health data

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Citizen-centric Approach

CONSENT

R&D innovation

- Academia
- Civil Society
- Public authorities
- Industry

# CITIZEN-CENTRIC ECOSYSTEM

SEPARATION OF DATA & SERVICE
DATA ACCESS, NOT DATA GOVERNANCE

Personalised products & services

vito

R&D innovation

Personalised products & services

- Open innovation ecosystem
- Systematic user co-creation approach
- Integration innovation in real life
- Operates as intermediary among companies, citizens, research & government
- Rapid prototyping and validation to scale up

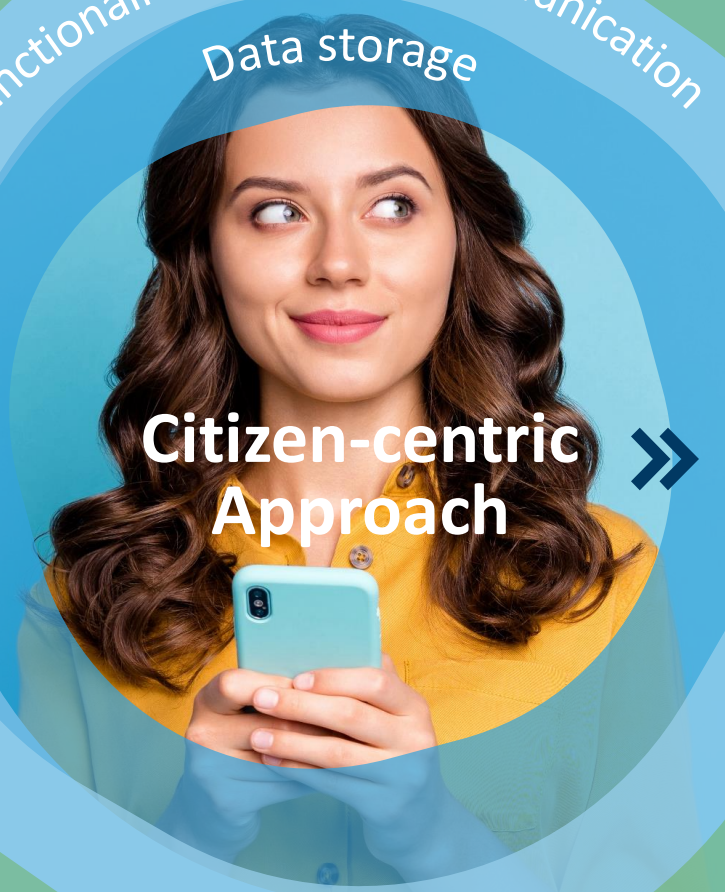
**A LEVEL PLAYING FIELD**

vito

Organisational & data governance

Functionalities: data & communication

Data storage



**Citizen-centric Approach** » **Citizen**

R&D innovation

we are

Personalised products & services

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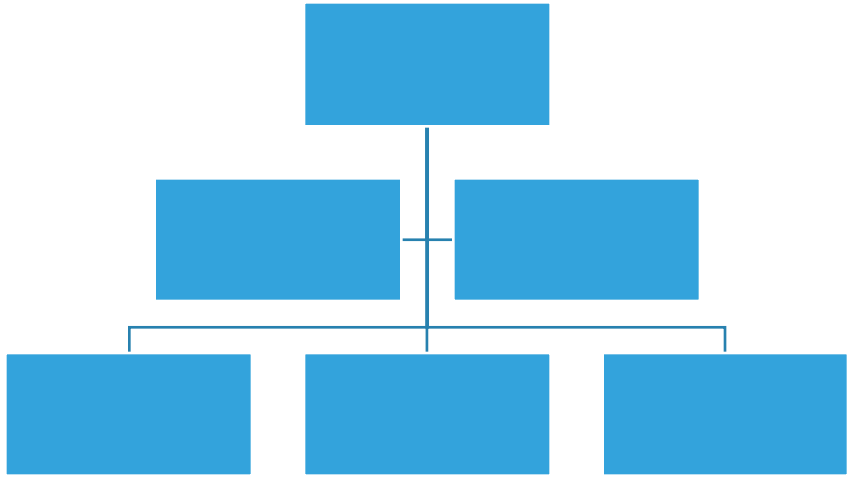
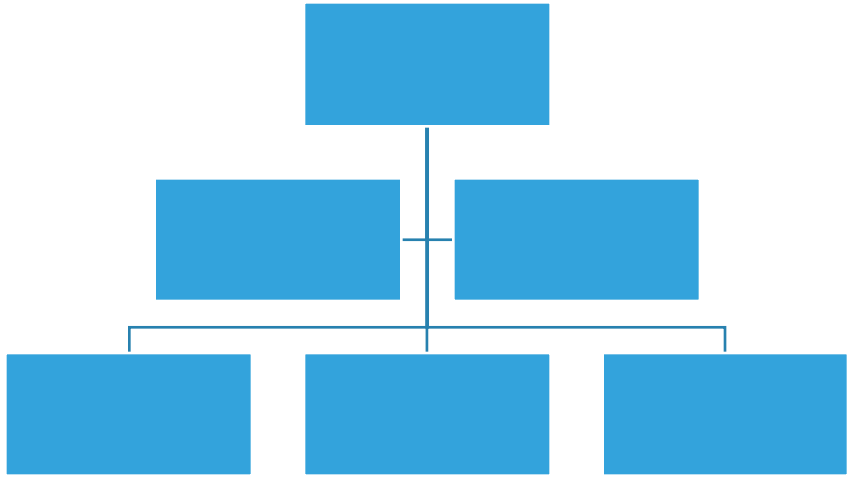
# LOCAL - FLANDERS - INTERREGIONAL

we are



# LOCAL - FLANDERS - **INTERREGIONAL**

we are



# INTERREGIONAL

## VANGUARD INITIATIVE

SMART HEALTH

PERSONAL DATA MANAGEMENT PLATFORM

DEPARTEMENT ECONOMIE WETENSCHAP & INNOVATIE

Sharing personal data? We do it every day and more and more often. **But what happens newt with that data?** Flemish Minister of Innovation Hilde Crevits is now co-investing in the development of an Interregional Platform for Personal Data contraining a personal digital safe. Flemish Research Centre VITO is developing the system and is further developing it in a broader partnership

