



The We Are Platform: a sustainable citizen-centric ecosystem for personal health data

Enriching the story tells us with lifestyle, health and wellbeing data

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Eufemed conference 2025



vito



Vlaams
patiënten
platform
Samen sterker

DOMUS
MEDICA





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The only future is a sustainable future

Pacesetter in the transition to sustainability

Countless challenges >< Solutions for big societal problems

Throughout their entire life, citizens should be able to find their way towards high quality integrated care, supported by care givers and technology

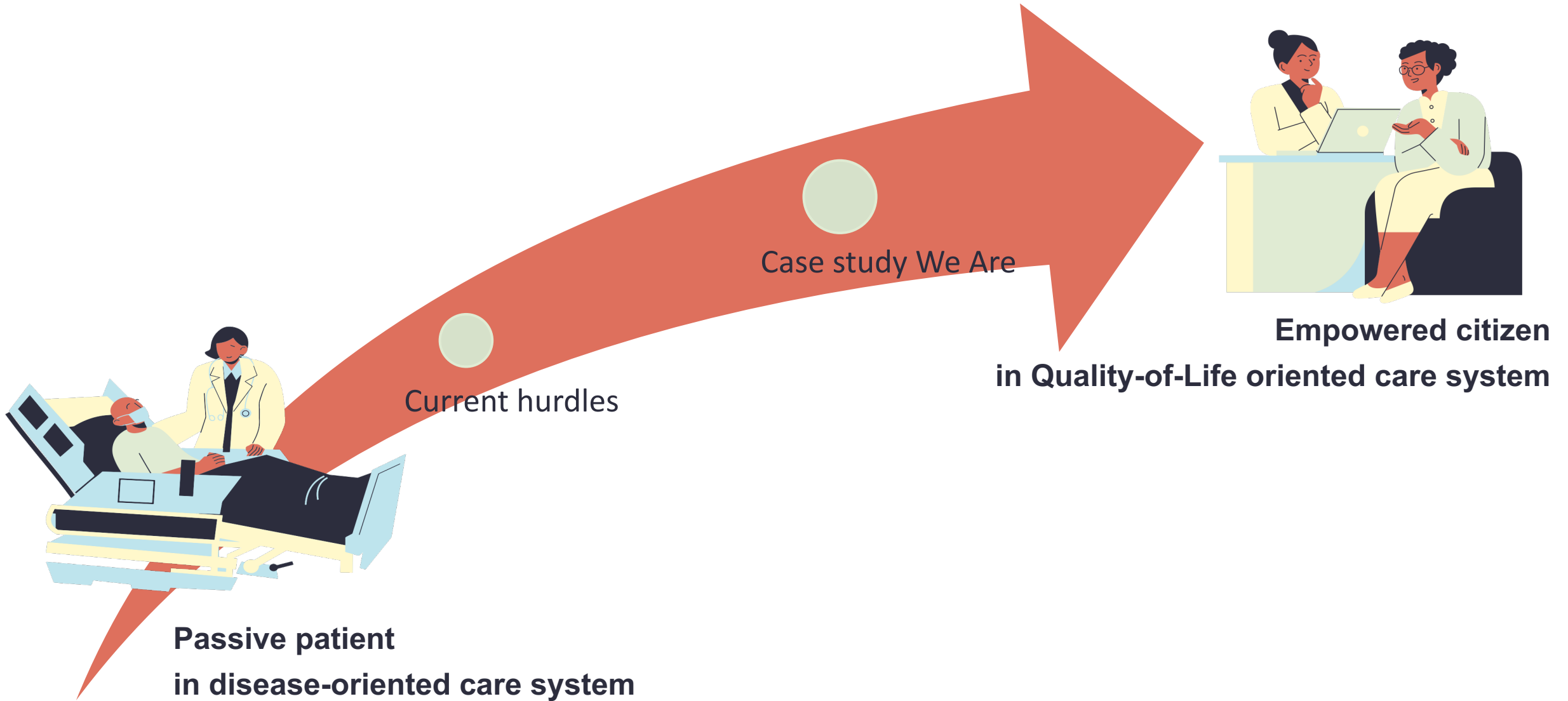


**Passive patient
in disease-oriented care system**



**Empowered citizen
in Quality-of-Life oriented care system**

Throughout their entire life, citizens should be able to find their way towards high quality integrated care, supported by care givers and technology

