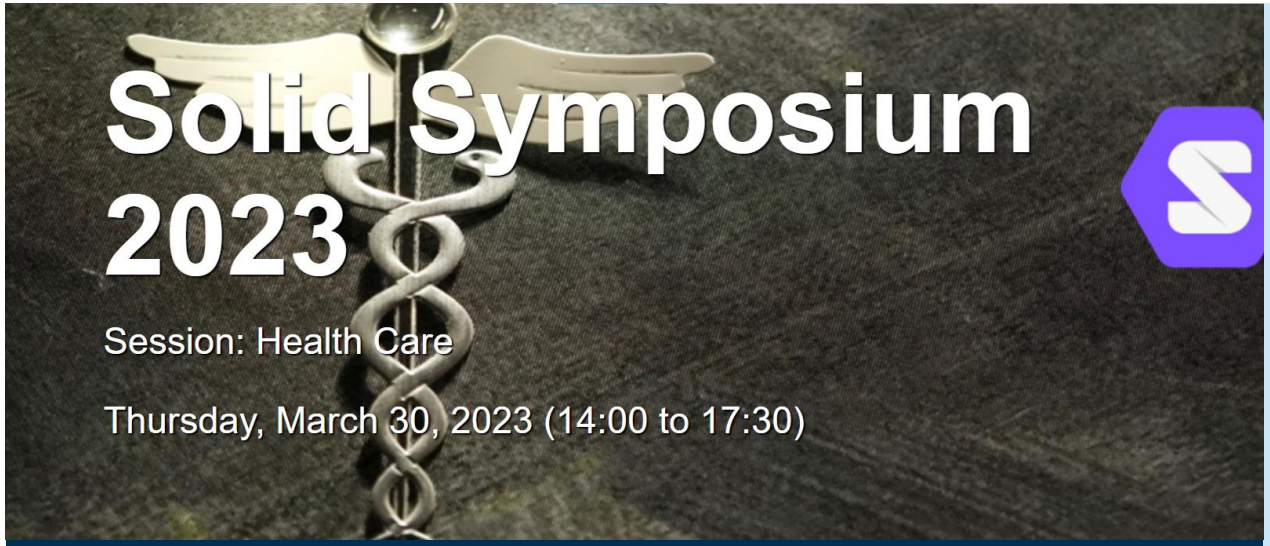


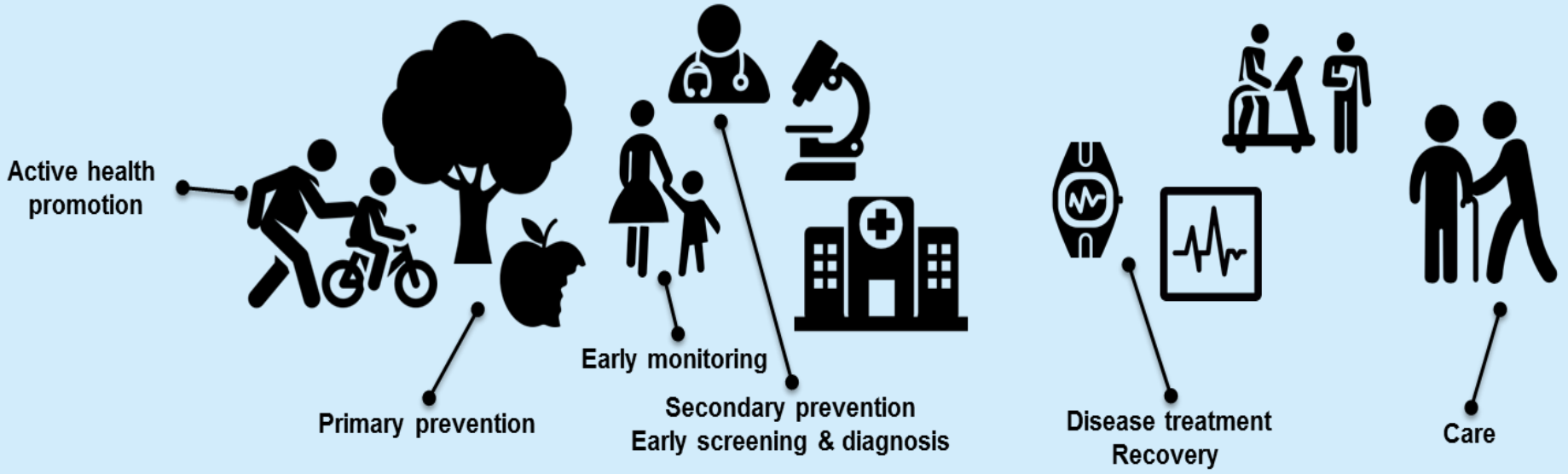
A CITIZEN-DRIVEN ECOSYSTEM FOR PERSONAL HEALTH DATA

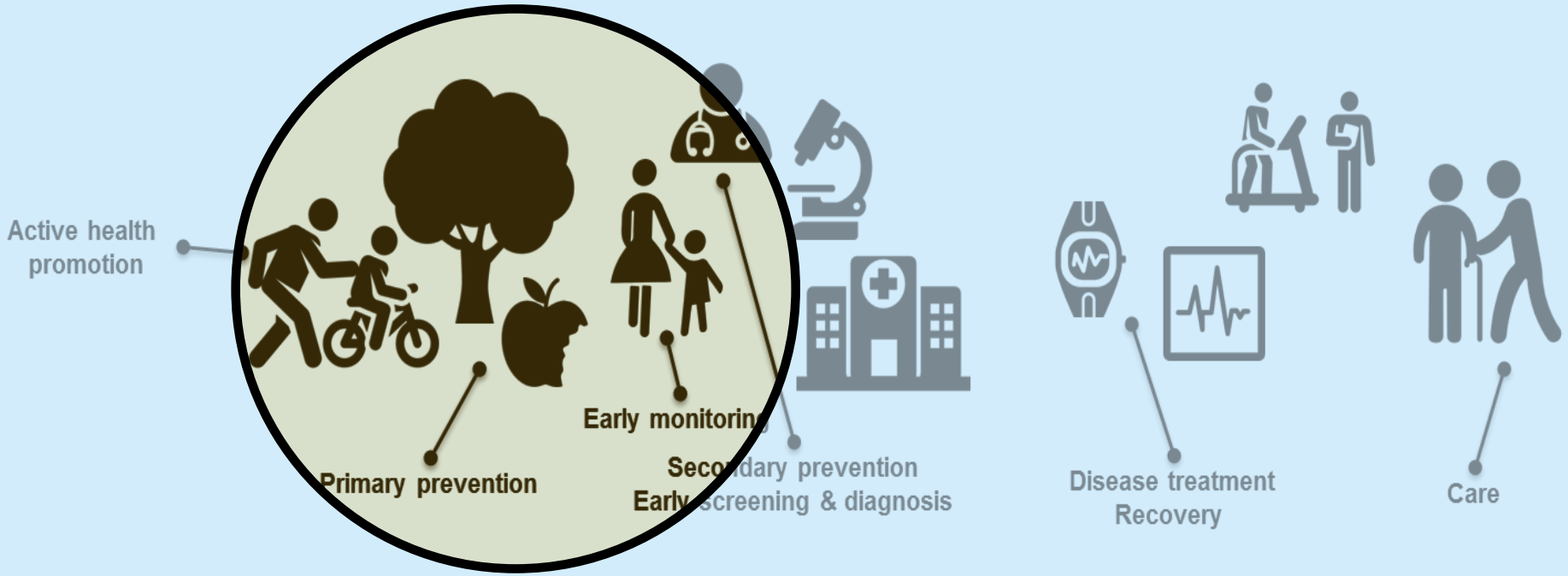
Nürnberg, Fraunhofer Augustiner Hof
30 March 2023

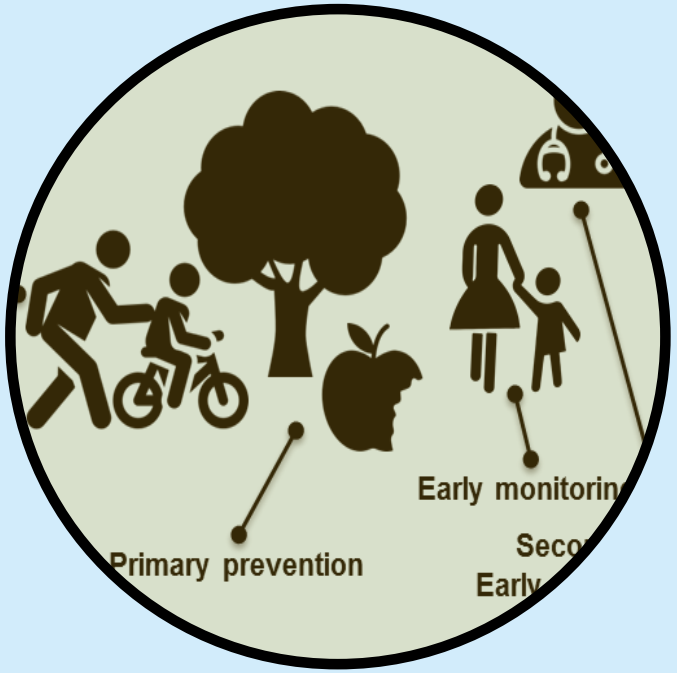
Slot:
Effects of decentralized health data in society, politics and EU-Data initiatives