# INTERREGIONAL

**VANGUARD INITIATIVE**

SMART HEALTH

PERSONAL DATA MANAGEMENT PLATFORM

DEPARTEMENT ECONOMIE WETENSCHAP & INNOVATIE

we are

## Inter-regional platform

## Regional ecosystems

- Regional Innovation Nodes
- Flanders
- East Netherlands
- Northern Ostrobothnia
- …

vito | UNIVERSITY OF TWENTE. | TECHMED CENTRE | OULU HEALTH | UNIVERSITY OF OULU

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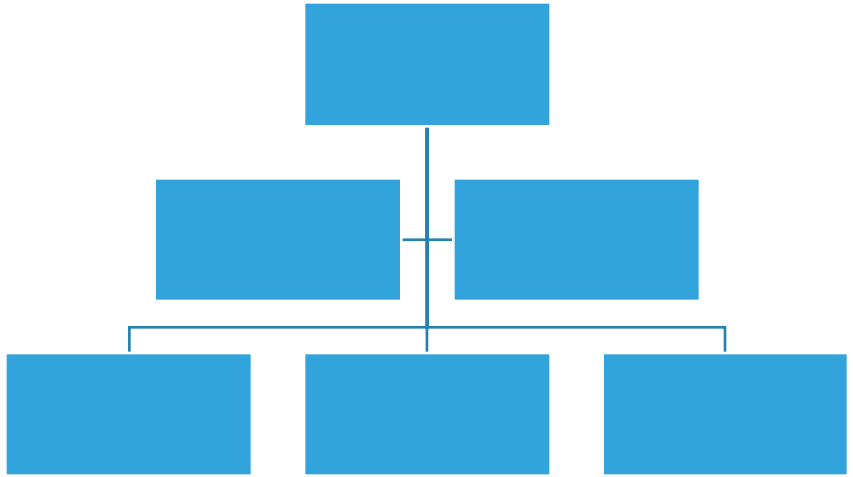
# LOCAL - **FLANDERS** - INTERREGIONAL

we are



# PARTNERSHIP

we are

DOMUS MEDICA

zorg net ICURO

vito

Vlaams Patiëntenplatform

Koning Boudewijnstichting

*Samen werken aan een betere samenleving*

# POLICY DOMAINS

we are

## INNOVATION

DEPARTEMENT
ECONOMIE
WETENSCHAP &
INNOVATIE

## HEALTH

DEPARTEMENT
WELZIJN
VOLKSGEZONDHEID
EN GEZIN

## DIGITIZATION

DIGITAAL
VLAANDEREN

vito

# we are

- **A citizen-centric ecosystem**

**Empowerment**

# we are

- A citizen-centric ecosystem
- **Separating data from applications**

**Digital Technology**

# we are

- A citizen-centric ecosystem
- Separating data from applications
- **Shaping applications**

**Innovation**

# we are

- **A citizen-centric ecosystem**

**Empowerment**

- Separating data from applications
- Shaping applications

Synergy Privacy & Innovation

Participatory Governance

TRUST

we are

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GUIDING PRINCIPLES

Synergy Privacy & Innovation

Participatory Governance

TRUST

we are

*Copyright principes: Fonds dr. Daniël De Coninck*

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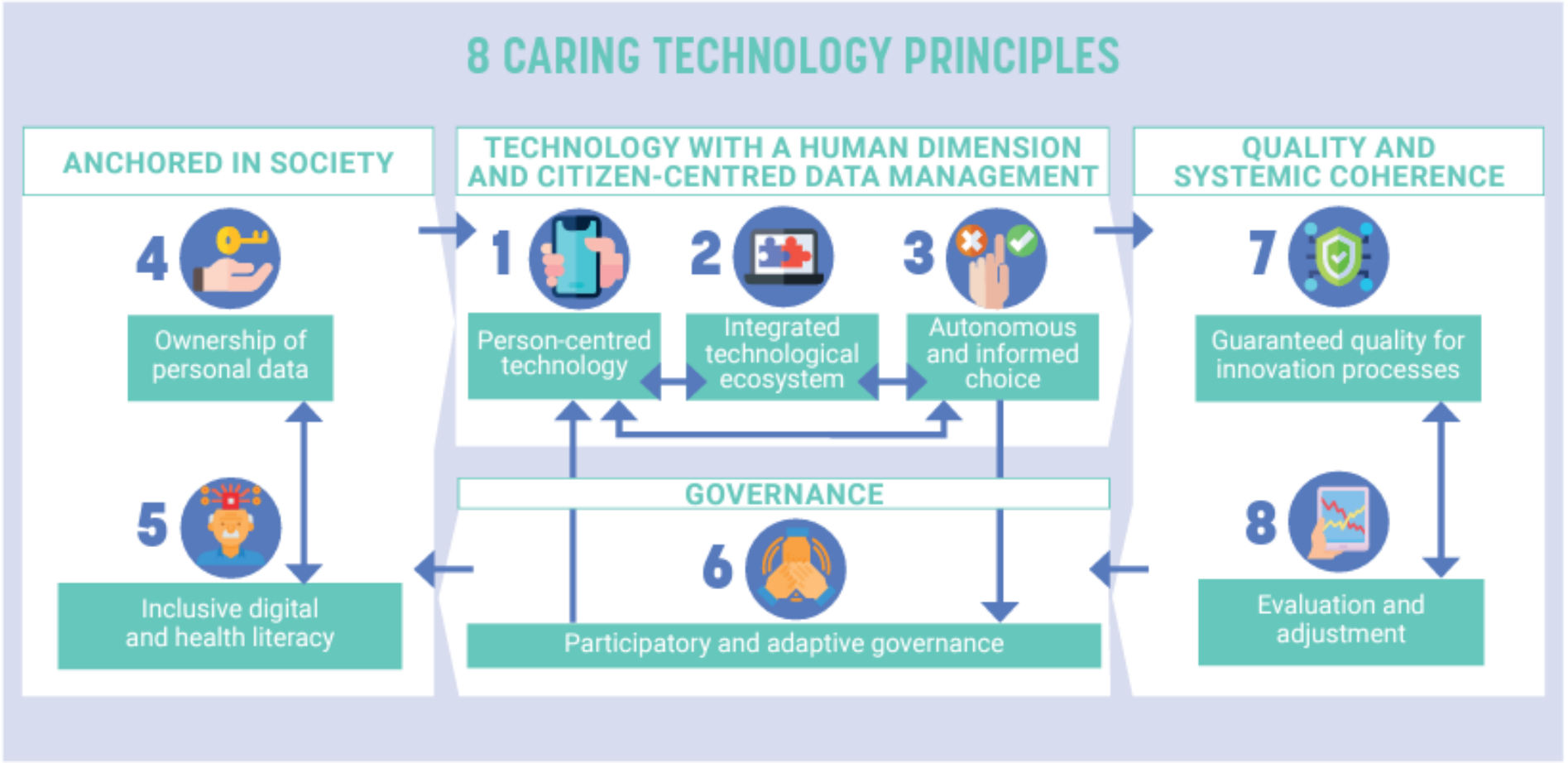
# FRAMEWORK OF CARING TECHNOLOGY PRINCIPLES: 8 GUIDING PRINCIPLES




