



We Are Use Cases

Elfi Goesaert, VITO



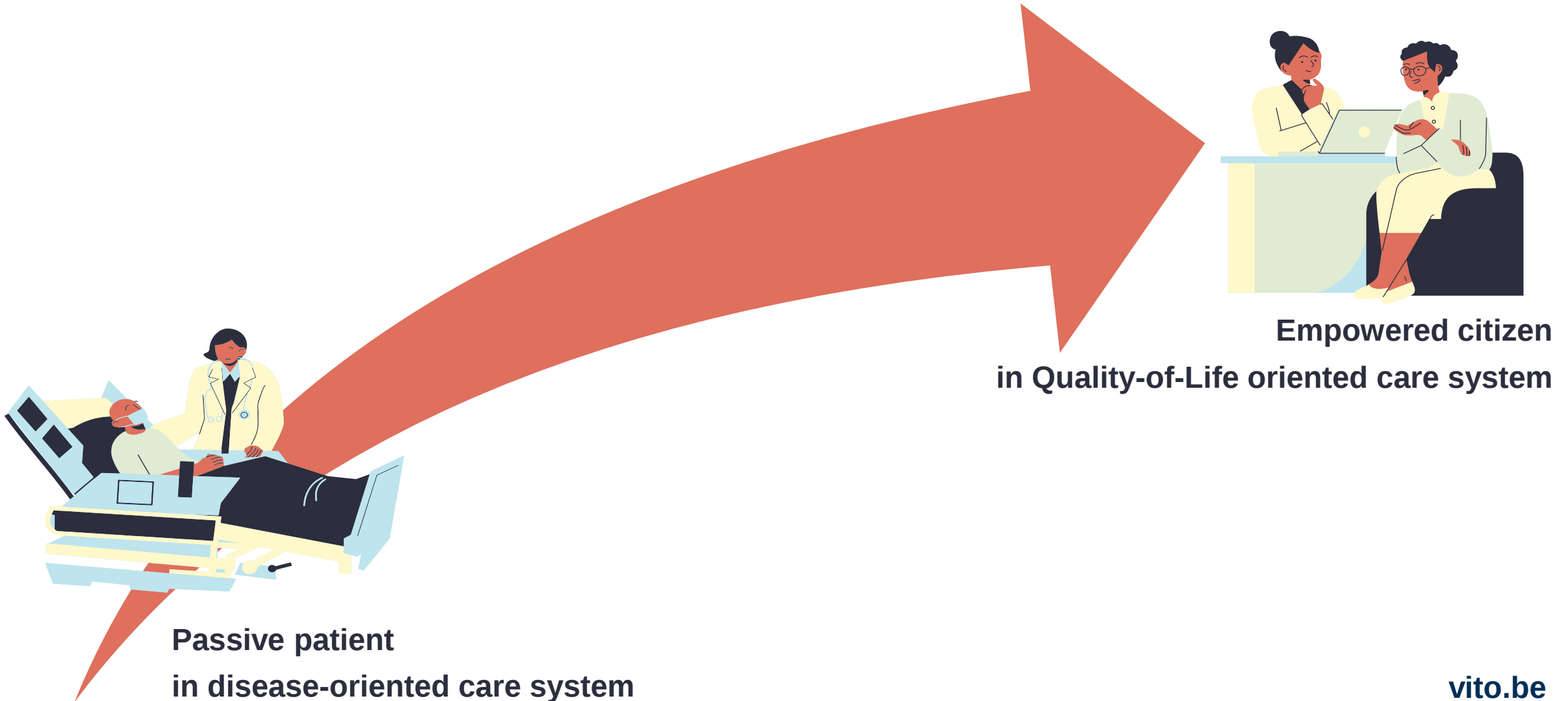


The only future is a sustainable future

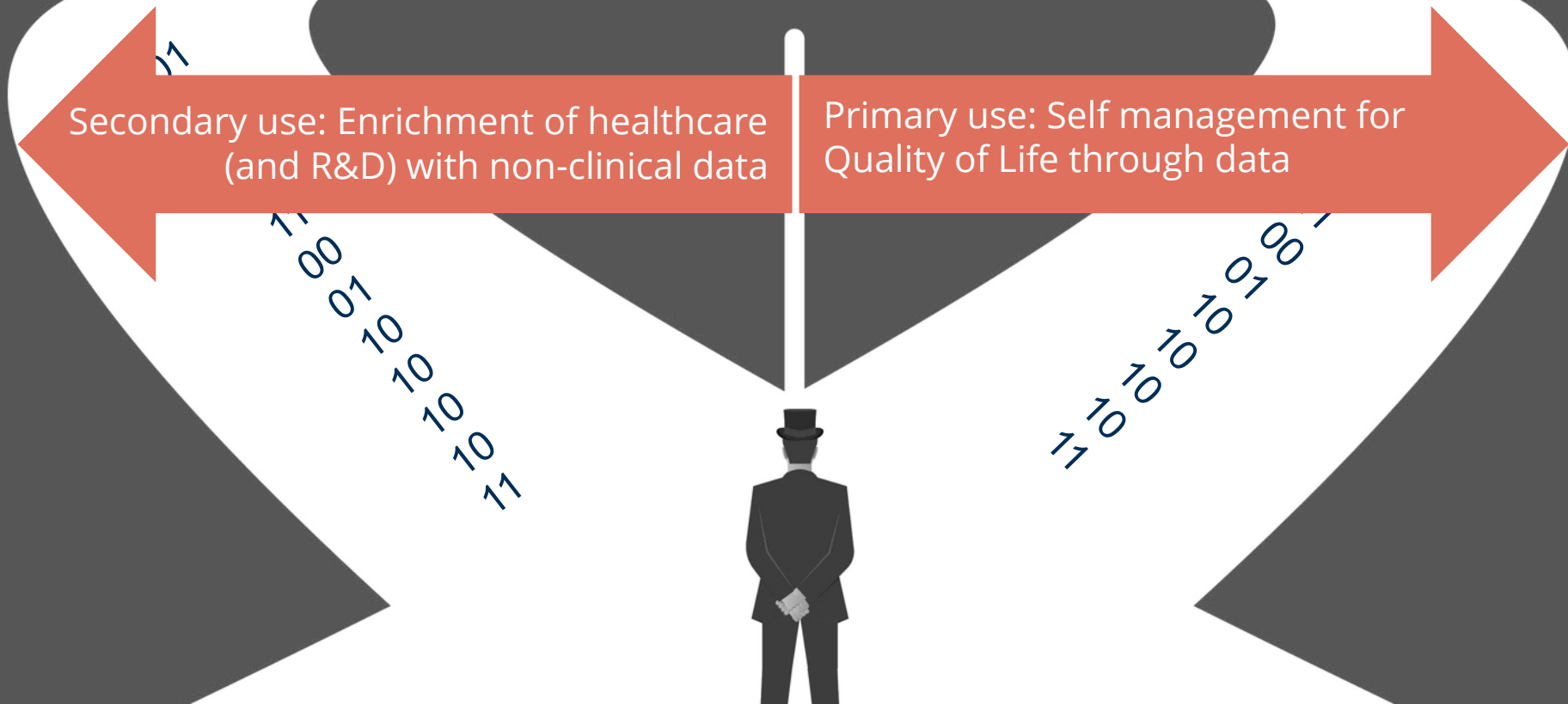
Pacesetter in the transition to sustainability

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



The human as the crossroads of his data





Creation and capture of personal health data



R&D innovation



Personalised products & services





SOLID



Move freely
between services



Reuse data across
APPS



Connect with anyone

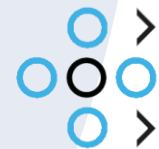


Select what you
share precisely

Data storage

Human-
centric
Approach

PERSONAL DATA
SPACES



we are

Roles and applications in the 'We Are' layers



Copyright principes: Fonds dr. Daniel De Coninck

Flemish patient survey

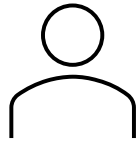
Flemish patient survey

What + context

- Survey of patient experience after hospital stay, validated survey developed by VPP
- Survey to look into the improvement of quality of care, followed up by the Flemish Institute for Quality of Care (VIKZ)
- Current situation
 - Mix of paper and digital versions
 - No single digital application
 - Two measurement periods/ year

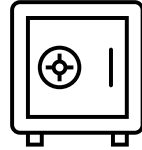
PREM SURVEY FLOW

- Patient gets invite after hospital stay
- Patient fills in survey



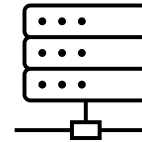
Patient gives consent to store the answers in his personal data vault (SOLID Athumi Pod)

Control over data in Athumi Pod with We Are AMA

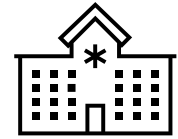


Patient gives consent to aggregate and pseudonymise the answers and share with VIKZ and the hospital

Extraction & data processing by VITO tool...