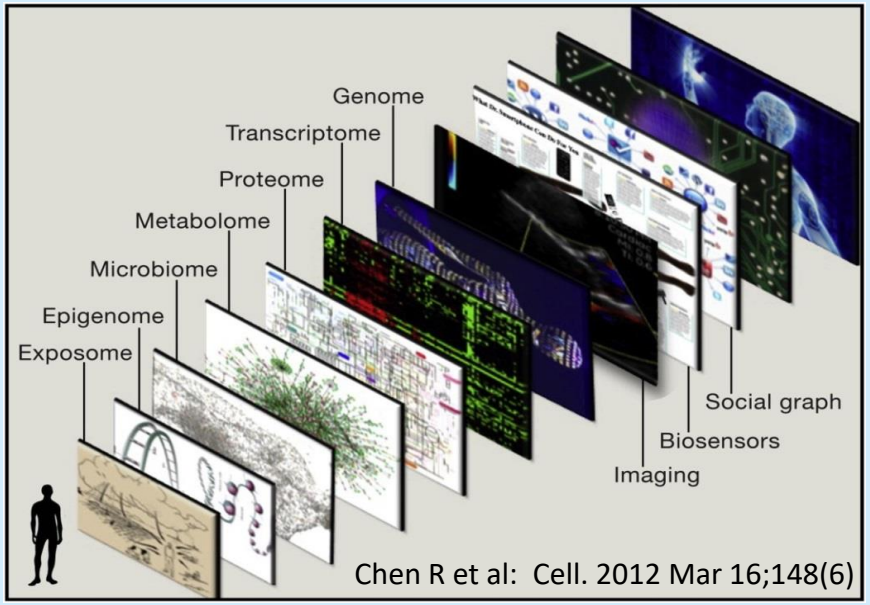
we are

Jef Hooyberghs
VITO – UHasselt
Belgium


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

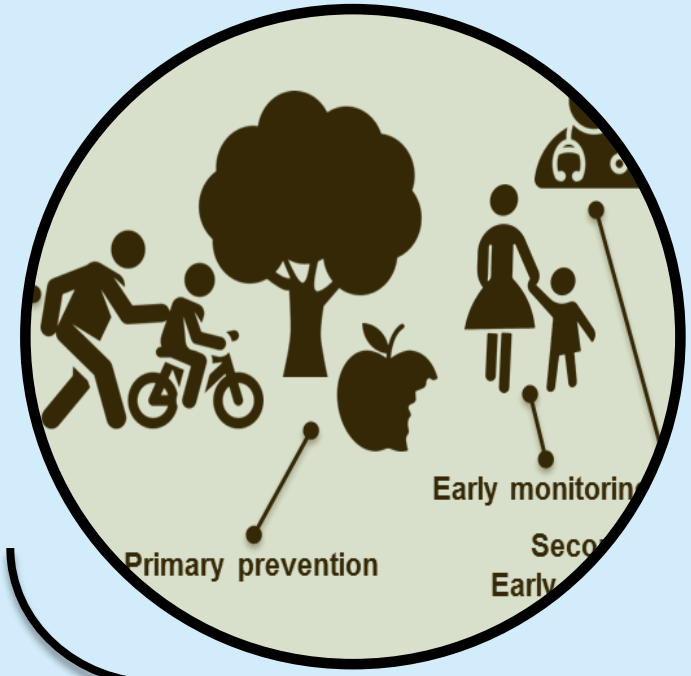

Active health promotion
Primary prevention
Early monitoring
Secondary prevention
Early screening & diagnosis
Disease treatment
Recovery
Care

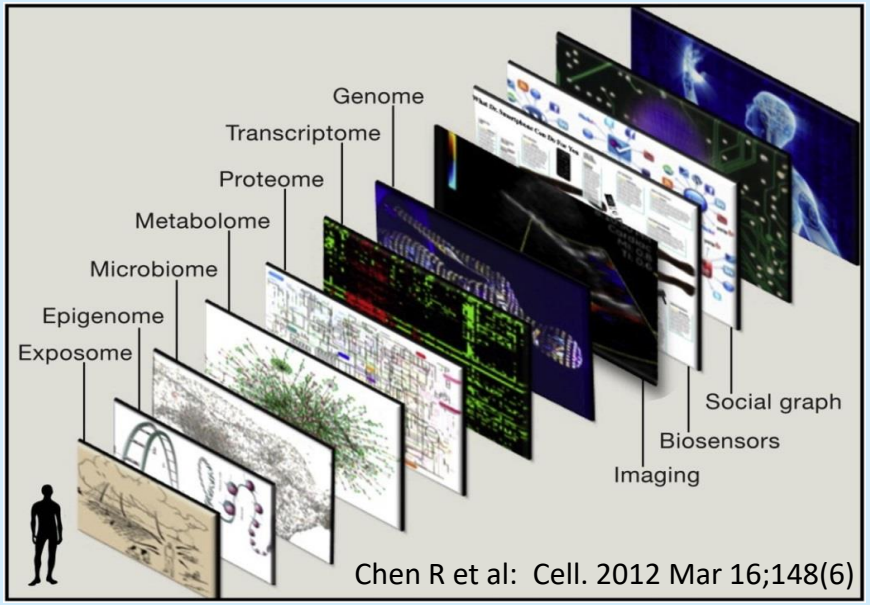




INTEGRATIVE PERSONAL OMICS PROFILE

vito





Chen R et al: Cell. 2012 Mar 16;148(6)