*https://www.fondsdanieldeconinck.be/initiative/caring-technology/?lang=en*

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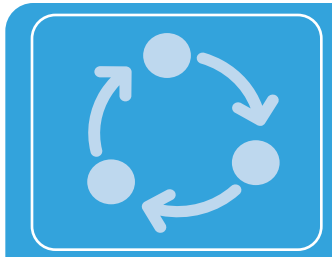
# BLUEPRINT
# RESPONDS TO NEEDS AND CHALLENGES

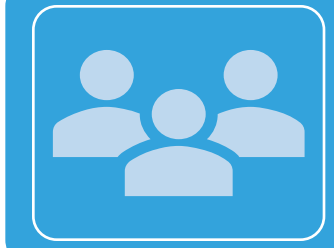


## Blueprint process guidance

- Objective decision making
- Making principles practical

## Good practices

- Learning to deal with modern technology
- Tech affordability
- Resistance to innovations
- …



## Workshops with management, workforce, …

- Idea implementation within organisation
- Gap between end-user and developer
- Tech integration

# BUSINESS MODEL OF GOVERNANCE (ECOSYSTEM)

## PROCESS

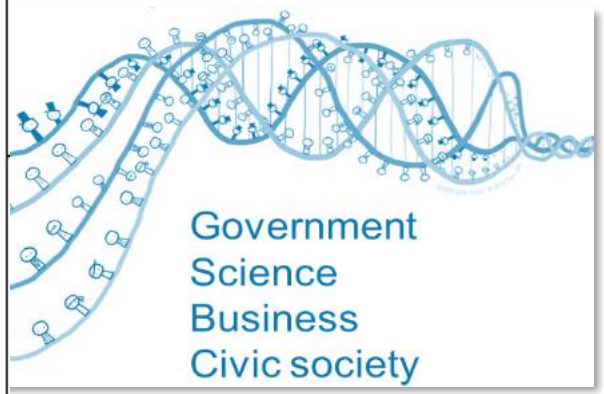
- Data creation/ capture/ curation
- Innovation based on collective data
- Ecosystem of personalized products & services
- A cooperative of citizens

## VALUE

- *A trusted Personal data Platform*
- *Ethics Legislation*

## PEOPLE

- Companies
- Citizens
- Health care providers
- Governments
- Research & innovation




## OUTCOMES

- *Preventive health care*
- *Citizen involvement*
- *Control over own data*
- *Fair competition*

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# we are

- A citizen-centric ecosystem
- **Separating data from applications**
- Shaping applications

**Digital Technology**

Move freely between services

Reuse data across APPS

Connect with anyone

Select what you share precisely

# TECHNOLOGY

we are

Vague but exciting ...

CERN DD/OC

Tim Berners-Lee, CERN/DD

Information Management: A Proposal

March 1989

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# Information Management: A Proposal


## Abstract

This proposal concerns the management of general information about accelerators and experiments at CERN. It discusses the problems of loss of information about complex evolving systems and derives a solution based on a distributed hypertext sytstem.


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First web page online 1990
Anyone can use the web
Decentralized architecture
Developers free to innovate
Royalty-free (decision by CERN 1993)
World Wide Web Consortium “W3C” for standardization

First web page online 1990
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World Wide Web Consortium “W3C” for standardization

**CONVERGENCE**: platforms and companies that combine and bundle many web-based services

- Loss of personal data to large organizations
- Loss of individual control of personal data
- Loss of level playing field, innovation

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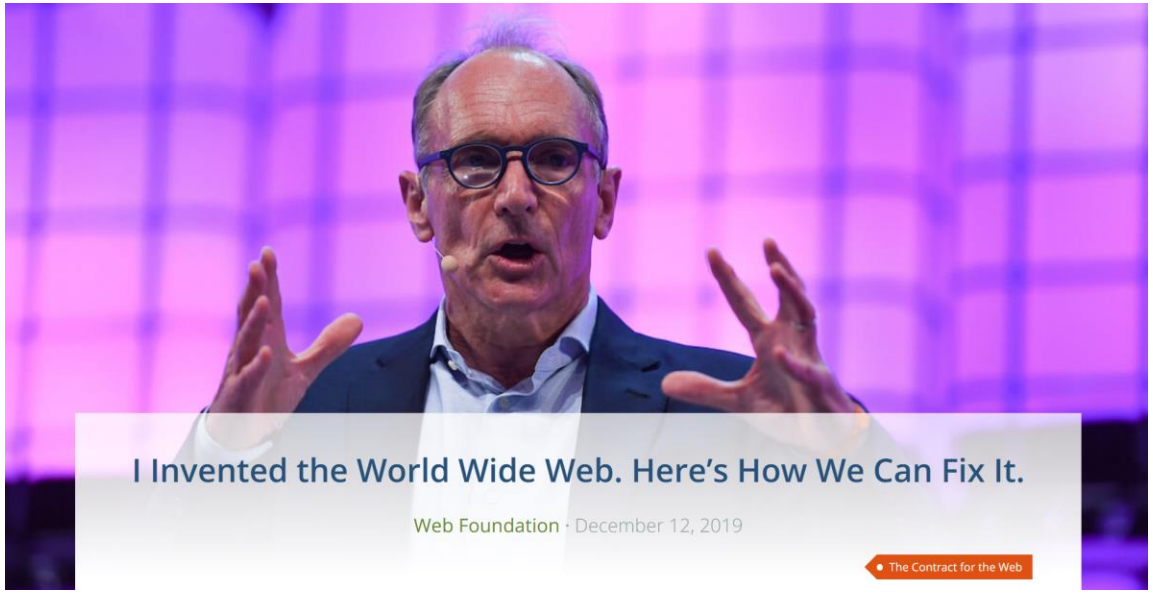
# “FIXING THE WEB”