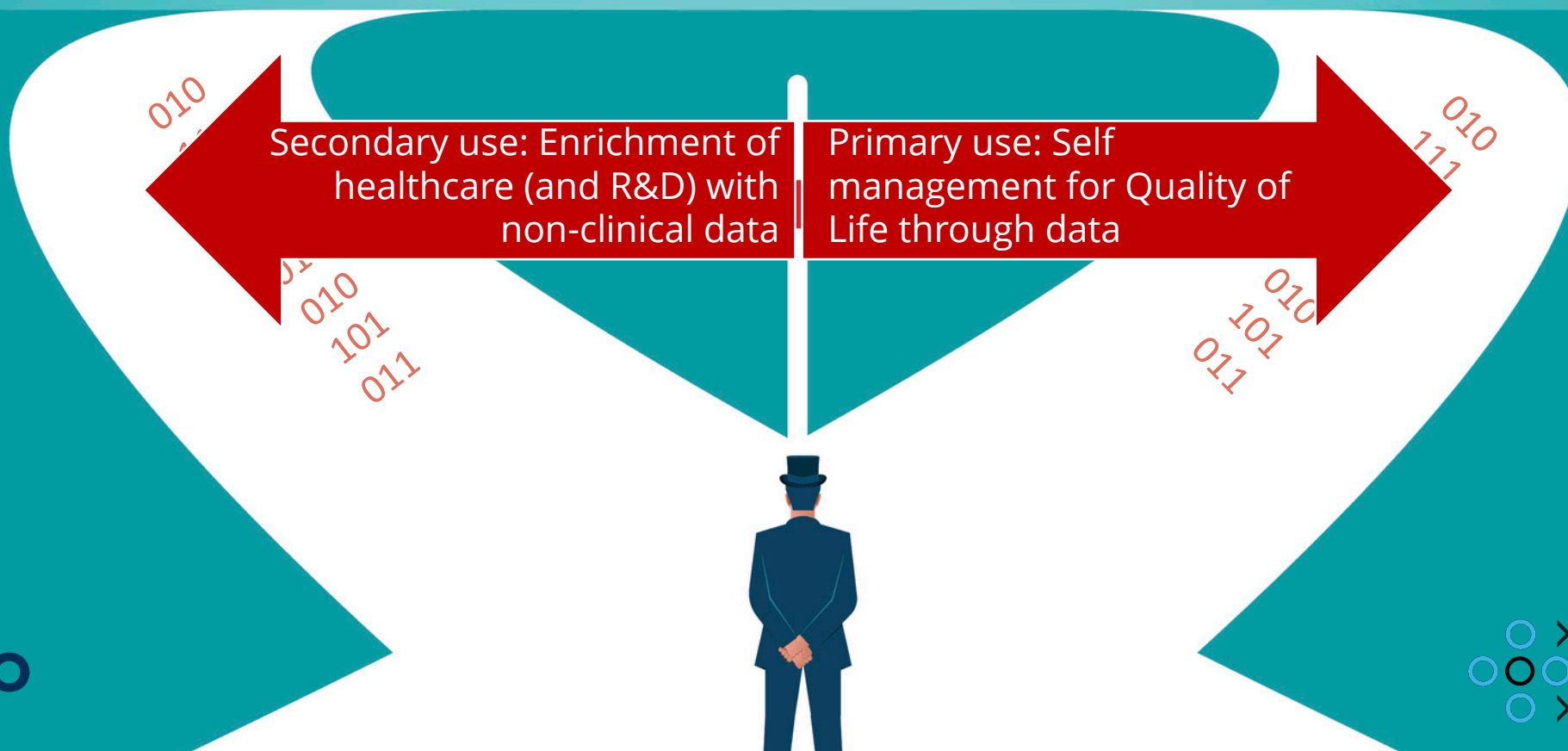




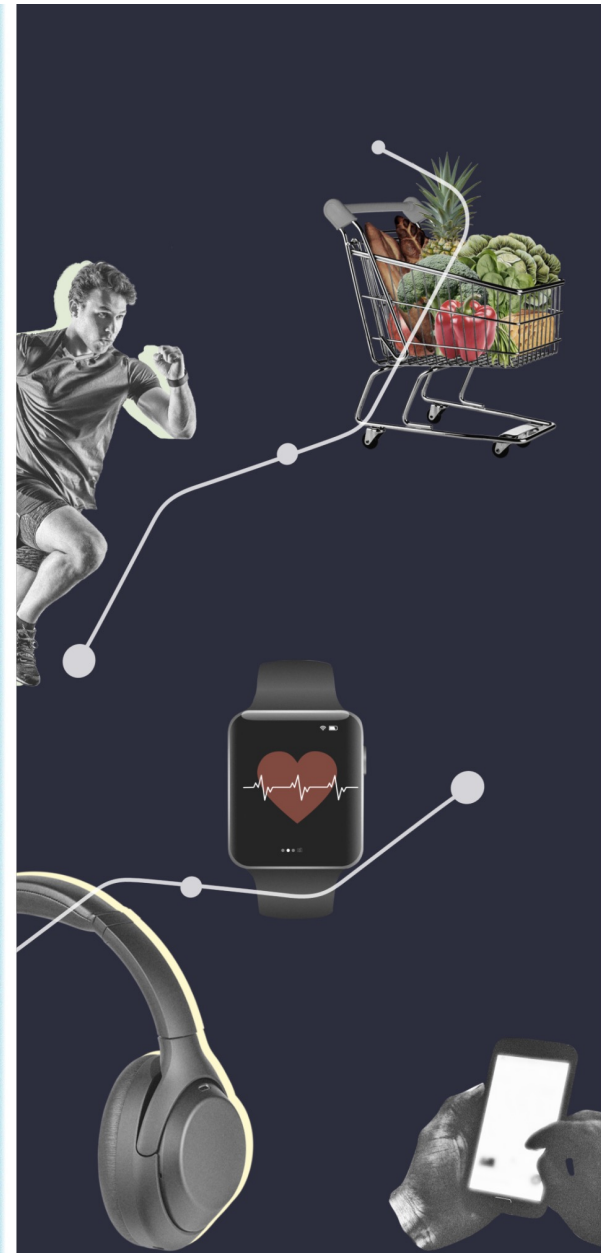
We Are



The human as the crossroads of his data



Applications & wearables

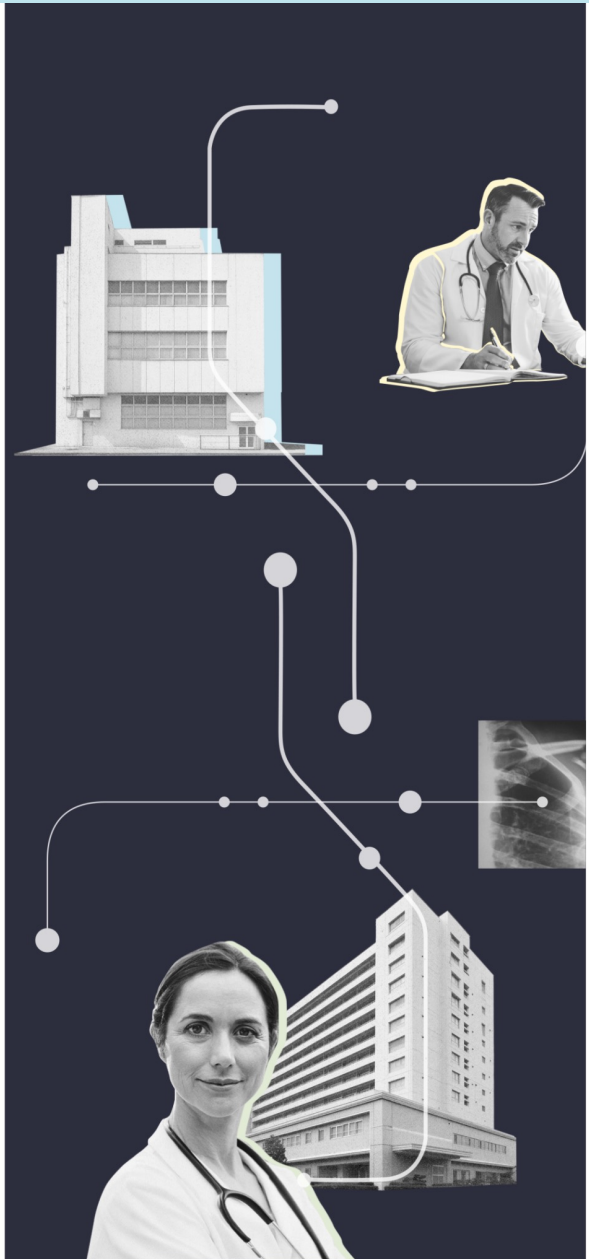


Citizen empowerment:
Self-management through data



Enrichment healthcare with
data from outside a clinical
practice

Health Care Professionals



Organisational & data governance

Functionalities: data & communication

Data storage



We Are

TECHNOLOGY



Move freely
between services