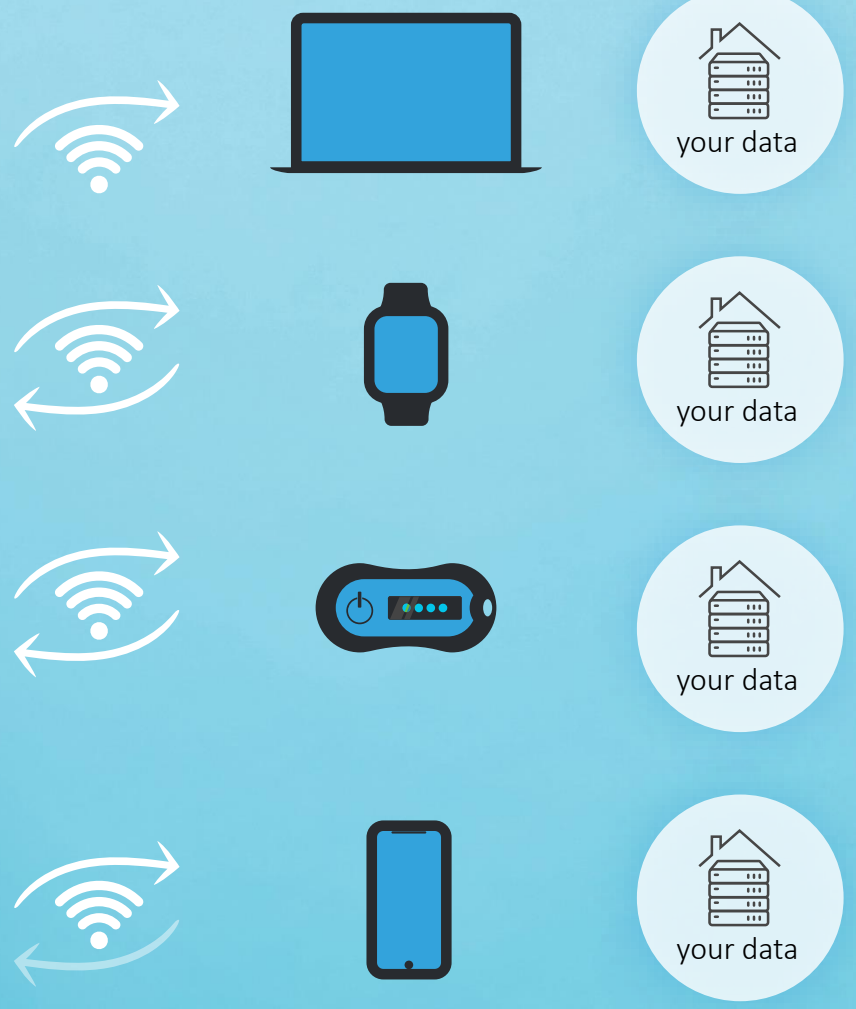
DATA DRIVEN PREVENTION

HIGHLY DIVERSE SET OF DATA

INDIVIDUAL DATA

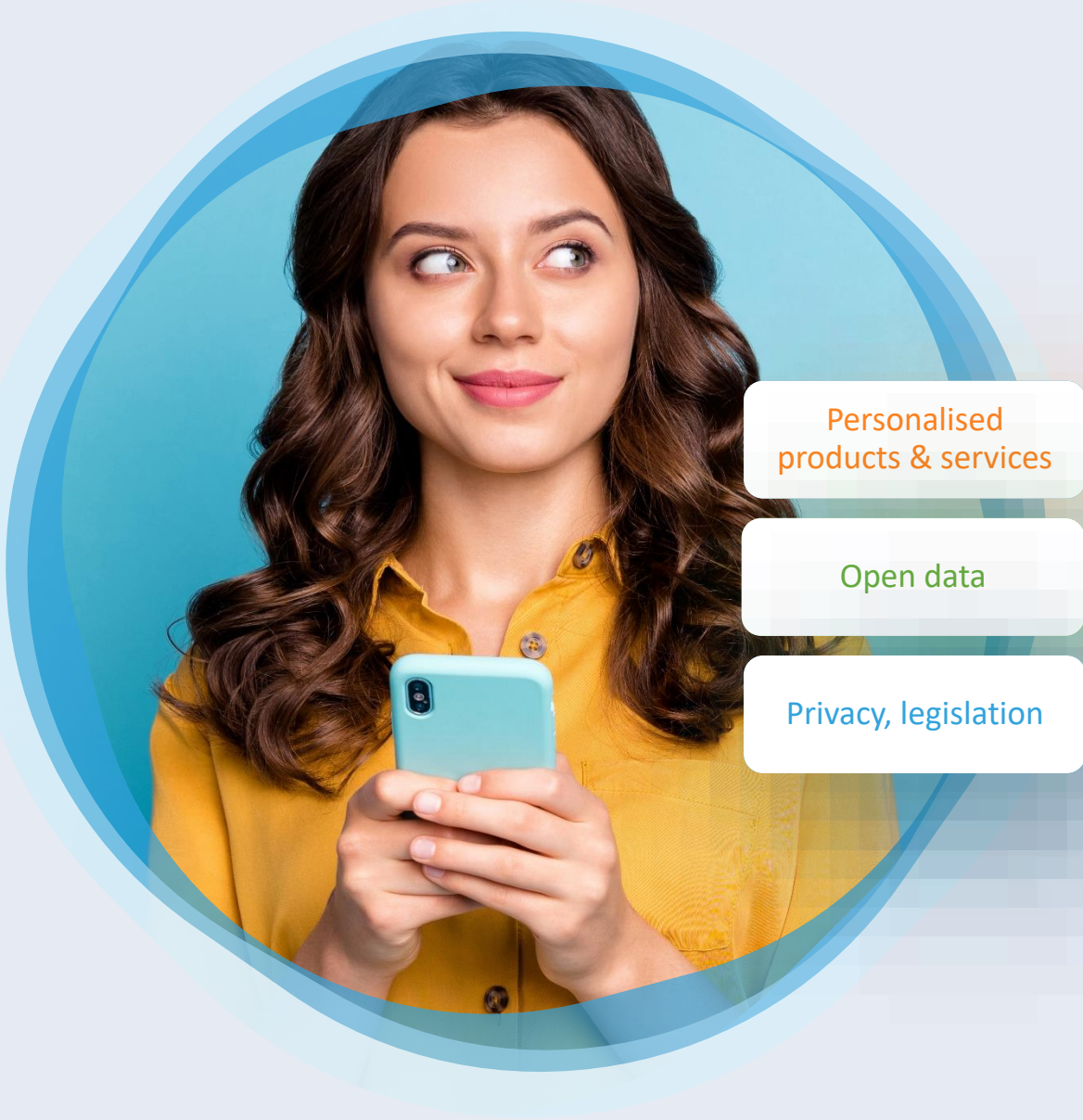
LONGITUDINAL DATA

vito



CURRENT ECOSYSTEM = APPLICATION-CENTRIC

vito

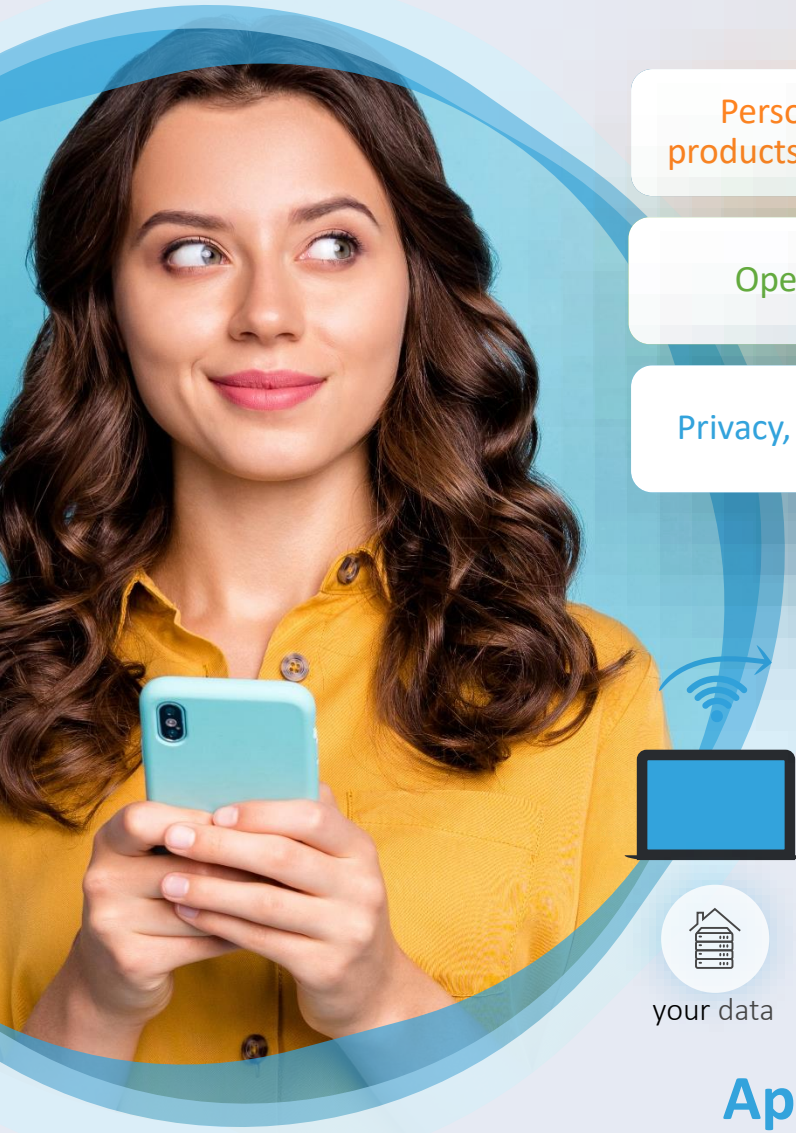


Personalised products & services	»	Data economy
Open data	»	Innovation
Privacy, legislation	»	Protect & engage end users