https://webfoundation.org/2019/12/i-invented-the-world-wide-web-heres-how-we-can-fix-it/

https://contractfortheweb.org/

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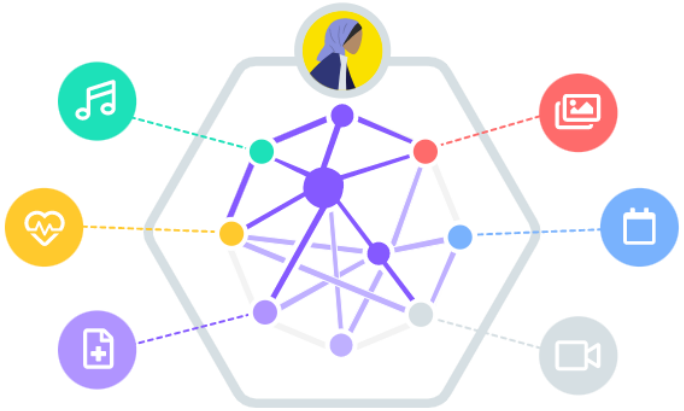
https://solidproject.org/

## SOLID

is a technical specification and architecture

- Originating from MIT
- Combination of W3C standards
- Builds on top of the existing Web

that lets people store their data securely
in decentralized data stores called Pods.



## A SOLID POD is

A website with data
Hosted by a webserver
Application agnostic interface
Can contain any data
Comply with Linked Data standards and using RDF

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# Technological challenges

- How do I run my Pod?
- How do I keep track of my data sharing connections?
- Can a partner also query my data directly?
- Can I delegate my data sharing to a trusted partner?

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# Technological challenges

- How do I run my Pod?

  Pod providers: companies or organizations that host your Pod

  - commercial
  - government public service
  - Flanders -> Data Utility Company

# Technological challenges

- How do I keep track of my data sharing connections?

  Via your Web Agent, software layer around your Pod

  Theoretical Example: Facebook on Solid
  - You tell your web agent to give FB access to the “Facebook” part of your Pod
  - You put your posts and comments in your Pod
  - Web agent notifies FB of new updates

  What’s the difference?
  - Original, and up-to-date, data, resides with you, under your control
  - You can switch to a FB competitor any time

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# Technological challenges

- Can a partner also query my data directly?

Effective querying of data assumes:

a data model (relational, XML, RDF, JSON, graph, …)
a query language (SQL, XPath, SPARQL, …)
agreement on form, organization, structure of data (**schema**)

Example: Facebook

FB advertises a schema in which they expect your posts and comments

Data in your Pod may be organized differently!
You may be using more than one app for your posts

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# Technological challenges

- Can a partner also query my data directly?

**Mediator**

Software that performs schema mapping
Transforms source schema to some target schema

POD query

Schema mapping serves double purpose: also restrict data sharing

Web community is building a schema mapping language standard

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# Technological challenges

- Can I delegate my data sharing to a trusted partner?

  Sure!

  Decentralized web of personal data can be a true network

  Citizens can give (partly, conditional, …) access to an aggregator

  That aggregator can then negotiate in the name of its clients with further partners