Reuse data across
APPS



Connect with
anyone



Select what you
share precisely

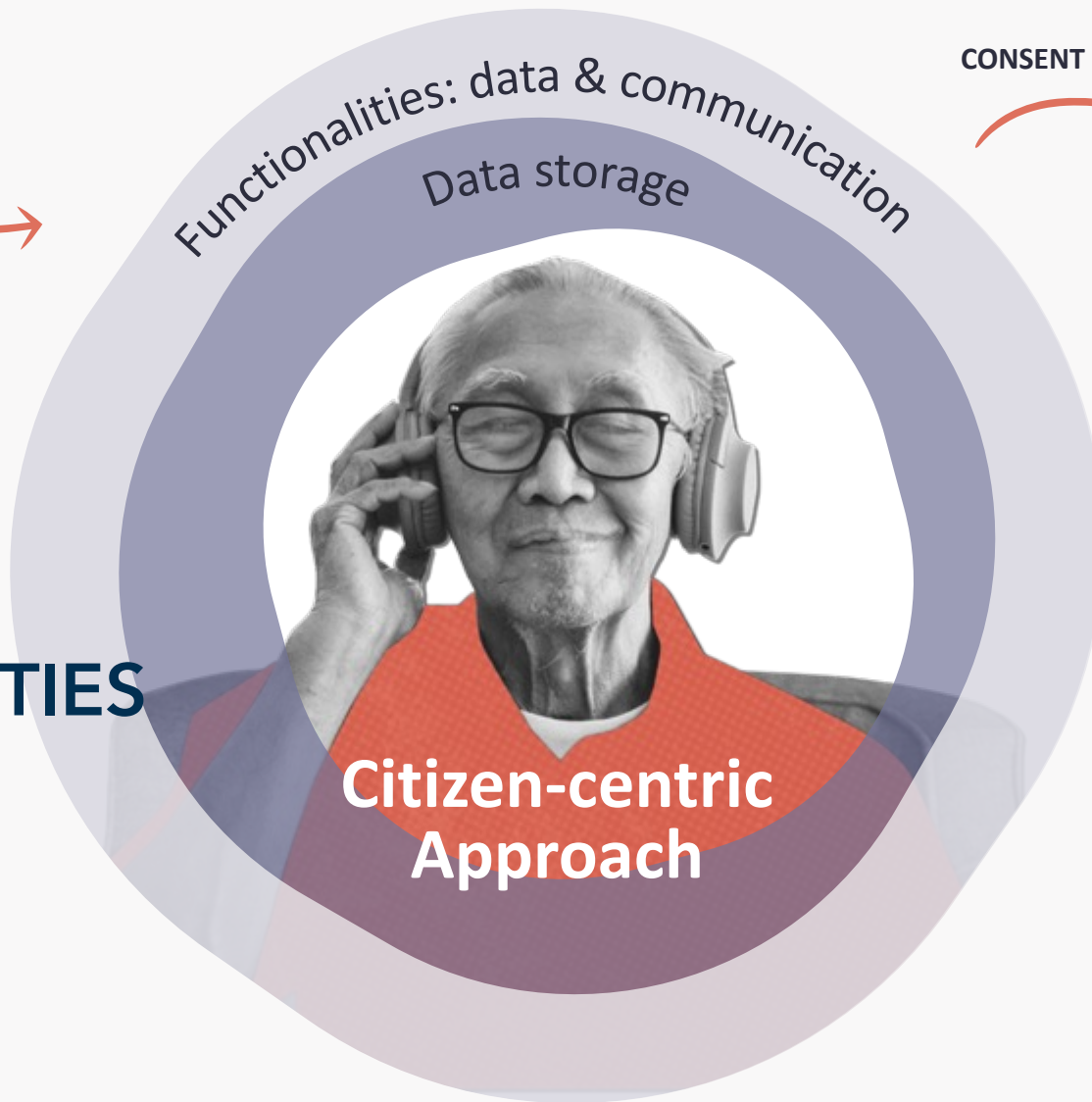


We Are





Creation and capture of personal health data



CONSENT



R&D innovation

Academia

Civil Society

Public authorities

Industry

FUNCTIONALITIES



Personal Information manager

- Dashboard

- Consent management application

R&D catalogue

Data formats / interoperability



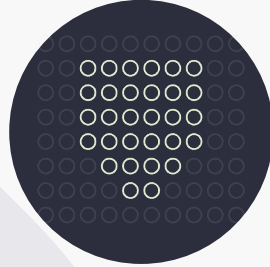
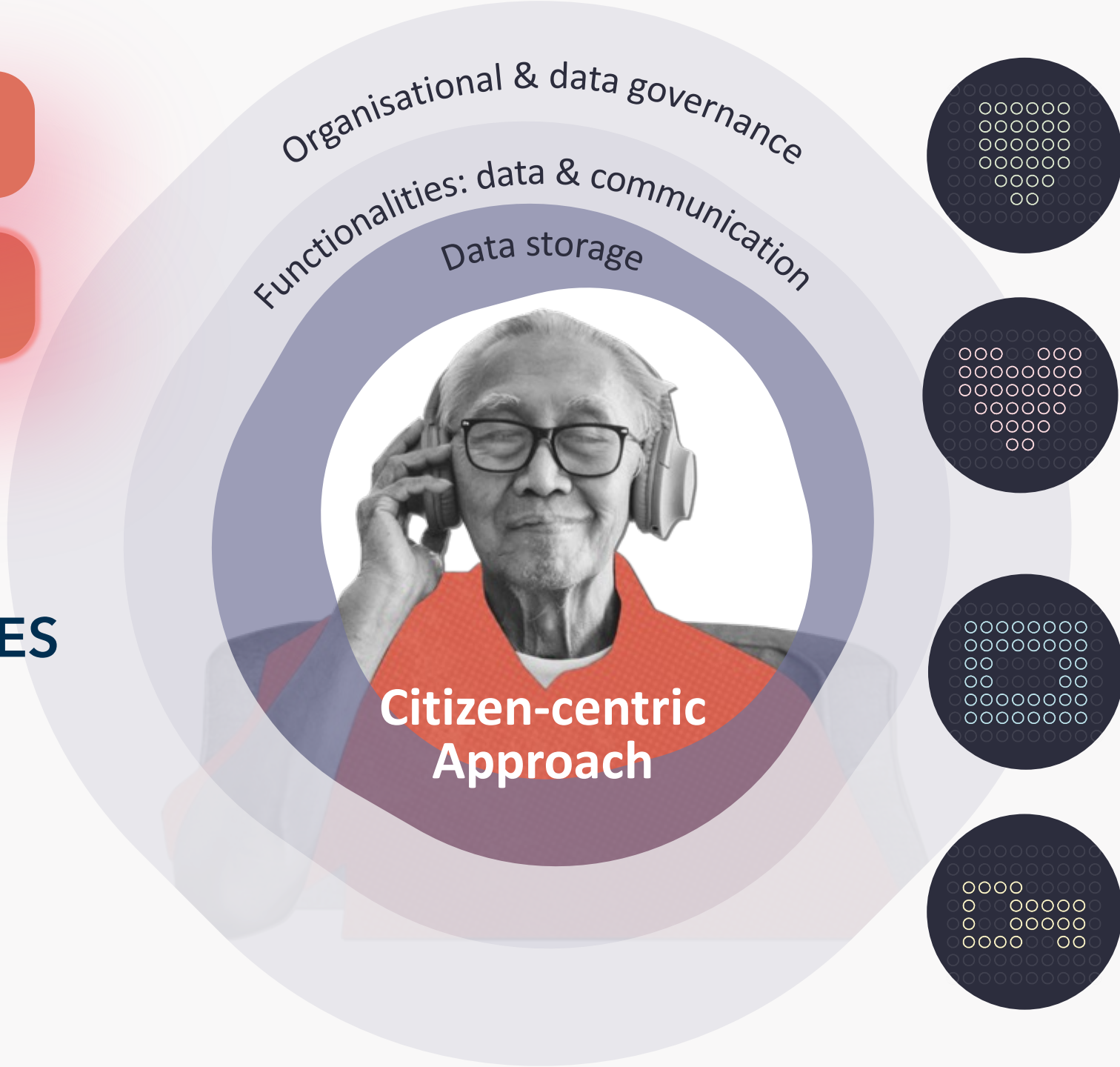
We Are