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

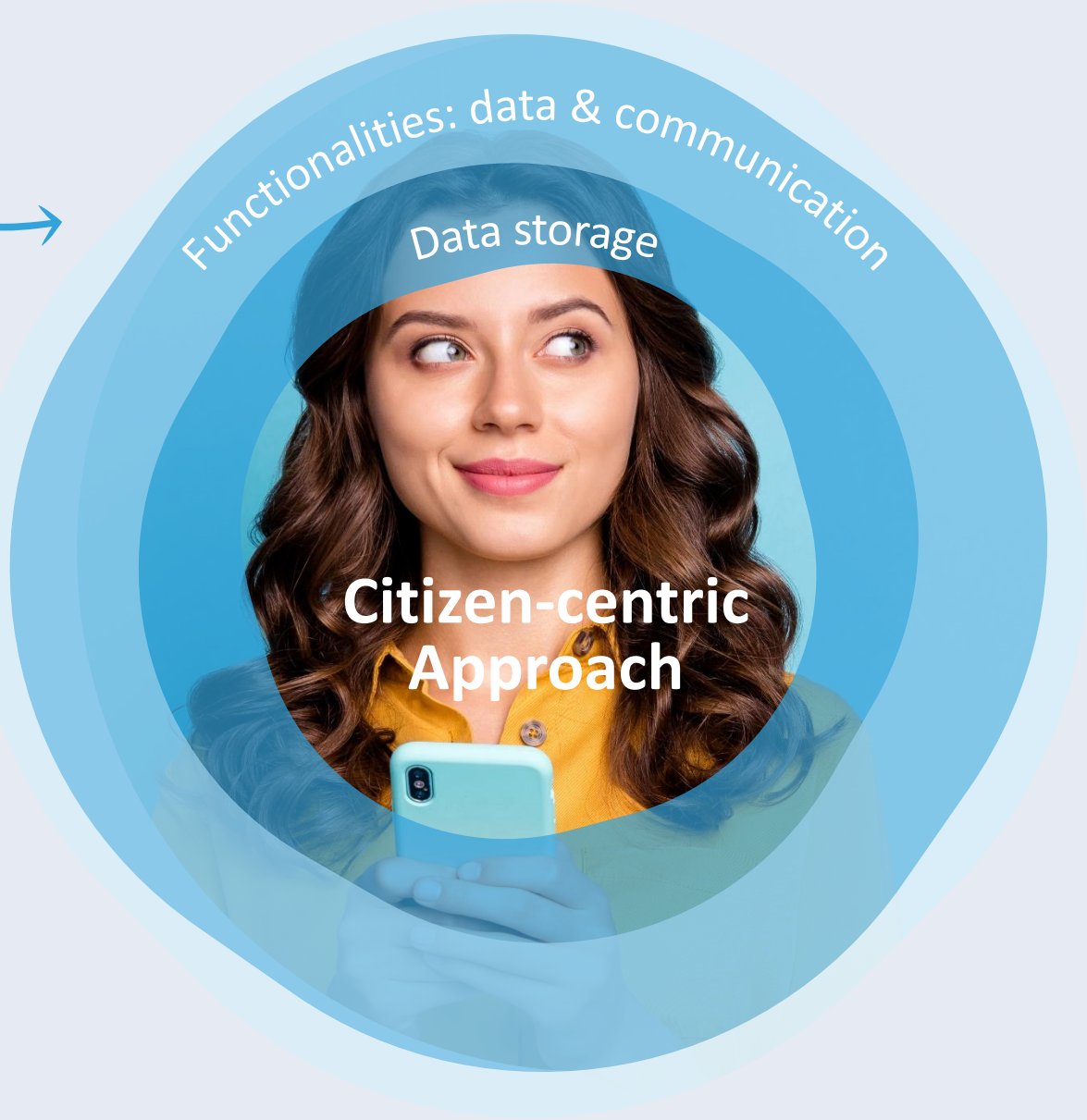
Global & European

vito

CITIZEN-CENTRIC ECOSYSTEM

vito

Creation and capture of personal health data



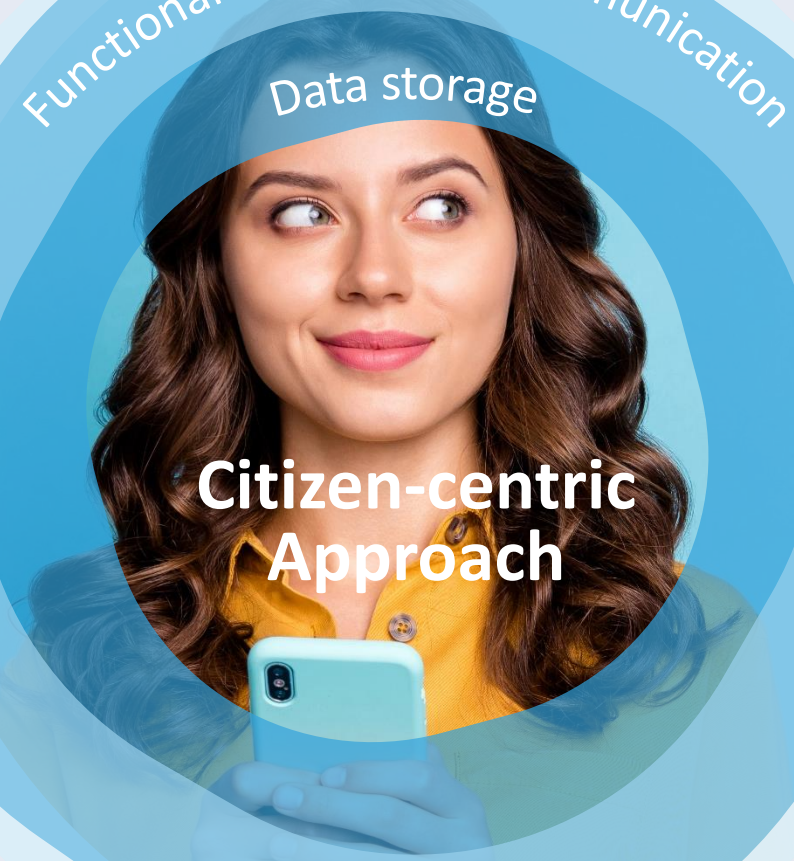
CITIZEN-CENTRIC ECOSYSTEM

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

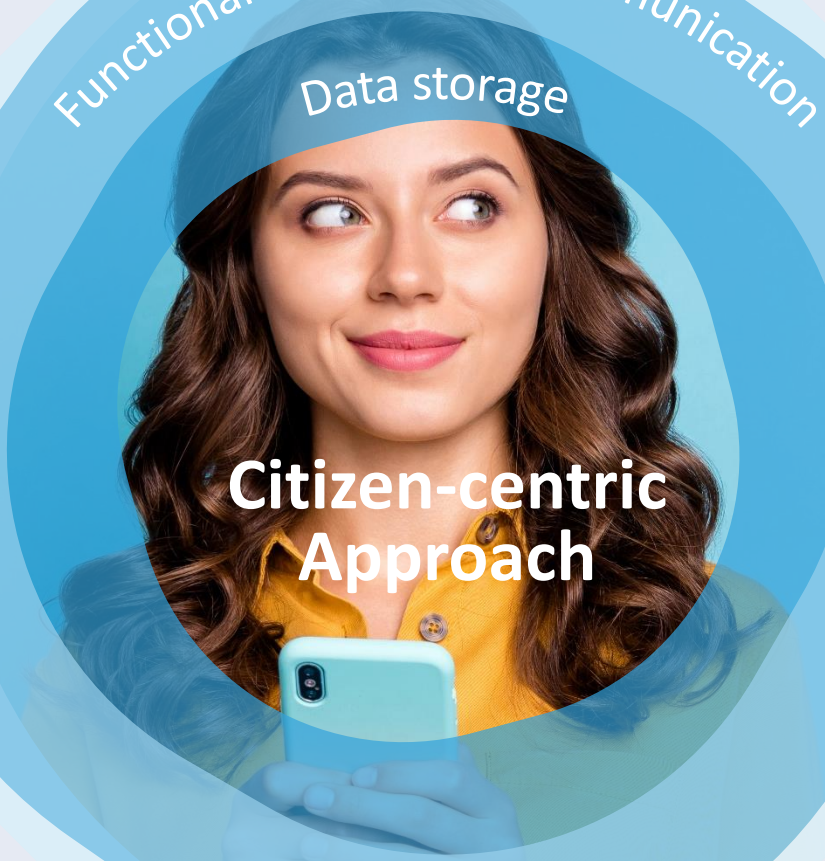
CITIZEN-CENTRIC ECOSYSTEM

vito

Creation and capture of personal health data

Functionalities: data & communication

Data storage



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

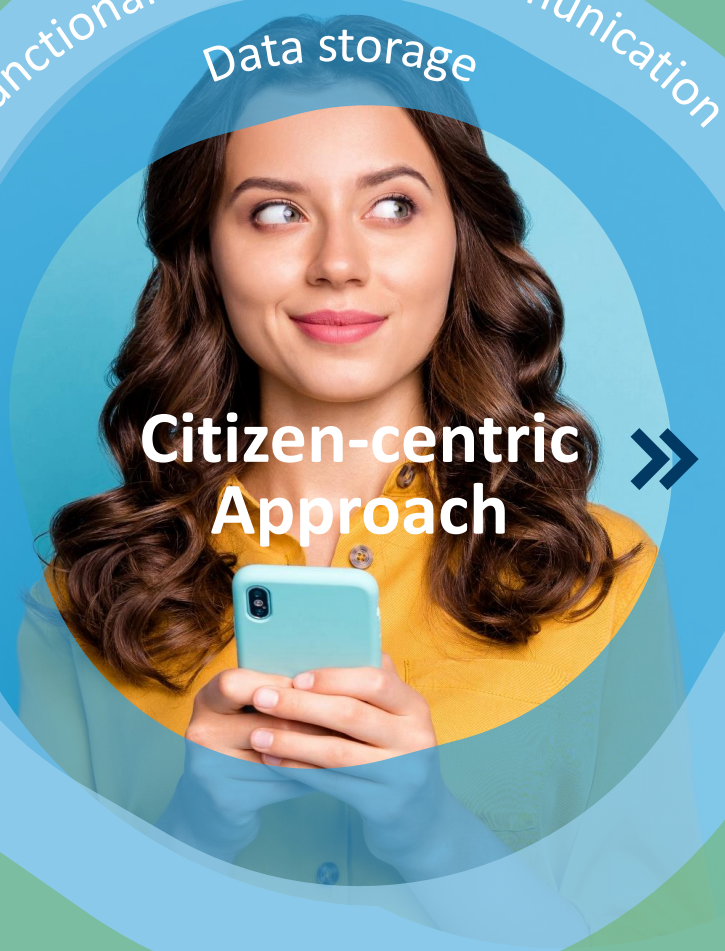
A LEVEL PLAYING FIELD

vito

Organisational & data governance

Functionalities: data & communication

Data storage



Citizen-centric Approach » **Citizen**

R&D innovation

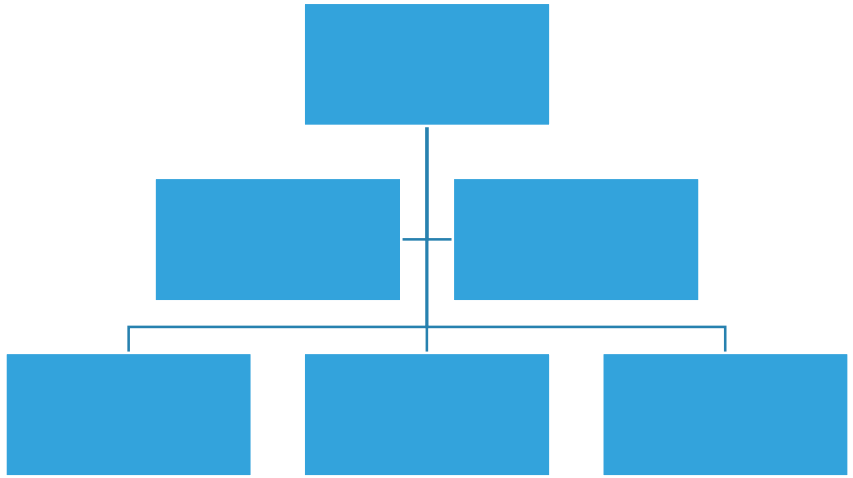
we are

Personalised products & services

vito

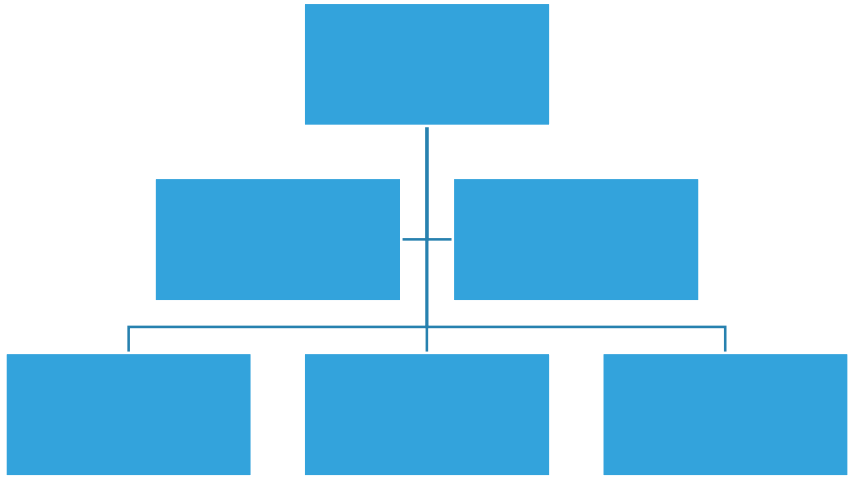
LOCAL - FLANDERS - INTERREGIONAL

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

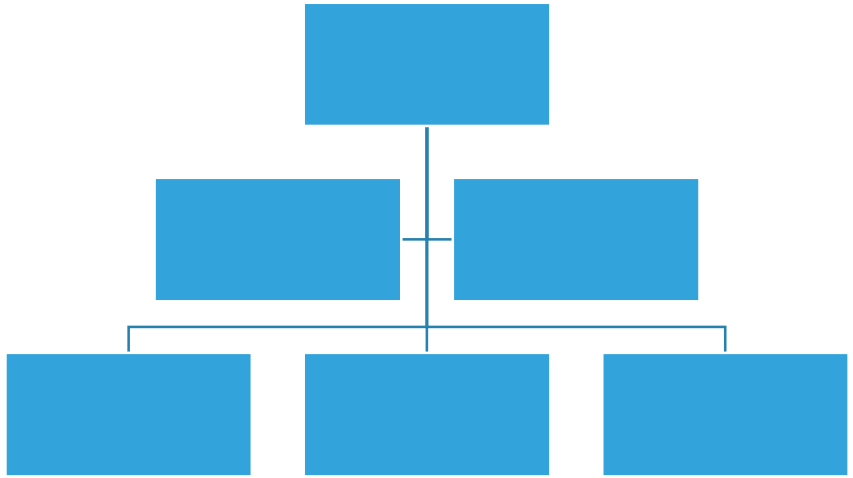
vito

European Commission

Health Priorities in the Digital Single Market Strategy

LOCAL - **FLANDERS** - INTERREGIONAL