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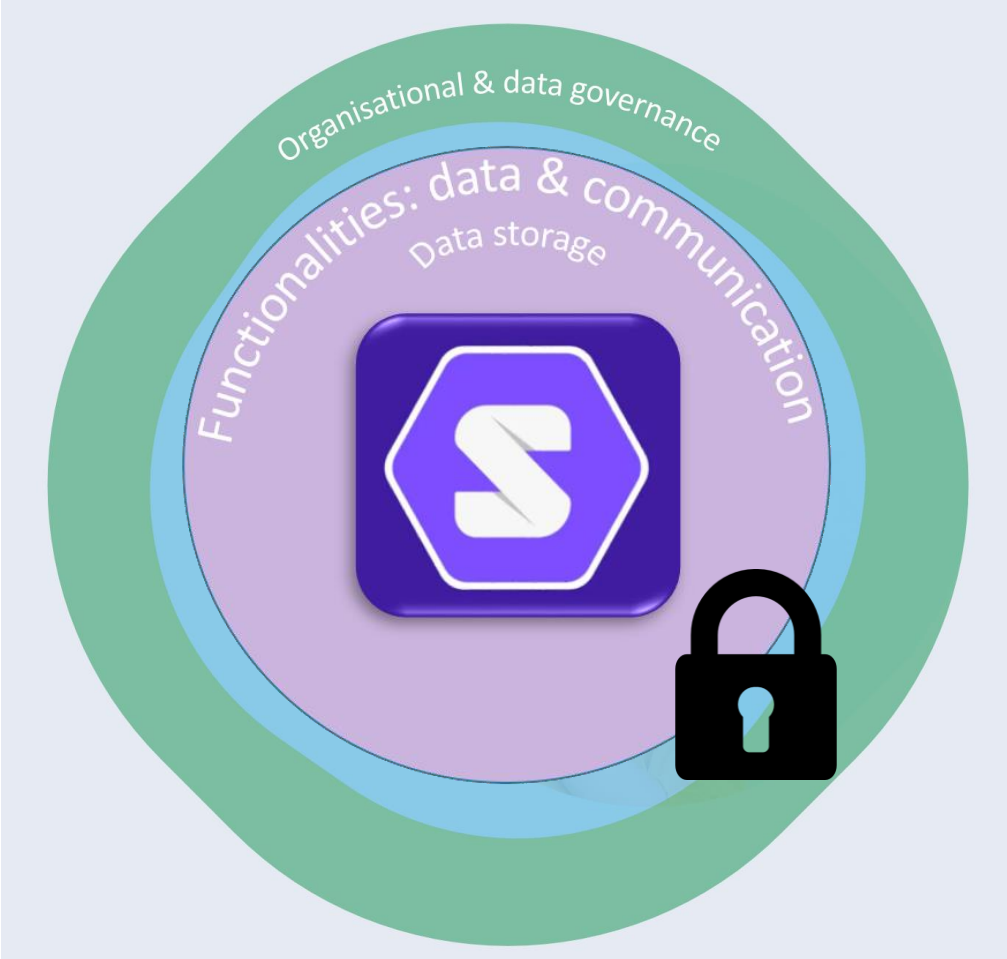
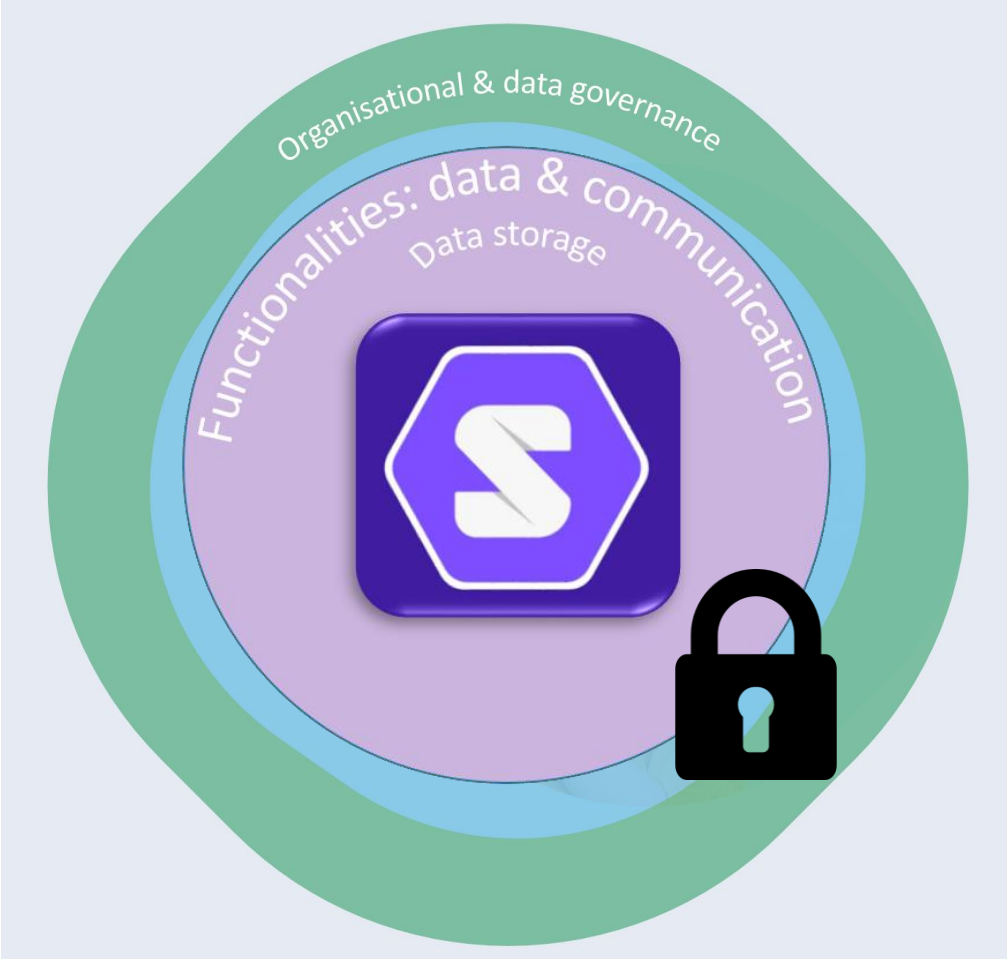
# TECHNOLOGY

we are




# TECHNOLOGY

we are




data utility company
*Server hosting*

DIGITAAL VLAANDEREN

SolidLab
*Expert advice*

DEPARTEMENT ECONOMIE WETENSCHAP & INNOVATIE

IT industry / SMEs
*Consultancy*

IT industry / SMEs
*App development*

TECHNOLOGY

we are

vito

# we are

- A citizen-centric ecosystem
- Separating data from applications
- **Shaping applications**

**Innovation**

Organisational & data governance

Functionalities: data & communication

Data storage

**Citizen-centric Approach** » **Citizen**

R&D innovation

Personalised products & services

# INNOVATIONS APPLICATIONS

we are

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save data

AGENTSCHAP INNOVEREN & ONDERNEMEN

https://savedata.be/en

- ***COOCK:*** Collective R&D and Collective knowledge sharing/dissemination
- ***PURPOSE:*** Valorizing (basic) research results by accelerating the introduction of technology and/or knowledge to a broad group of companies.

vito vision on technology

imec

flanders.healthTech bridging technologies for healthcare innovation

**Define relevant Use Cases**

**Define the Business Case**

**Request for Funding (or not)**

**Implement Use Cases**

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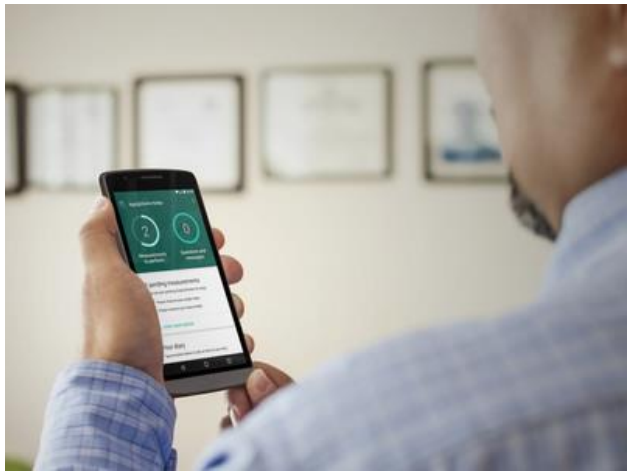
# USE CASE: TELEMONITORING