GUIDING PRINCIPLES

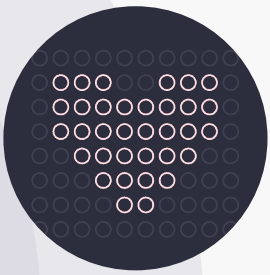


Participatory Governance

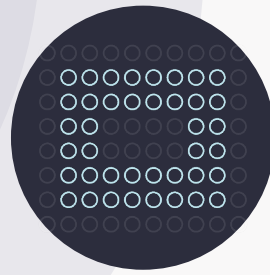
Synergy Privacy & Innovation



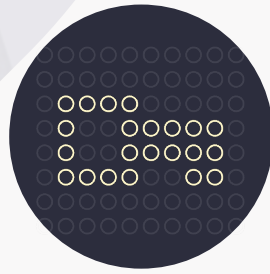
Quality & Efficiency



Care & Equality

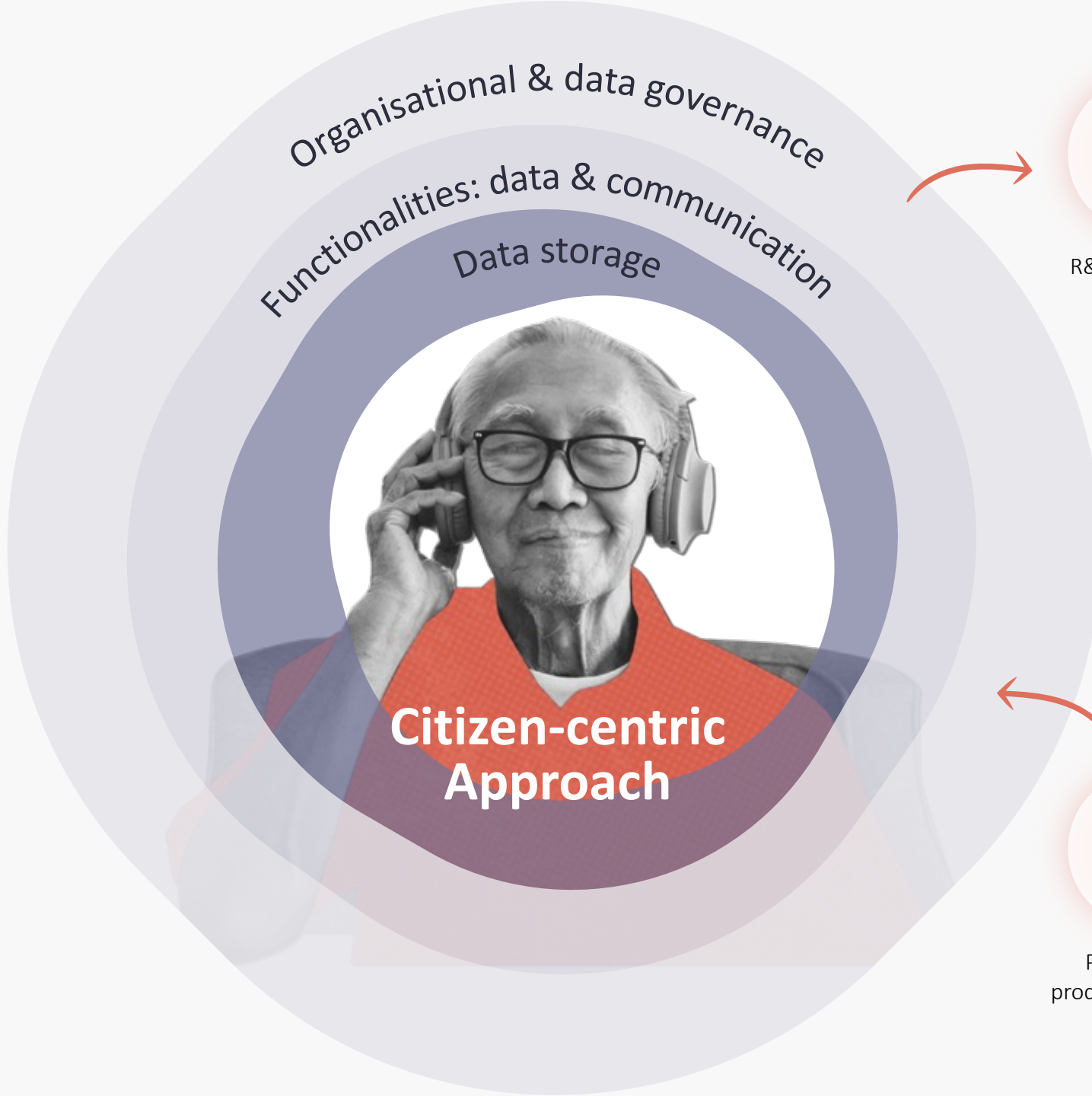


Autonomy & Solidarity



Privacy & Security

A LEVEL PLAYING FIELD



Organisational & data governance

Functionalities: data & communication

Data storage

Citizen-centric
Approach



R&D innovation

Open innovation ecosystem

Value-chain for companies,
citizens, research &
government

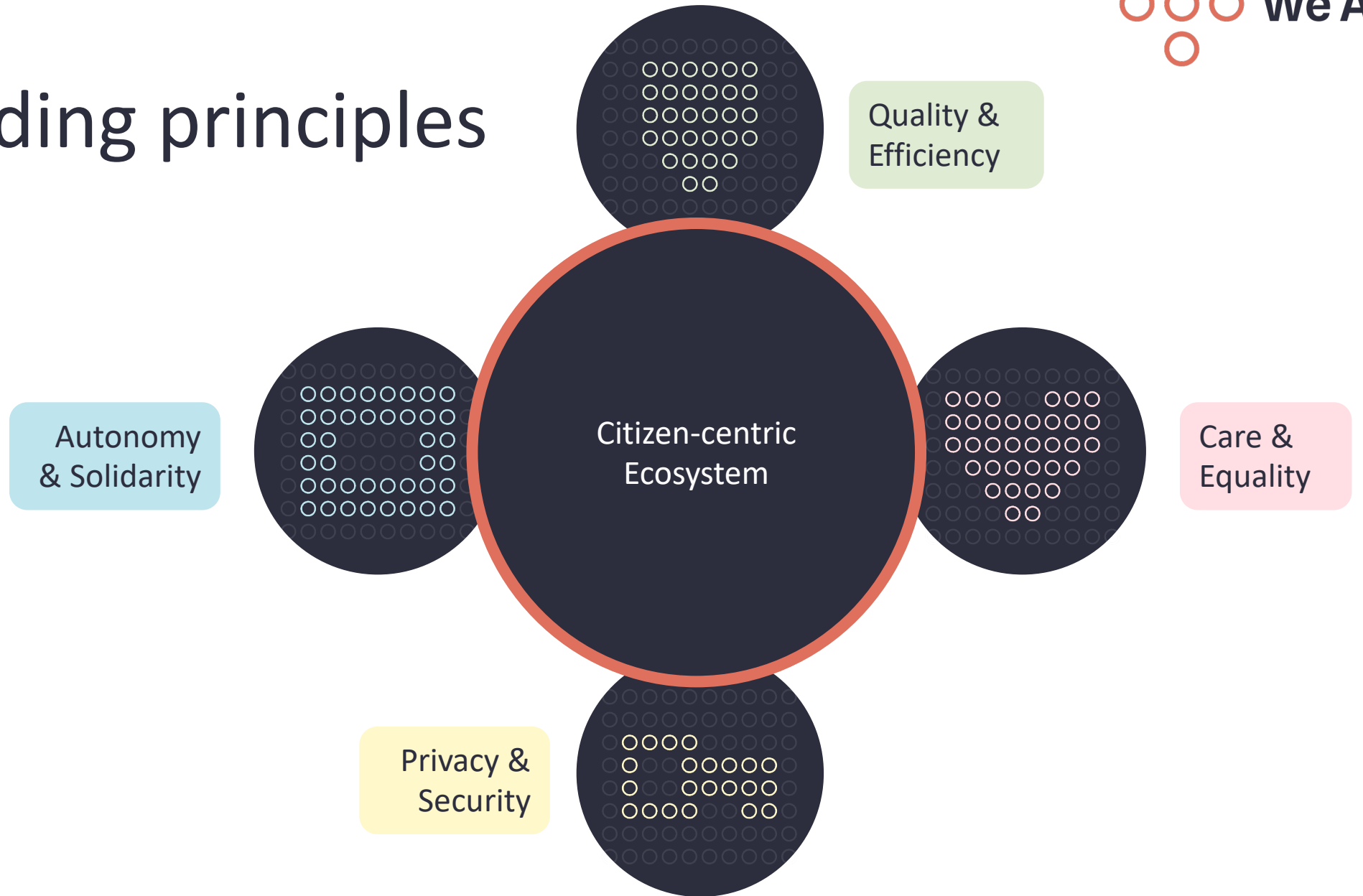
Systematic user co-
creation approach

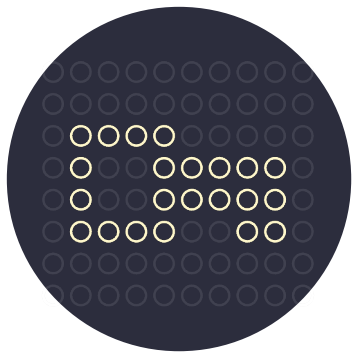
Proof of concept,
validation to scale up



Personalised
products & services

Our guiding principles

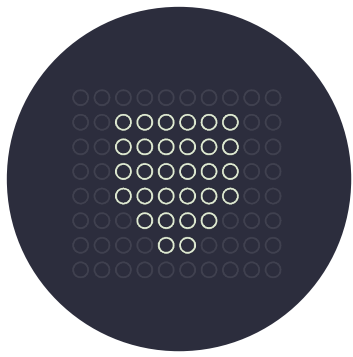




Privacy & Security

Guarantee the rights of platform users in terms of privacy and security of data storage and management

- Security
 - Lack of trust in privacy regulation
 - Strong preference for anonymized data for research and policy
 - Concern about a lack of an overview of personal data used