we are



PARTNERSHIP

we are

DOMUS MEDICA

zorg net ICURO

vito

Vlaams Patiëntenplatform

Koning Boudewijnstichting

Samen werken aan een betere samenleving

vito

POLICY DOMAINS

we are

INNOVATION

DEPARTEMENT
ECONOMIE
WETENSCHAP &
INNOVATIE

HEALTH

DEPARTEMENT
WELZIJN
VOLKSGEZONDHEID
EN GEZIN

DIGITIZATION

DIGITAAL
VLAANDEREN

vito

KICK OFF

we are

Q3 - 2022

Data Utility Company

DEPARTEMENT ECONOMIE WETENSCHAP & INNOVATIE

DEPARTEMENT WELZIJN VOLKSGEZONDHEID EN GEZIN

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

GUIDING PRINCIPLES

Synergy Privacy & Innovation

Participatory Governance

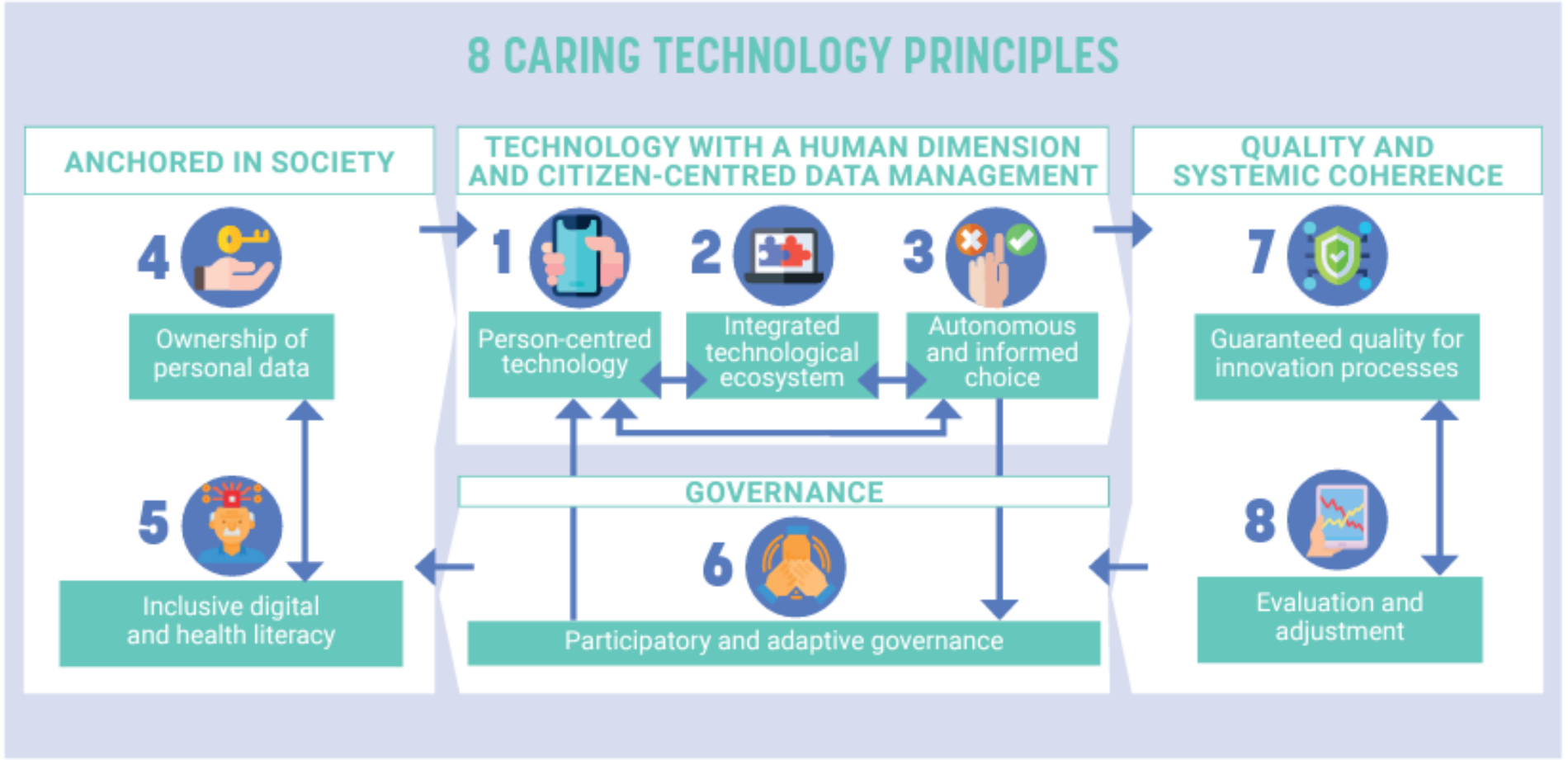
TRUST

we are

Copyright principes: Fonds dr. Daniël De Coninck

vito

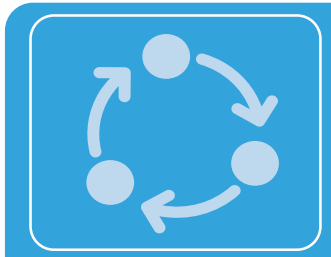
FRAMEWORK OF CARING TECHNOLOGY PRINCIPLES: 8 GUIDING PRINCIPLES



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

vito

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

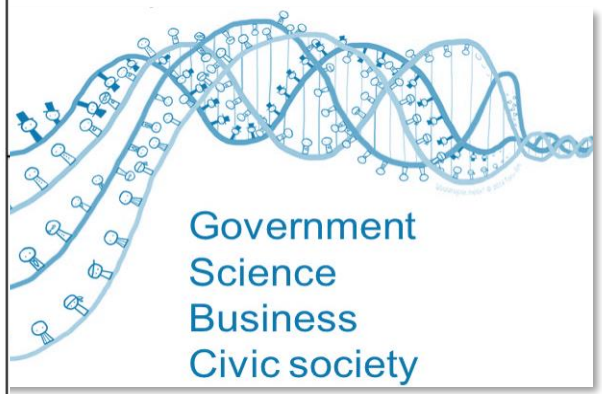
- Data creation/ capture/ curation
- Innovation based on collective data
- Ecosystem of personalized products & services
- A cooperative of citizens