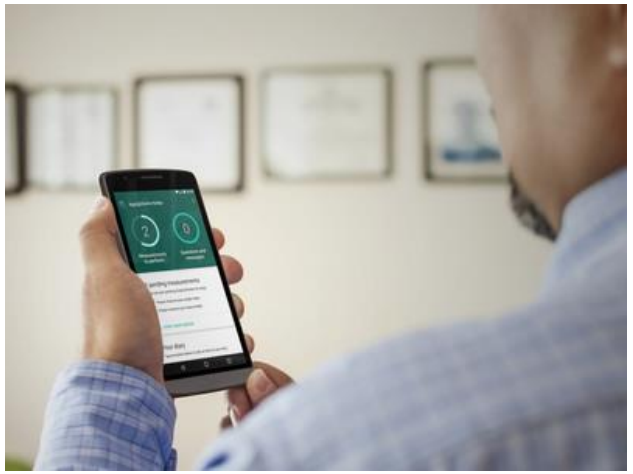


- J&J en BeWell:

- CLL: Chronic lymphocytic leukaemia
  - Treatment
  - Watch & wait

- Goal: expand telemonitoring to watch & wait
  - Greater need for follow up
    - Uncertainty
    - Impact on quality of life

# USE CASE: TELEMONITORING



janssen | PHARMACEUTICAL COMPANIES OF Johnson & Johnson

BeWell innovations

## Needs in this use case

- Give patients more control
- Get applications linked to data to improve quality of life & follow-up
  - Personalized advice
  - Contact health care professional when problems arise
- Attention to ethical & legal framework

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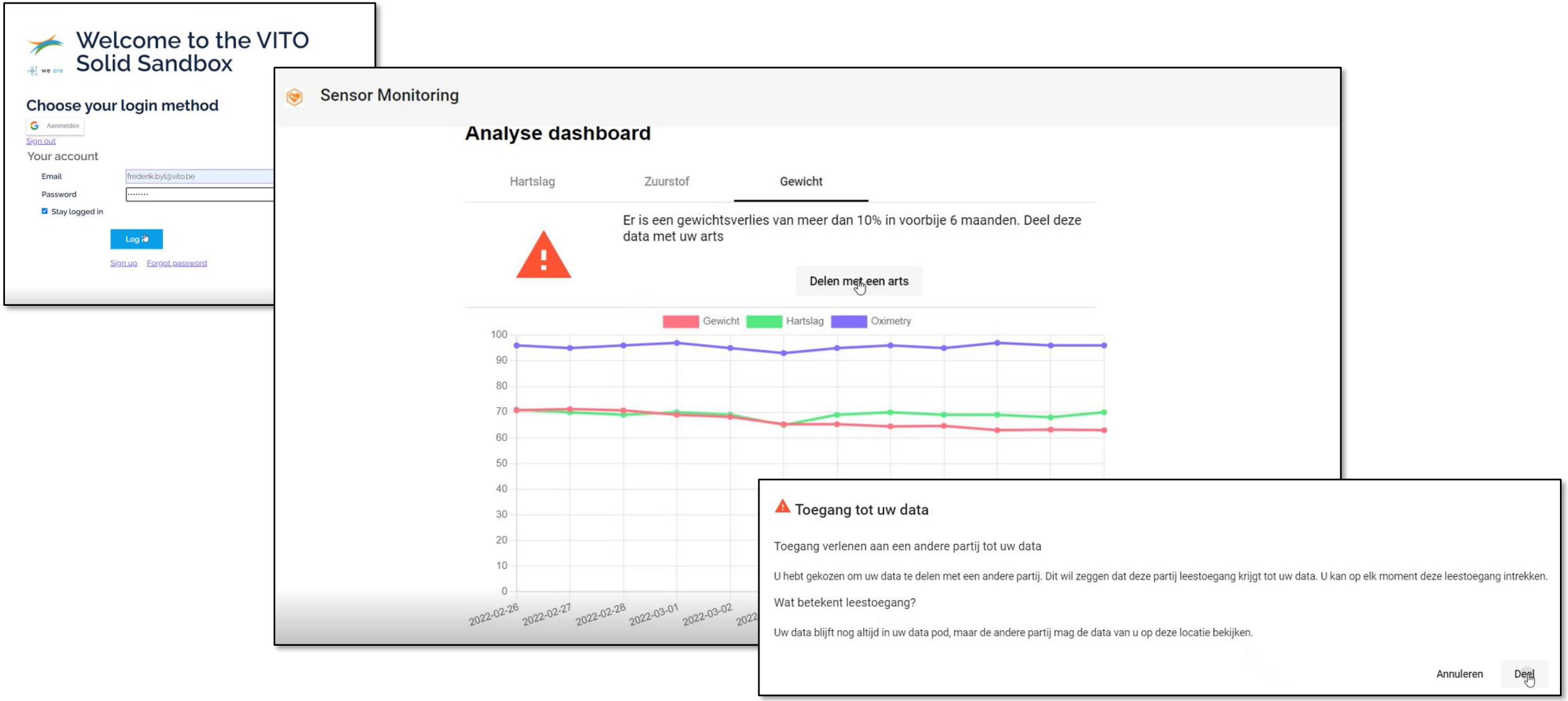
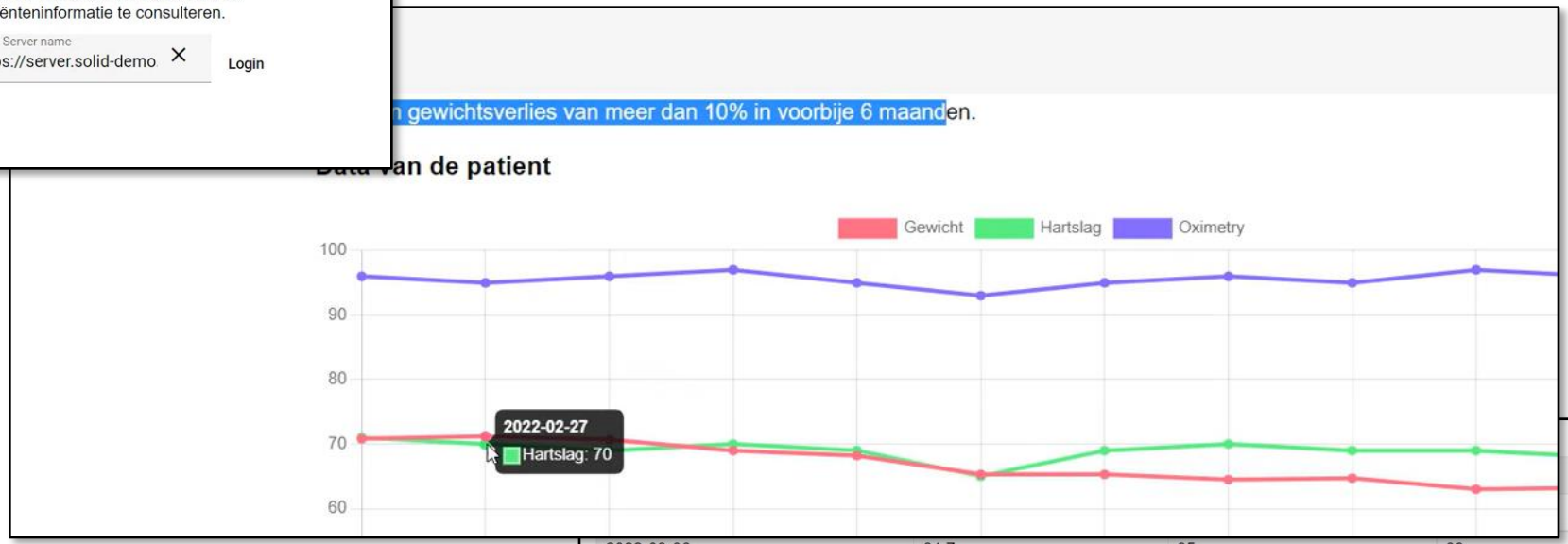
# PATIENT CONTROLS PERSONAL HEALTH SENSOR DATA