 - Due to phishing attempt experiences
- Privacy
 - Data sensitivity
 - Fear of normative culture, with punishment of citizens who do not follow norms
- Socio-demographic influence: Biggest fears in elderly, less-educated, lack of trust in the internet, lack of knowledge in applications with health data

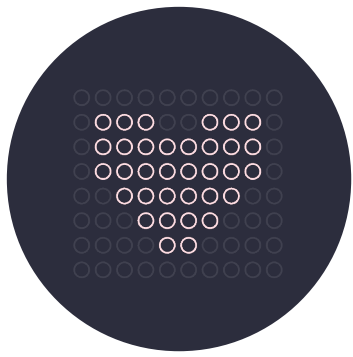


Quality & Efficiency



Provide a data platform that supports optimal integration of quality health data

- Efficiency
 - Only once principle
 - Validated and qualitative health data needed for better care and quality of life
 - Citizen-generated data is valuable, when source of the data is known
- Quality
 - More inclusive data

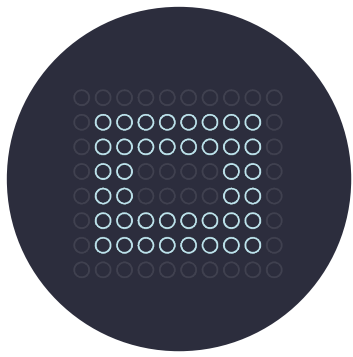


Care & Equality



Commit to equal access for citizens and other stakeholders

- Equality
 - Fully inclusive system
 - Take into account various needs and preferences: elderly and low-educated individuals
- Care needs
 - Improve digital and health literacy with education and support
 - Accessible and user-friendly system
 - Digital solution do not replace human contact