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*

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

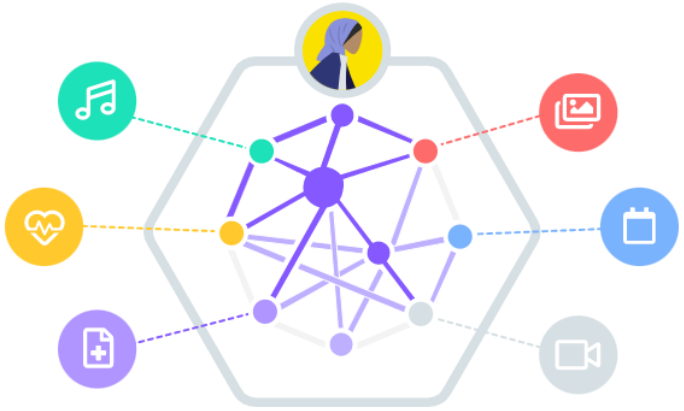
https://solidproject.org/

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

vito

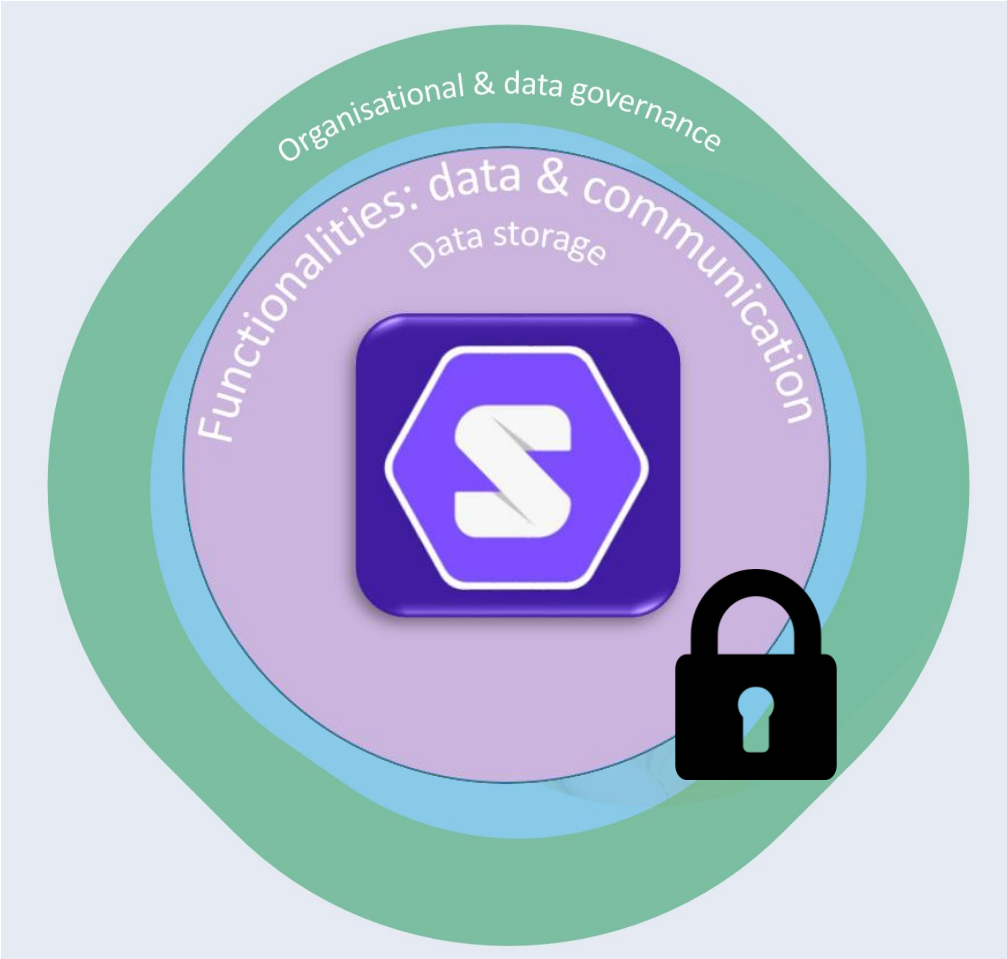
Technological challenges

- 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?

TECHNOLOGY

we are

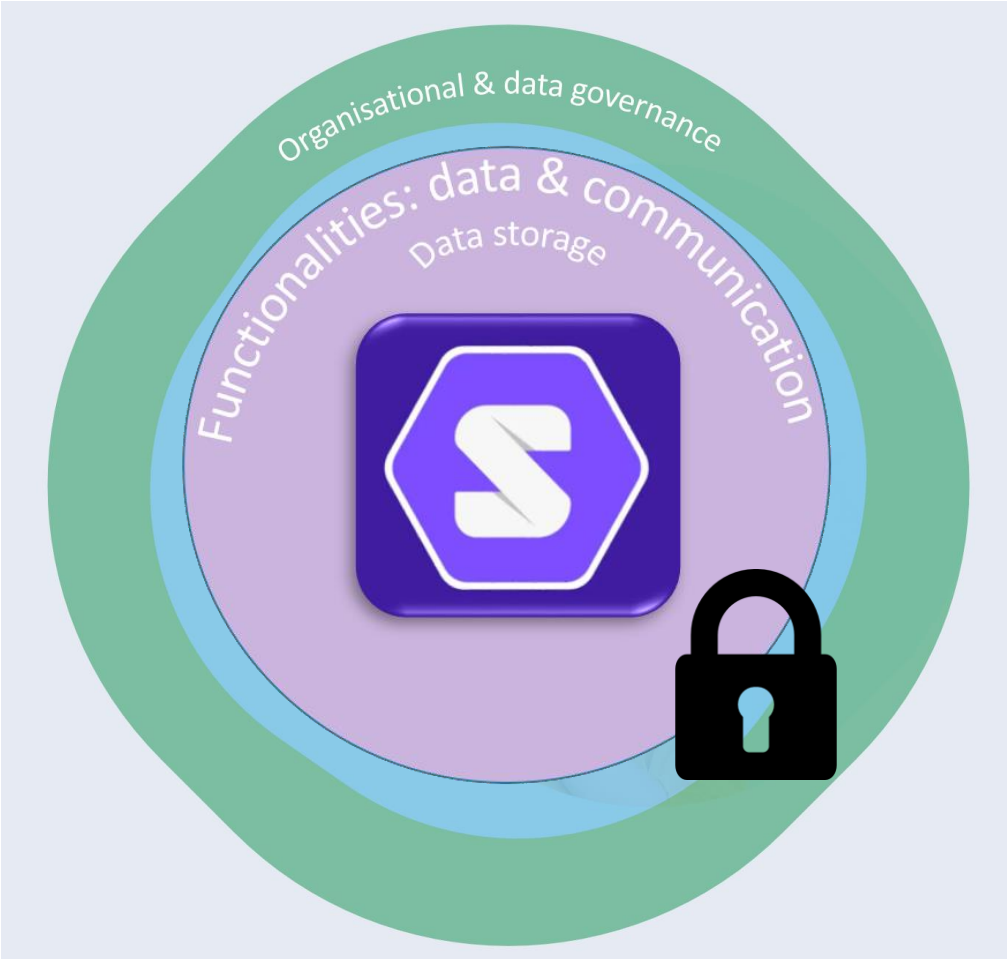
vito



TECHNOLOGY

we are

vito



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

vito

R&D innovation

Personalised products & services

INNOVATIONS APPLICATIONS

we are

vito

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

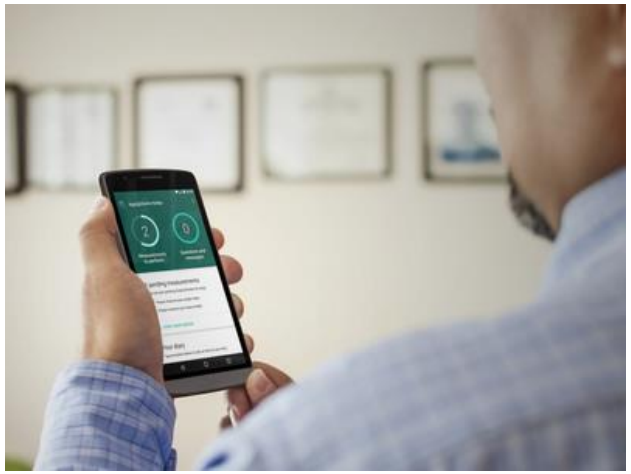
Define the Business Case

Request for Funding (or not)