# GENERAL PRACTITIONER MONITORS & PROVIDES FEEDBACK




| | | | |
|---|---|---|---|
| 2022-03-06 | 64.7 | 95 | 69 |
| 2022-03-07 | 63 | 97 | 69 |
| 2022-03-08 | 63.2 | 96 | 68 |
| 2022-03-09 | 63 | 96 | 70 |

**Beantwoorden**

Geef feedback

Beste Frederik, uw oximetry en hartslag liggen binnen de voor u acceptabele grenzen. Een gewichtsverlies van 10% over 6 maanden kan wijzen op een onderliggend probleem. Gelieve zo snel mogelijk een afspraak te maken om verder te onderzoeken.
Vriendelijke groeten,
Jens

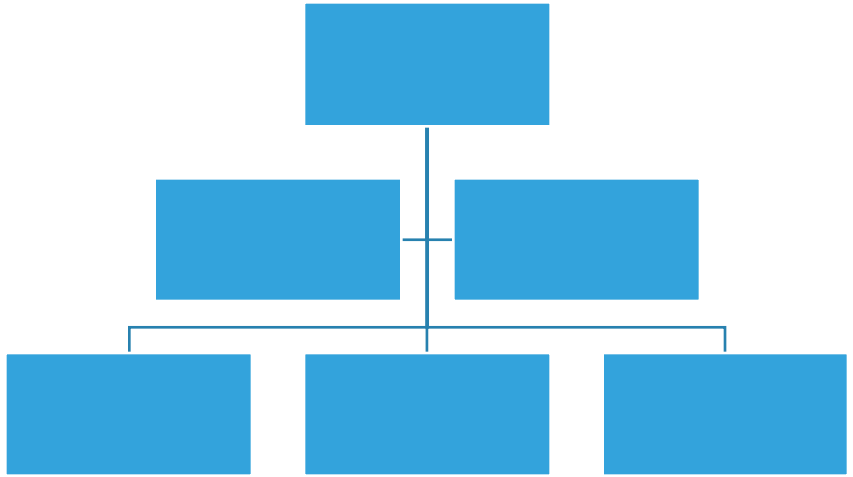
Verstuur

save data

vito

# LOCAL - FLANDERS - INTERREGIONAL

we are



# EMPOWER CITIZENS ON HEALTH PROMOTION

BIBOPP

**Tools** for **self-management** on **health promotion** and **prevention**

**Co-creation** and **participation** with **all stakeholders**

vito domus medica LiCalab Living & Care

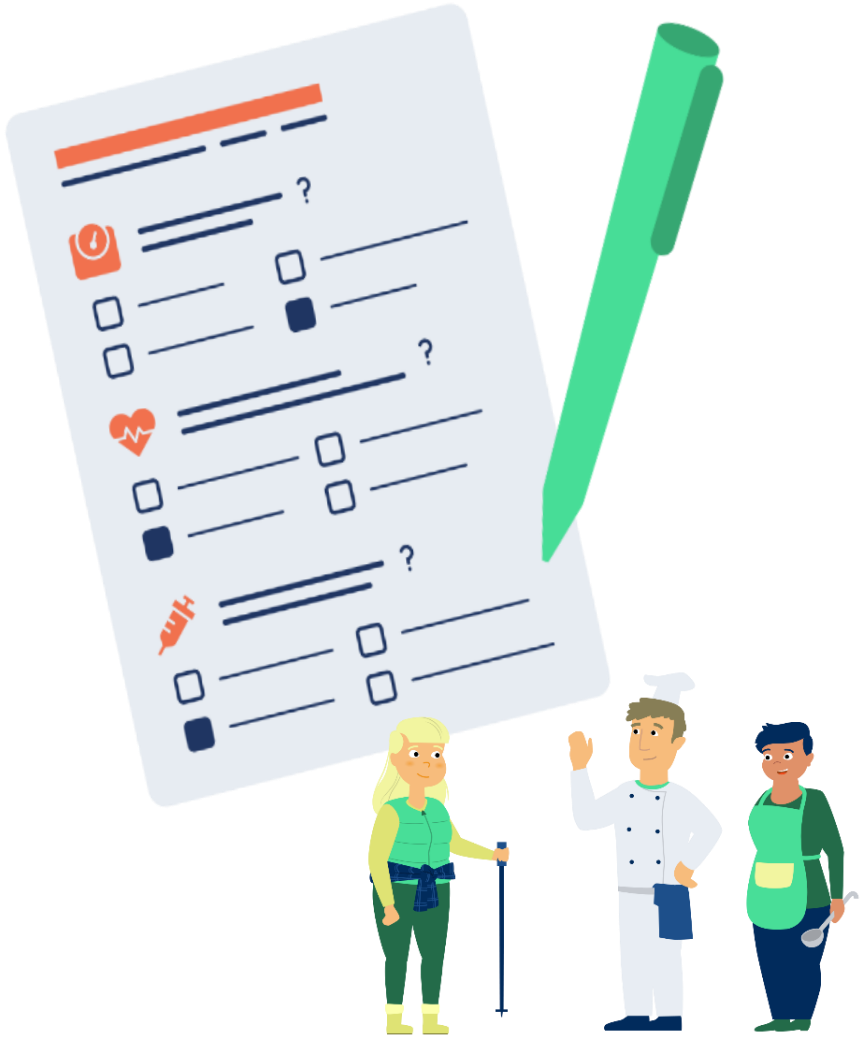
vito

# CREATION AND CAPTURE OF PERSONAL HEALTH DATA

## REAL WORLD DATA

Online surveys

Through digital services



Medical background

Lifestyle

Behavior

Personal preferences

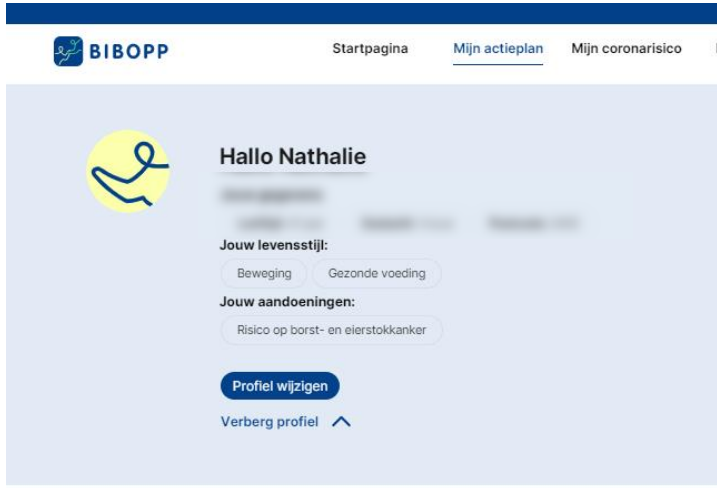
…

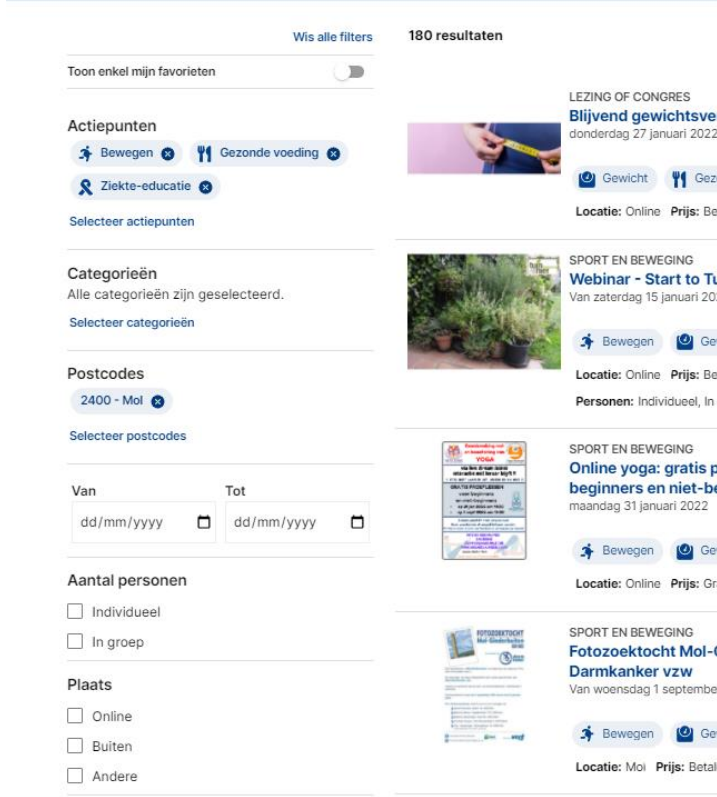
domus medica

GEZONDHEIDSGIDS

vito

# REUSE OF DATA




Hallo! Ik ben Bob, de automatische gesprekspartner van BIBOPP. Ik help je graag bij vragen.

Hoe werk ik? Ik stel een aantal vragen. Ik laat verschillende antwoorden zien. Klik op het antwoord dat past bij je vraag.