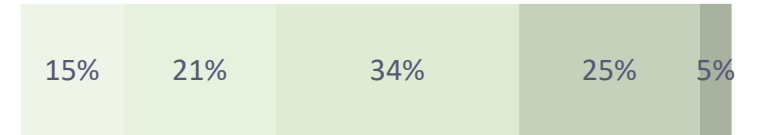


Autonomy & Solidarity



Start from citizens' wishes regarding the management of their health data

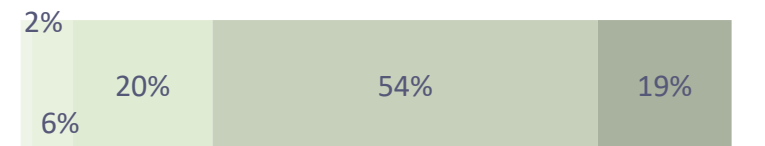
- **Autonomy**
 - Health Self-management
 - Shared decision making on health data management
 - Participation of citizen when deciding on secondary use of data
 - Control over what data, with who and why are the biggest concerns
- **Solidarity**
 - More willingness to share data with not-for-profit organizations
 - Independent governance structure to assure data being used for 'good'
 - 30% reports data-altruism: Sharing data with no direct personal gain
 - Common good is most linked with independent organization that work towards a higher goal, care providers and knowledge institutes



I am willing to share health data even if I don't have a direct personal benefit



I am willing to share health data if it benefits society



I am willing to share health data if I know what they are used for

■ Helemaal oneens ■ Oneens ■ Noch eens, noch oneens ■ Eens ■ Helemaal eens

We Are in practice:
Telemonitoring in
cancer patients





Rise of telemonitoring services

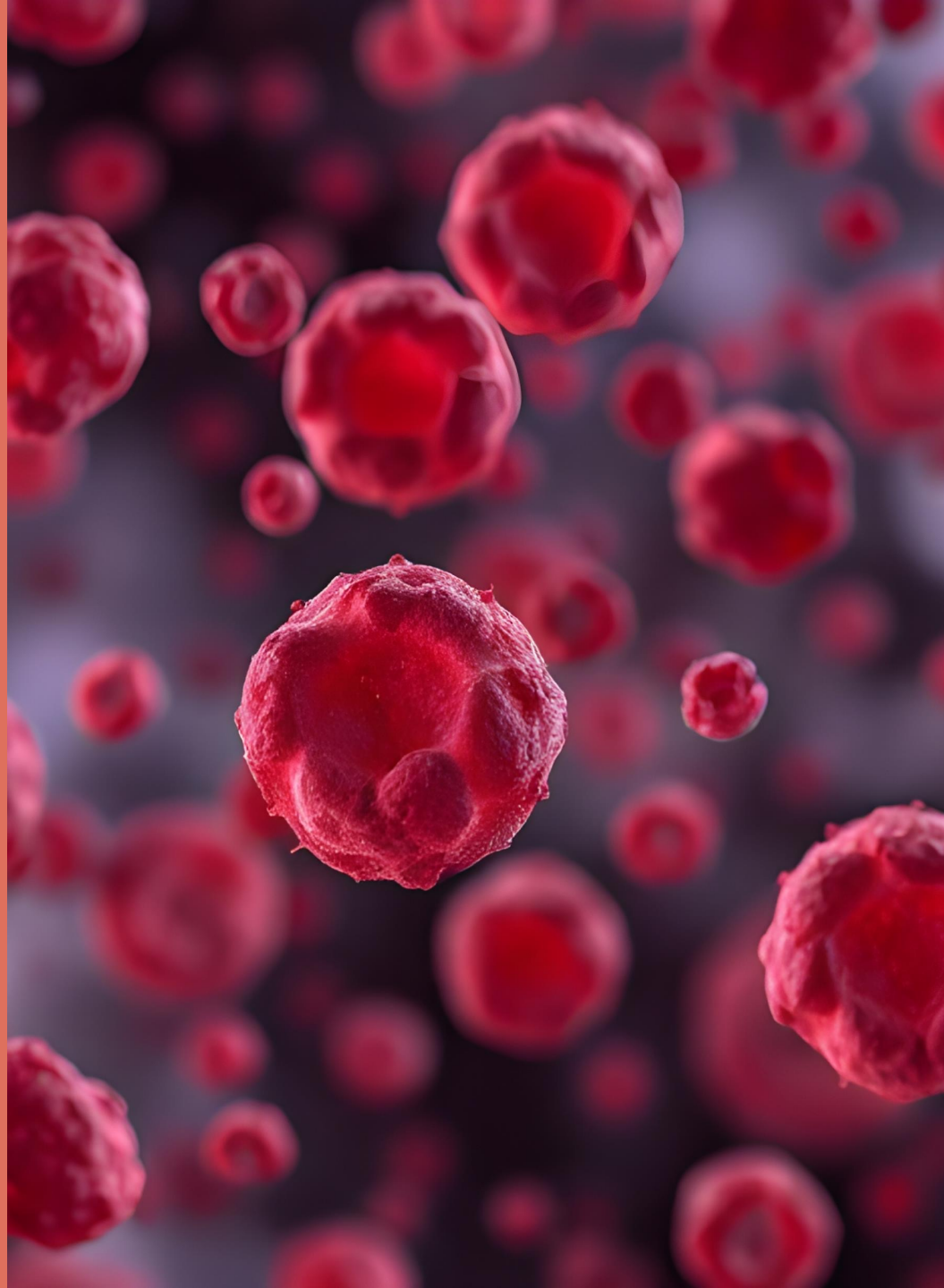
- ✔ Detect symptoms earlier
- ✔ Better connection with health team
- ✔ Self management
- ✘ Not for all patients
- ✘ No connection with lifestyle