Implement Use Cases

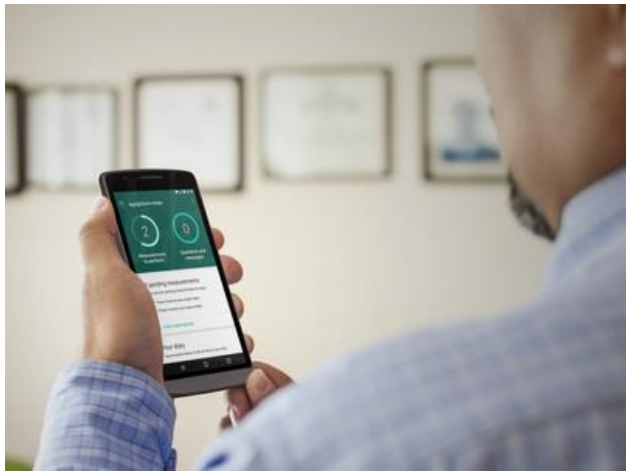
vito

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

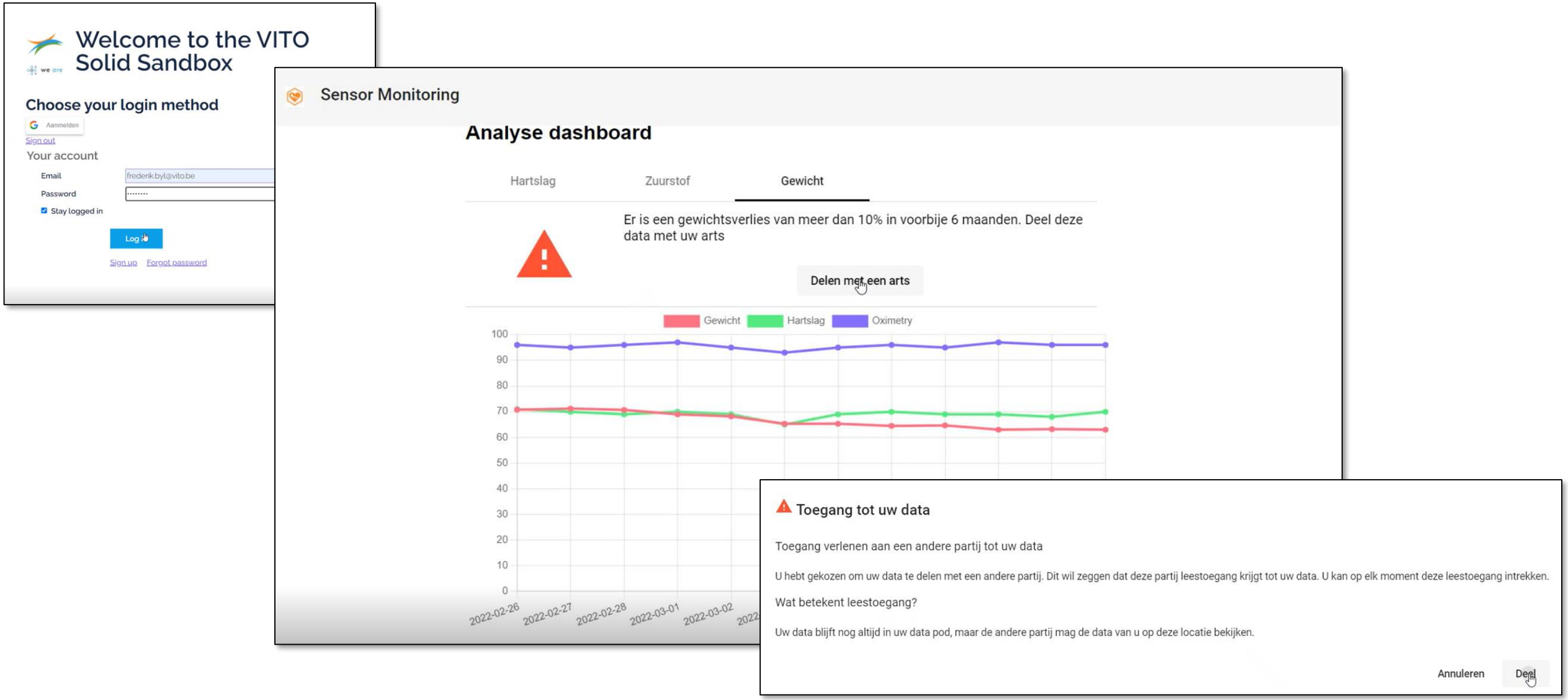
BeWell innovations

Needs in this use case

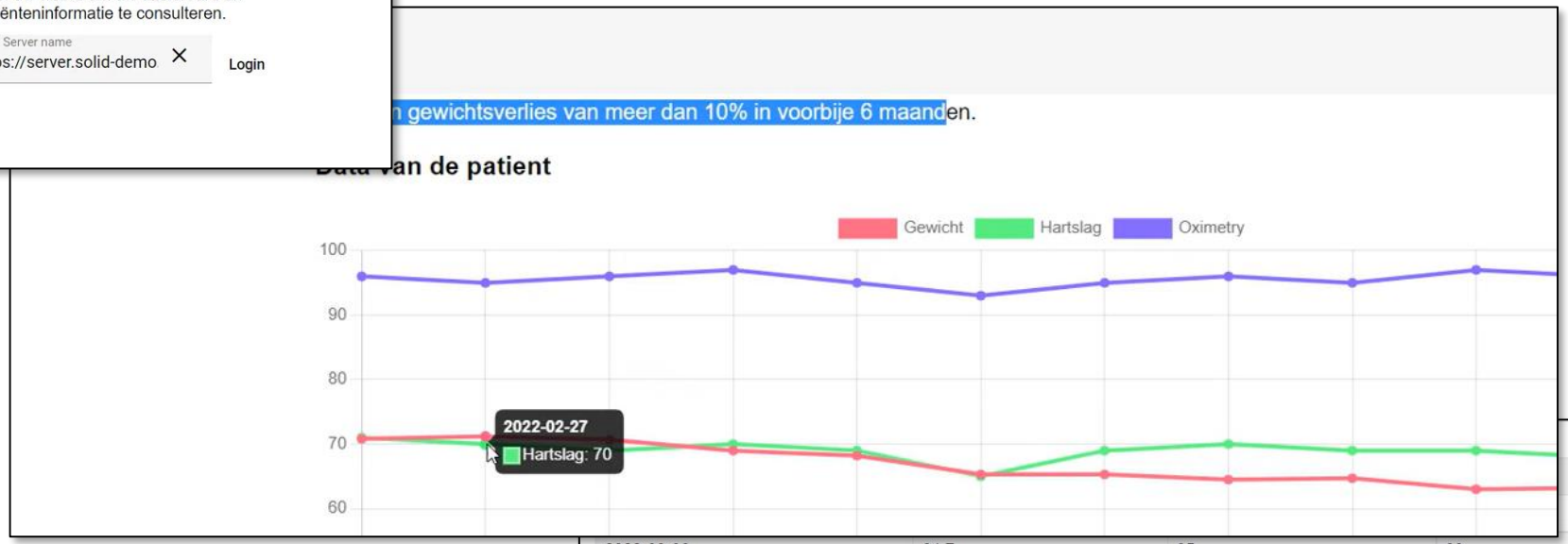
- Give patients more control
- Get applications linked to data to improve quality of life & follow-up
  - Personalized advice
  - Contact health care professional when problems arise
- Attention to ethical & legal framework