... and shared with VIKZ and the hospital



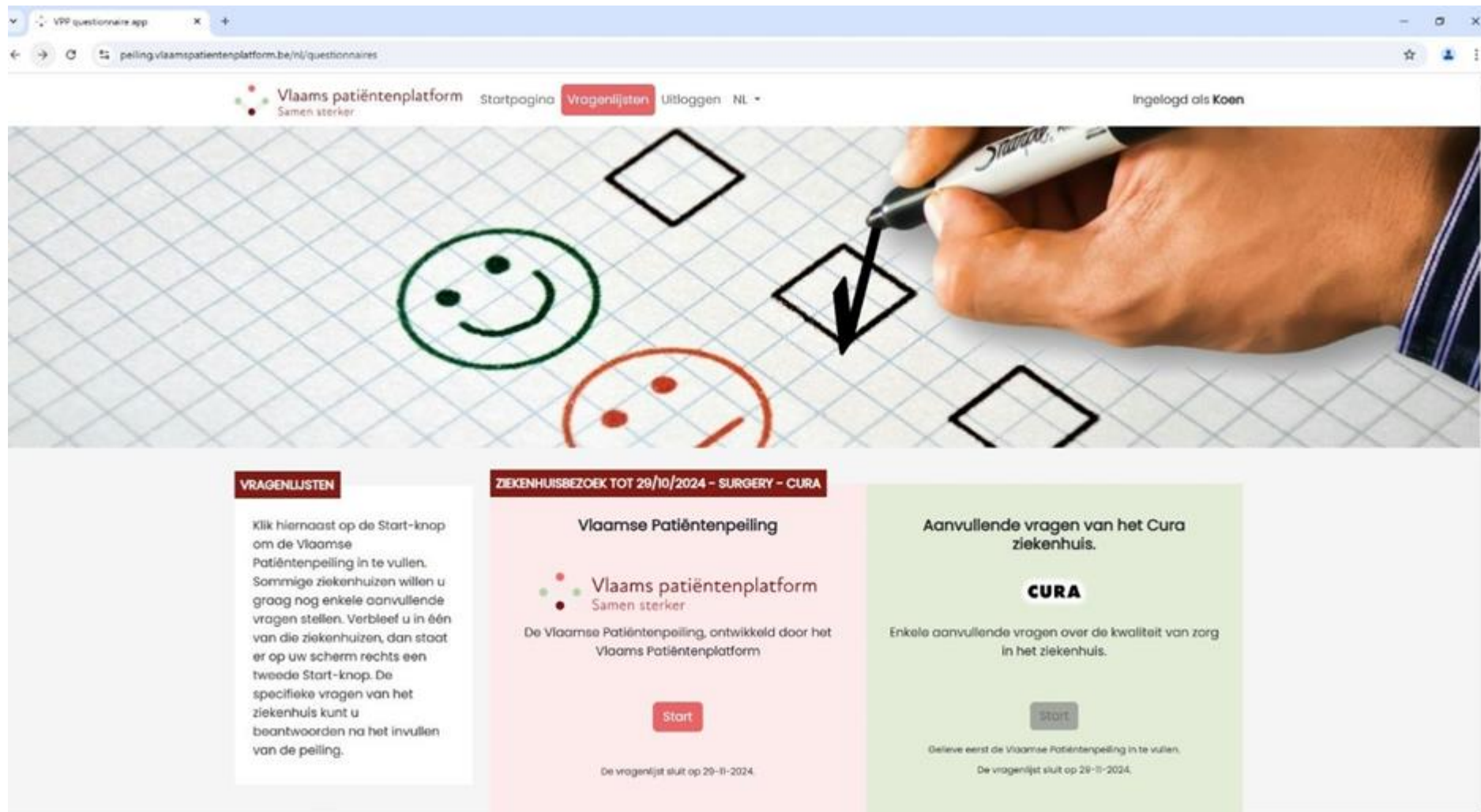
Hospital



VIKZ

Technologie

A view on the application



Data processing tool

The basics

1. Automated process that runs on planned timepoints (e.g. monthly)

2. Consents for data sharing since last run

3. Data is read from the Pods, excluding immediate identifiers (e.g. name, e-mail, WebID,..)