**A telemonitoring
solution which
could mean so
much more...**

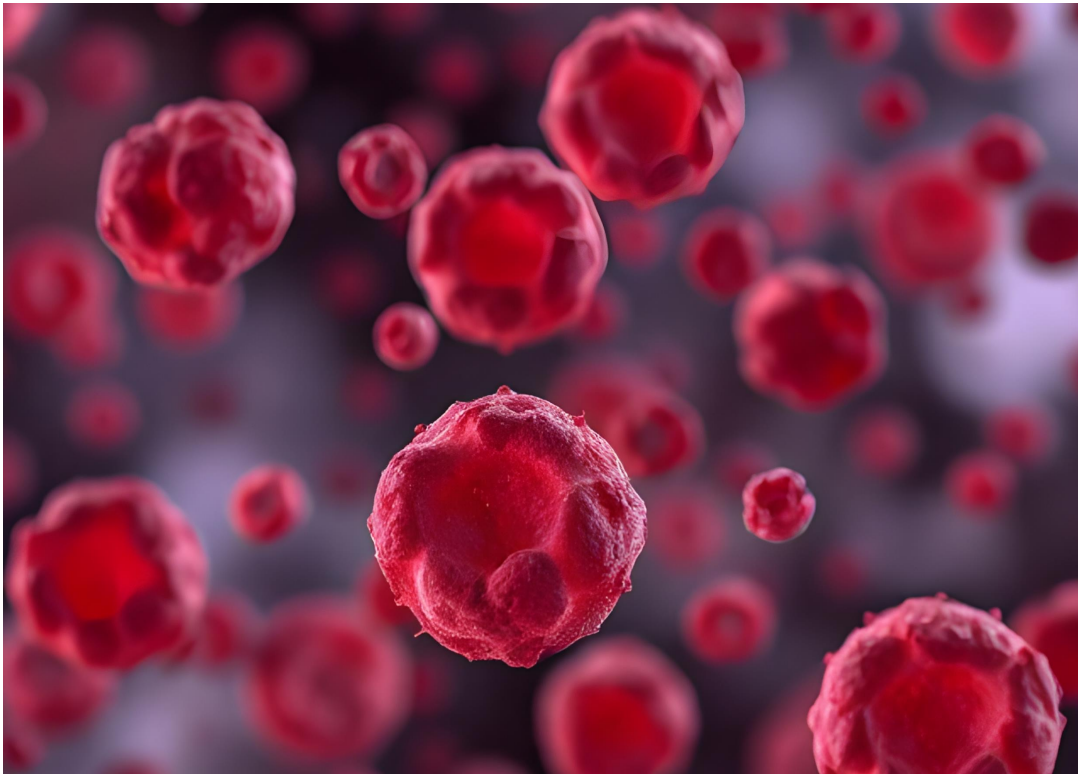


We Are in practice: Rare
disease patient journey
survey



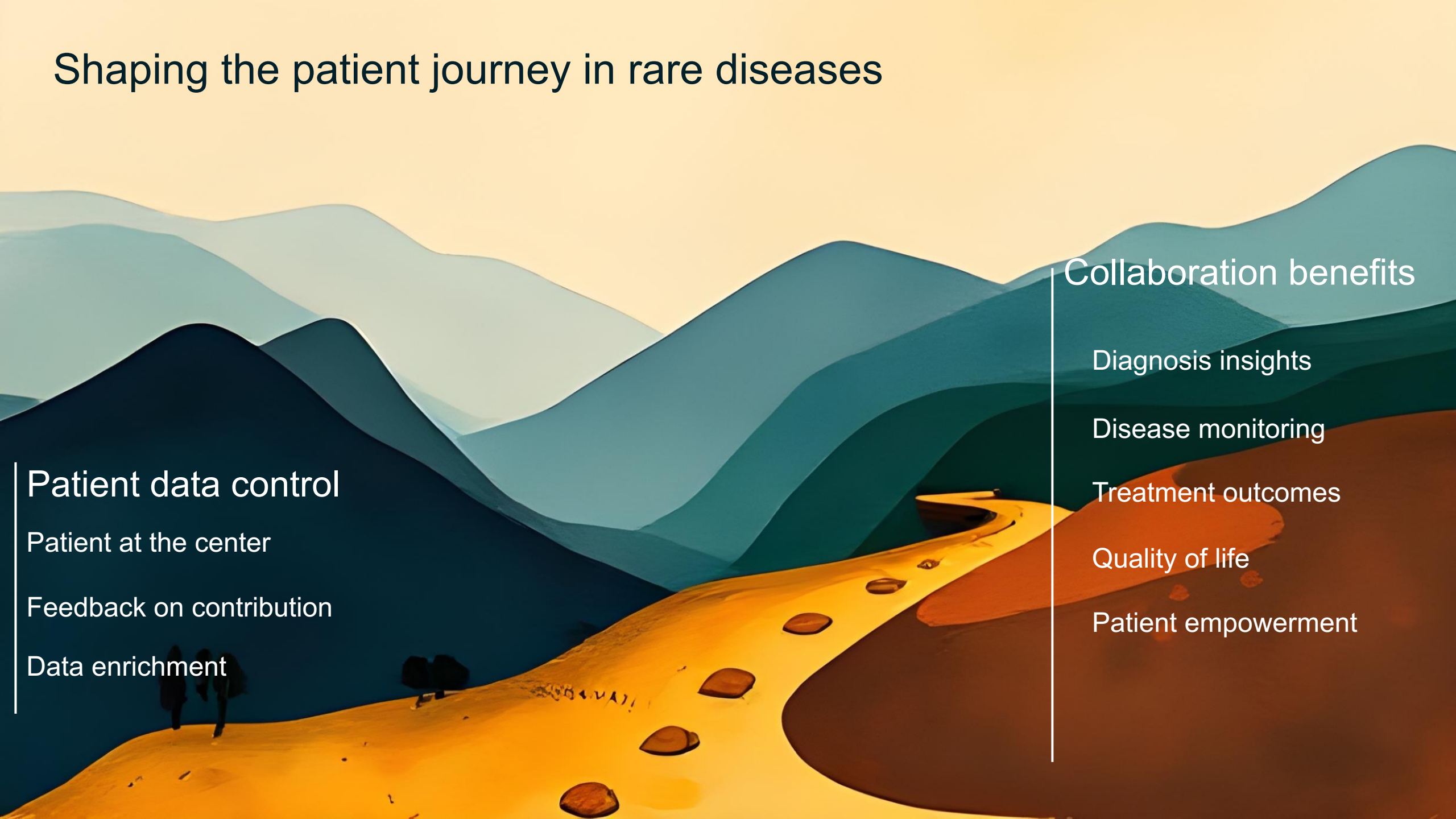
TTP – rare blood disorder

What is TTP?



- Thrombotic Thrombocytopenic Purpura
- Blood clots formed in all organs due to faulty enzyme
- Treatment: plasma donation without faulty enzyme
 - 13-16 bags needed per patient
 - Long hospital stay

Shaping the patient journey in rare diseases



Patient data control

Patient at the center

Feedback on contribution

Data enrichment

Collaboration benefits

Diagnosis insights

Disease monitoring

Treatment outcomes

Quality of life

Patient empowerment

Use Case 2: TTP rare disease survey

Measuring patient journey & quality of life

■ Context & setting the scene

- Consortium formed to better capture patient journey of rare disease
- Project sponsors: Takeda & Sanofi, with research partners from KU Leuven and UC Louvain, experts and patient community (no legal entity)
- In the project, Zenjoy was assigned to developing the survey application.
- VITO provided the enabling tools to set up the back end to connect with the Athumi pod, visualize consent management and process the data for research.