vito

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

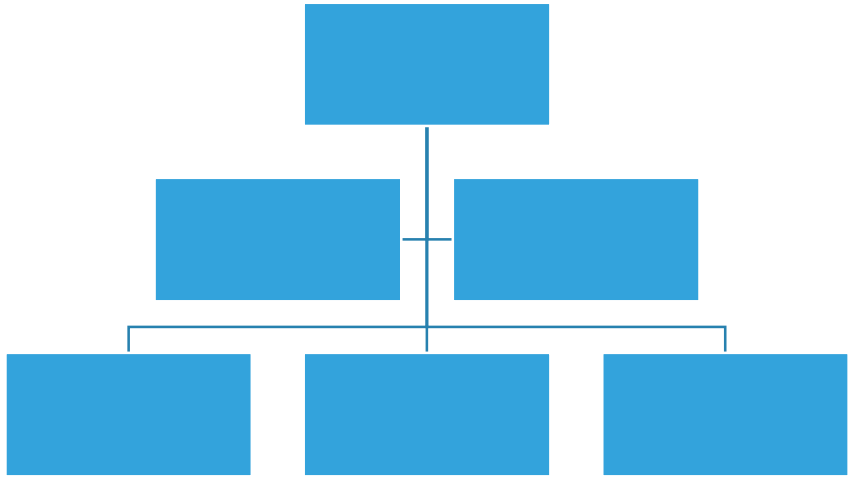
Geef feedback

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

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

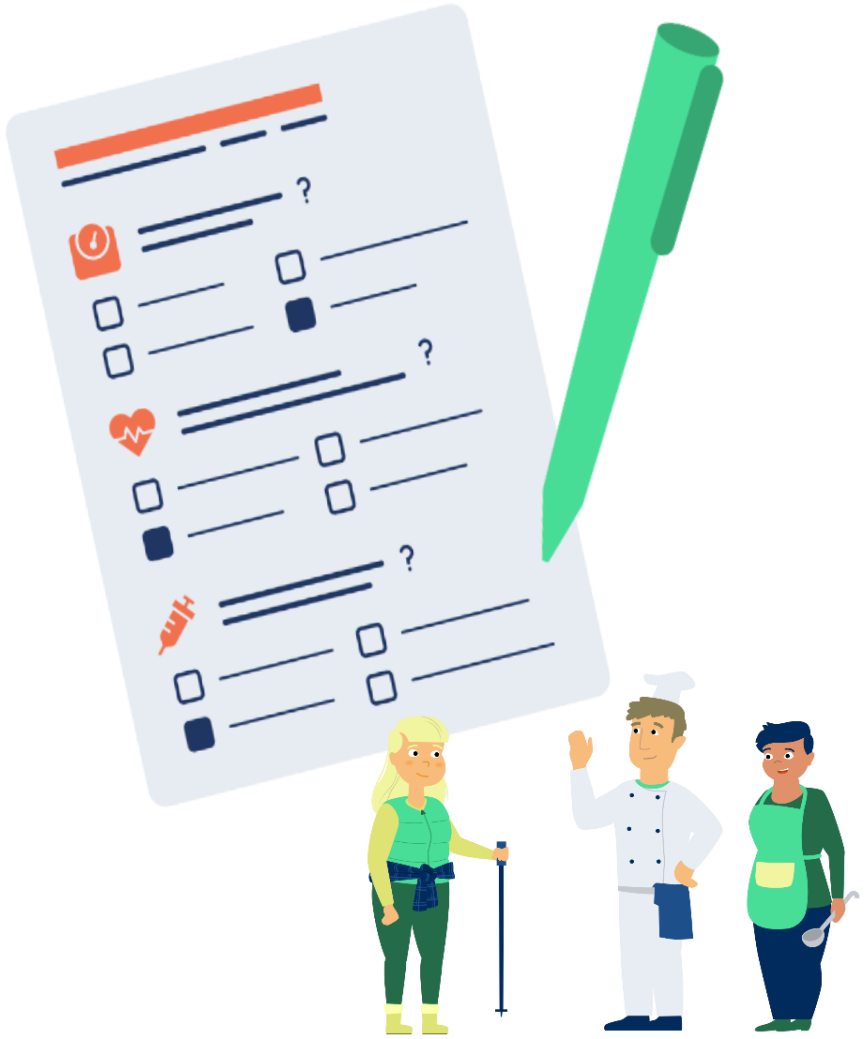
vito

CREATION AND CAPTURE OF PERSONAL HEALTH DATA

REAL WORLD DATA

Online surveys

Through digital services



Medical background

Lifestyle

Behavior

Personal preferences

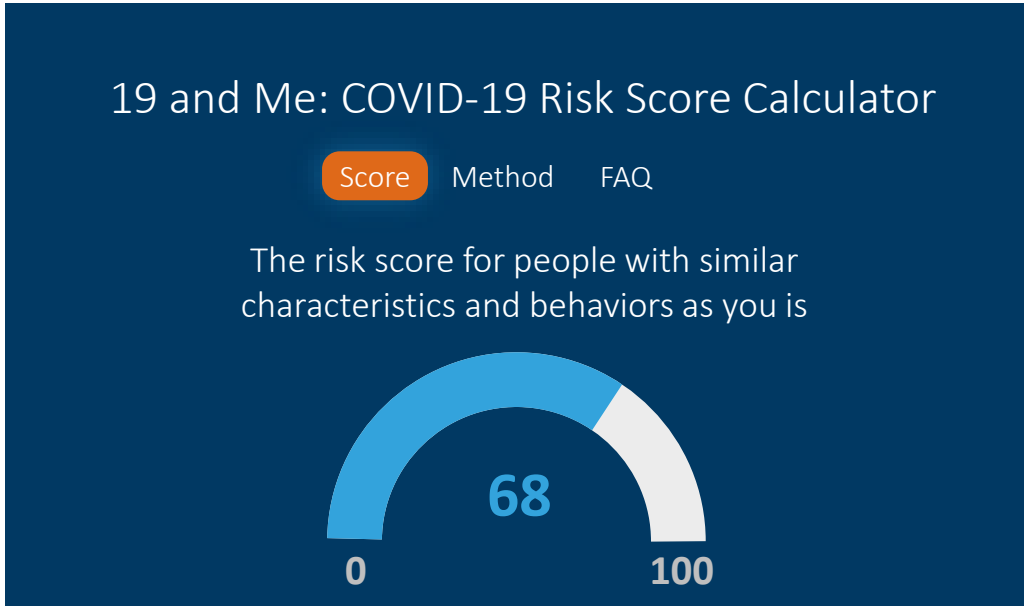
…

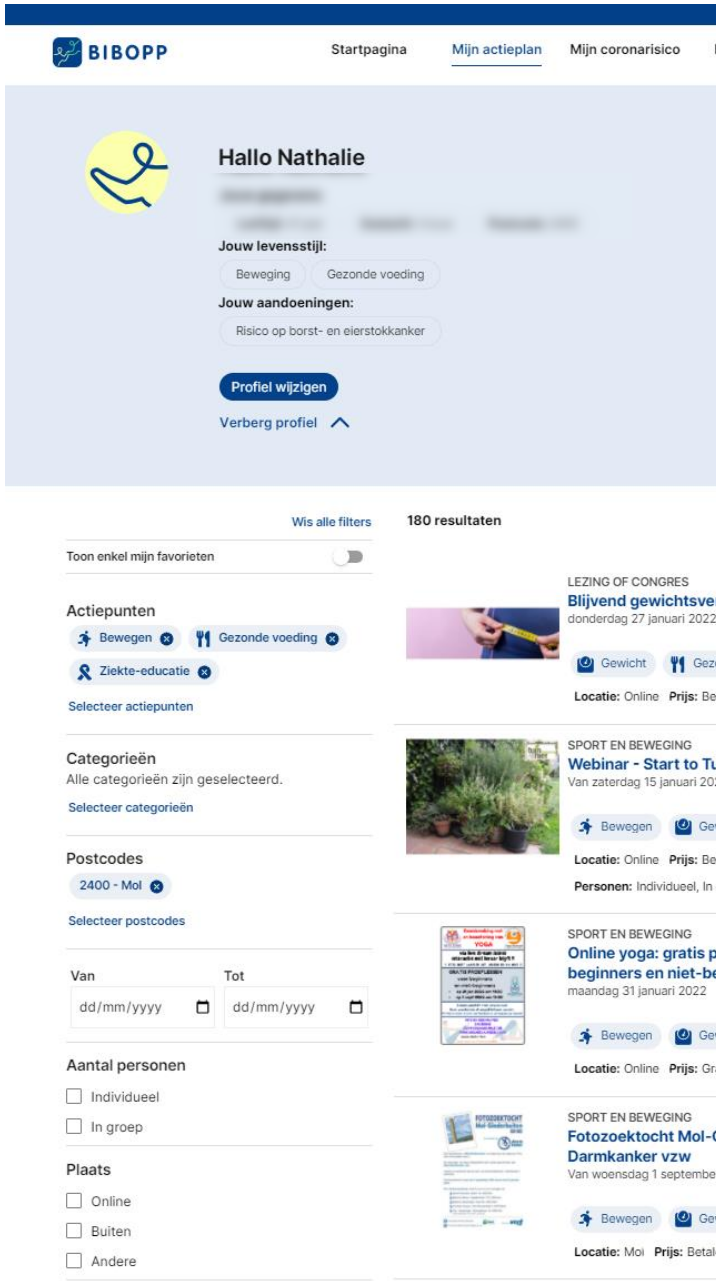
domus medica

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**

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

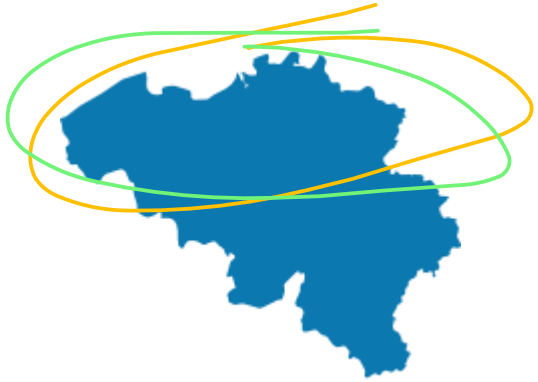
Population Health Management based on real-life data

Participation: co-creation and follow-up

R&D

Blueprint on implementation of **caring technologies**

we are

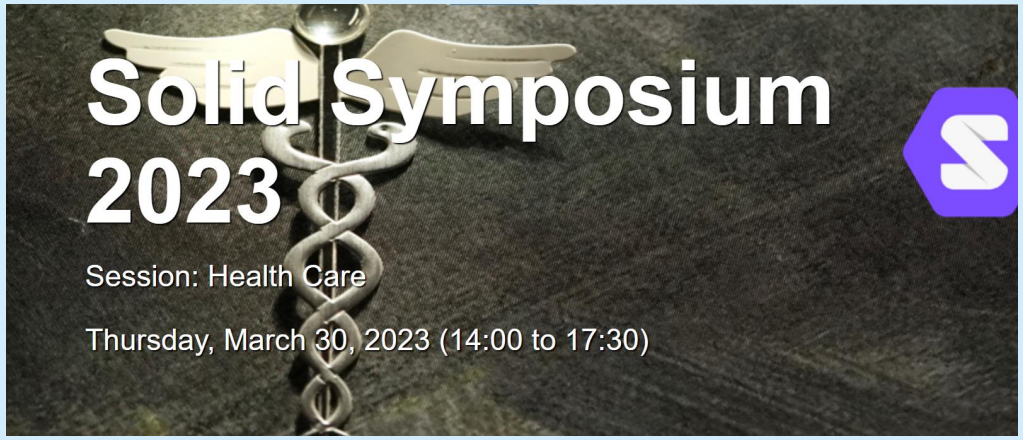


AGENTSCHAP INNOVEREN & ONDERNEMEN

Interreg EUROPEAN UNION

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

Allow **ownership** of data



Contact points:

Jef.hooyberghs@uhasselt.be
Bart.buelens@vito.be
Nathalie.lambrechts@vito.be

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

THANK YOU

Jef Hooyberghs, VITO - UHasselt