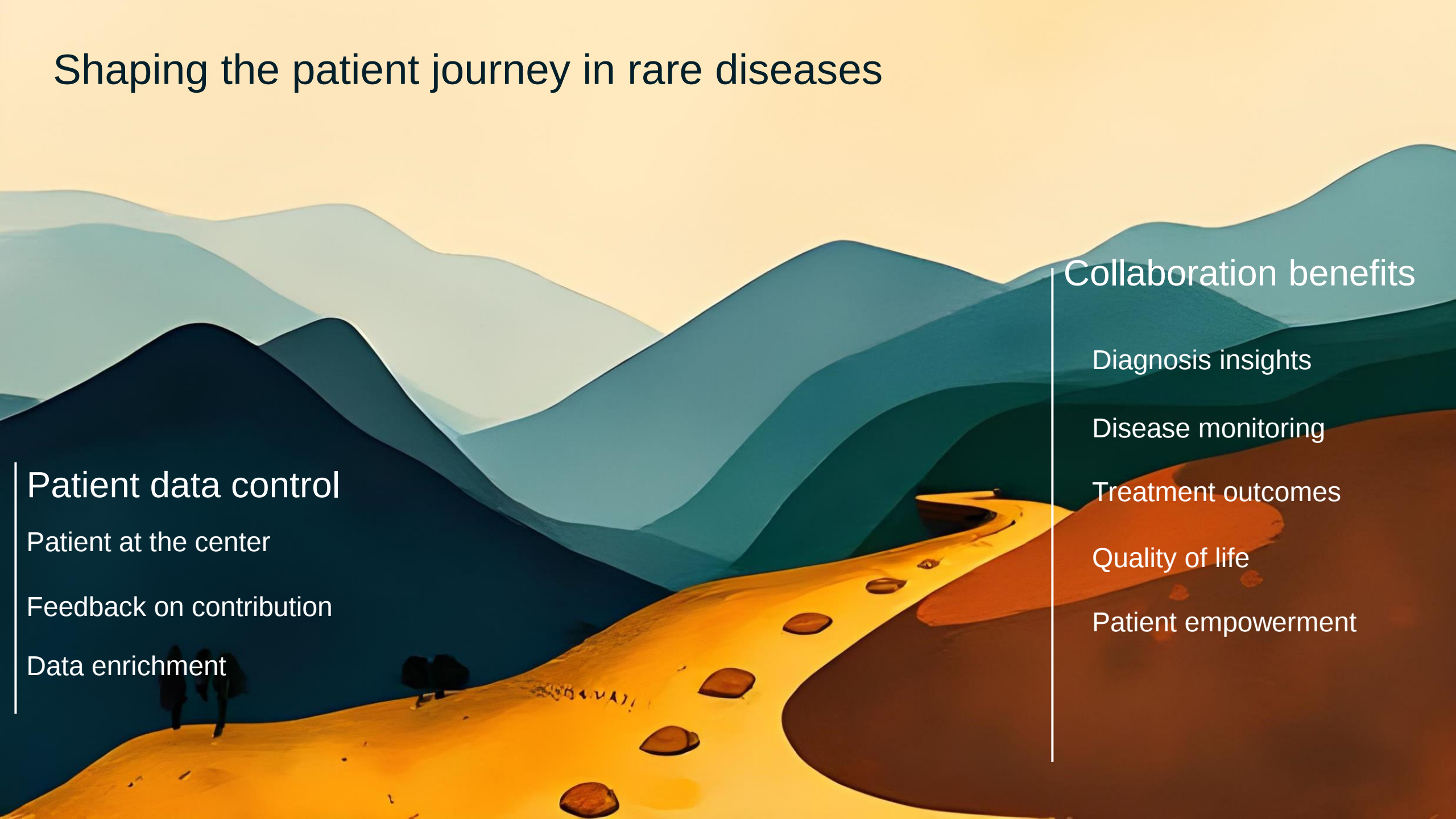
4. Data are collected in one file (RDF, SOLID format)

5. Conversion to XML according to VIKZ template

6. Results kept on secure FTP server of VIKZ for further analysis

TTP survey

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

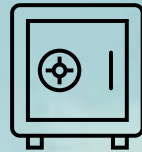
Patient empowerment

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...