Laten we starten! Waarover gaat je vraag precies?

Klik op één van de knoppen om te antwoorden:

# CITIZEN

Based on **health-related needs** and **wishes,** through **human-centered design**

Interreg 2 Seas Mers Zeeën EMPOWERCARE

European Regional Development Fund

Koning Boudewijnstichting

*Samen werken aan een betere samenleving*

With **Health and digital literacy** organizations

True **informed consent:** We Are

# CARE PROVIDER

**Integrated care**

Technological: connected to national eHealth platform (EHR)

Referral: different actors primary care zones

**Evidence-based** population screening

Interreg 2 Seas Mers Zeeën EMPOWERCARE

Koning Boudewijnstichting
*Samen werken aan een betere samenleving*

DOMUS MEDICA

EERSTELIJNSZONE

TURNHOUT

BALDEMORE

# POLICY

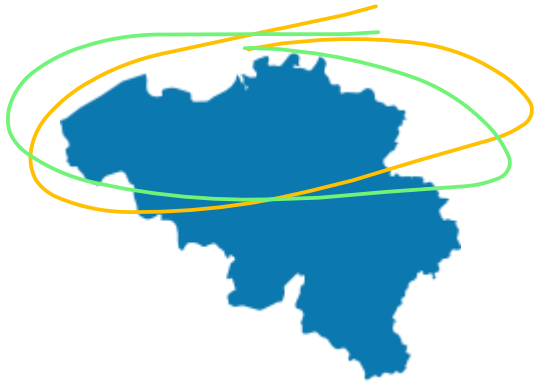
**Population Health Management** based on real-life data

**Participation**: co-creation and follow-up

## R&D

Blueprint on implementation of **caring technologies**

we are



AGENTSCHAP INNOVEREN & ONDERNEMEN

Interreg EUROPEAN UNION

**Support to share data** for **own well-being** and **public interest**,

Allow **ownership** of data

**34th International Conference**
**on Advanced**
**Information Systems Engineering**

06/06/2022 - 10/06/2022, LEUVEN 2022

https://we-are-health.eu
https://bibopp.be

# THANK YOU

Jef Hooyberghs, VITO - UHasselt