TTP SURVEY JOURNEY

- Patient learns about the survey from doctor or TTP community
- Patient or caregiver fills in survey in the Zenjoy-app



Patient gives consent to store the answers in his personal data vault (SOLID Athumi Pod)

Control over data in We Are AMA



Patient gives consent to aggregate and pseudonymise the answers and share with researchers

Extraction & data processing by VITO tool...



... and shared with researchers (KUL and UCL)



Insights shared with patient and TTP community



Insights shared with experts and Sanofi/Takeda, working on treatments for TTP



Vragenlijst voor mensen die leven met TTP

NL EN FR

Deze nationale patiëntenenquête heeft als doel verschillende aspecten van trombotische trombocytopenische purpura (TTP) vanuit het perspectief van de Belgische patiënt in kaart te brengen. Het onderzoekt **hoe personen deze ziekte ervaren, welke impact het heeft op het dagelijks leven, en hoe deze werd gediagnosticeerd en behandeld**. De enquête werd ontwikkeld door een onderzoeksconsortium van Belgische partners, waaronder de TTP-gemeenschap (patiëntenvereniging), VITO (een wetenschappelijk instituut), academische professoren van KU Leuven en UCLouvain, en de farmaceutische bedrijven Takeda en Sanofi.

Stap 1 - Identificeer jezelf

Door in te stemmen met deelname aan deze patiëntenenquête, gaat u ermee akkoord dat de academische partners van dit consortium uw gegevens anoniem en in combinatie met gegevens van alle deelnemers kunnen analyseren.



Linking the larger ecosystem



Organisational & data governance

Functionalities: data & communication

Data storage



Connector

Enrichment of **healthcare** (and R&D) with non-clinical data



Personalized, evidence- and value-based cure and prevention through federated analytics

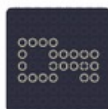


We Are

Home

Krijg terug grip op je persoonlijke gegevens

Snelle links



Autorisaties

Beheer de toegang tot uw persoonlijke gegevens

We Are

Persoonlijke gegevens zoals persoonlijke voorkeuren, stappentellers, reisbewegingen, internetzoekopdrachten, etc. Onze gegevens zijn alomtegenwoordig in ons leven en in de samenleving. We kunnen ons leven niet meer voorstellen zonder gegevens en apps. De coronacrisis heeft er ook voor gezorgd dat nog meer zaken online gebeuren, zoals teleconsultaties of de corona waarschuwingsapp, Coronalert. Ondanks de vele voordelen en mogelijkheden is momenteel het vermoeden van ongeoorloofd gebruik van gegevens hoog.

Als burgers worden we ons steeds meer bewust van het gebruik van gegevens door derden en de belangrijkheid ervan. Kenniscentra, universiteiten, overheden en bedrijven hebben gegevens nodig om nieuwe technologieën te kunnen ontwikkelen, onderzoek te doen naar ontwikkelingen, ziektes, etc.

We Are wil ervoor zorgen dat burgers vertrouwen hebben in hoe hun gegevens worden gebruikt.

Wie zijn wij

Het bouwen van het We Are-systeem vereist veel expertise. Daarom **We Are is een partnerschap van verschillende partijen:**



[Show more](#)

Wat we doen

Voorzichtigheid is geboden bij het gebruik van persoonlijke gezondheidsgegevens voor innovatie. Allereerst moeten de gegevens bijdragen aan het verbeteren van de gezondheid, het welzijn en de kwaliteit van leven van individuen in hun dagelijkse leven. Het We Are

Toepassingen



Overzicht toepassingen



Koppeling Vitalink x SOLID

De brug tussen twee ecosystemen

Koppeling Vitalink x SOLID

TOEGANGSVERZOEK

Gegevens schrijven

Wie

Vitalink

Data

https://storage.sandbox-pod.datanutsbedrijf.be/d20d74ca-dca6-4edd-9cca-f99eca4d19d5/ttp_acc/

Doel

Opslaan in datakluis

Datum

27/01/2025

[Goedkeuren](#)

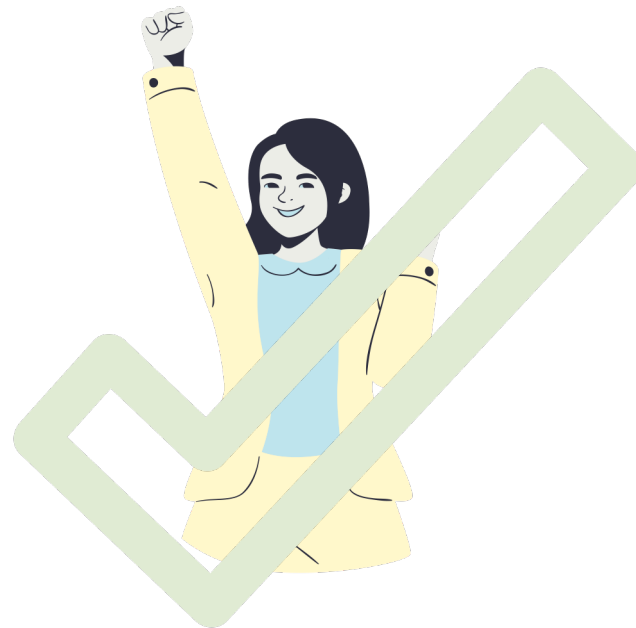
Weigeren

Meer informatie over hoe We Are uw persoonsgegevens verwerkt of hoe u uw rechten kan uitoefenen, leest u in de [privacyverklaring van We Are](#).

Meer informatie over hoe Athumi uw persoonsgegevens verwerkt of hoe u uw rechten kan uitoefenen, leest u in de [privacyverklaring van Athumi](#).

Koppeling Vitalink x SOLID

Je resultaten werden succesvol toegevoegd aan je persoonlijke kluis





[Zie resultaten](#)

Datakluis




3 compartimenten

 Zoeken ...




Vlaams Patiëntenplatform

6 gegevensrecords



[Koppeling Vitalink x SOLID](#)

20 gegevensrecords



Garmin

120 gegevensrecords

PREVENTION THROUGH STANDARDIZED AND HUMAN-CENTRIC INTERVENTIONS IN THE EUROPEAN HEALTH DATA SPACE

 We Are



SOLID4HEALTH
Datadeling in de preventieve gezondheidszorg



WELLDATA Data Space for Prevention



Prevention through **cross-border** health **data exchange and standardization**, in line with technical and ethical guidelines.



Efficient, preventive, and data-driven care



Collaboration between healthcare professionals



Supporting the development of health applications



THANK YOU

For more information:

<https://we-are-health.be/nl>

<https://interregvland.eu/data-ruimte-voor-preventie/over-ons>

Elfi.Goesaert@vito.be



Vlaamse
overheid



NEXT
GEN
EU



WellData newsletter