Insights shared with patient and TTP community



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

TTP COMMUNITY *it's in my blood*

ALLES WAT U WILT WETEN OVER TROMBOTISCHE TROMBOCYTOPENISCHE PURPURA

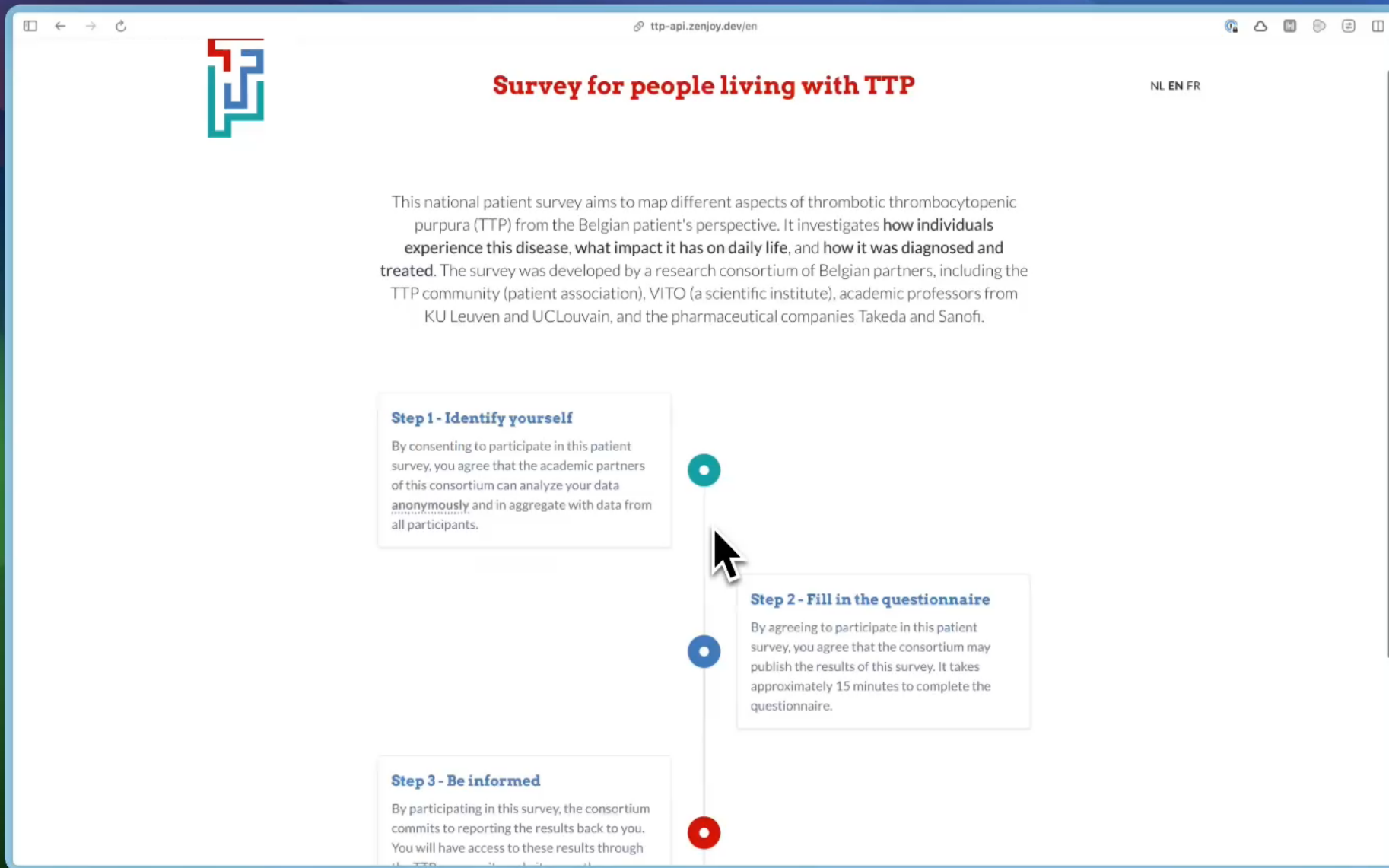


KU LEUVEN

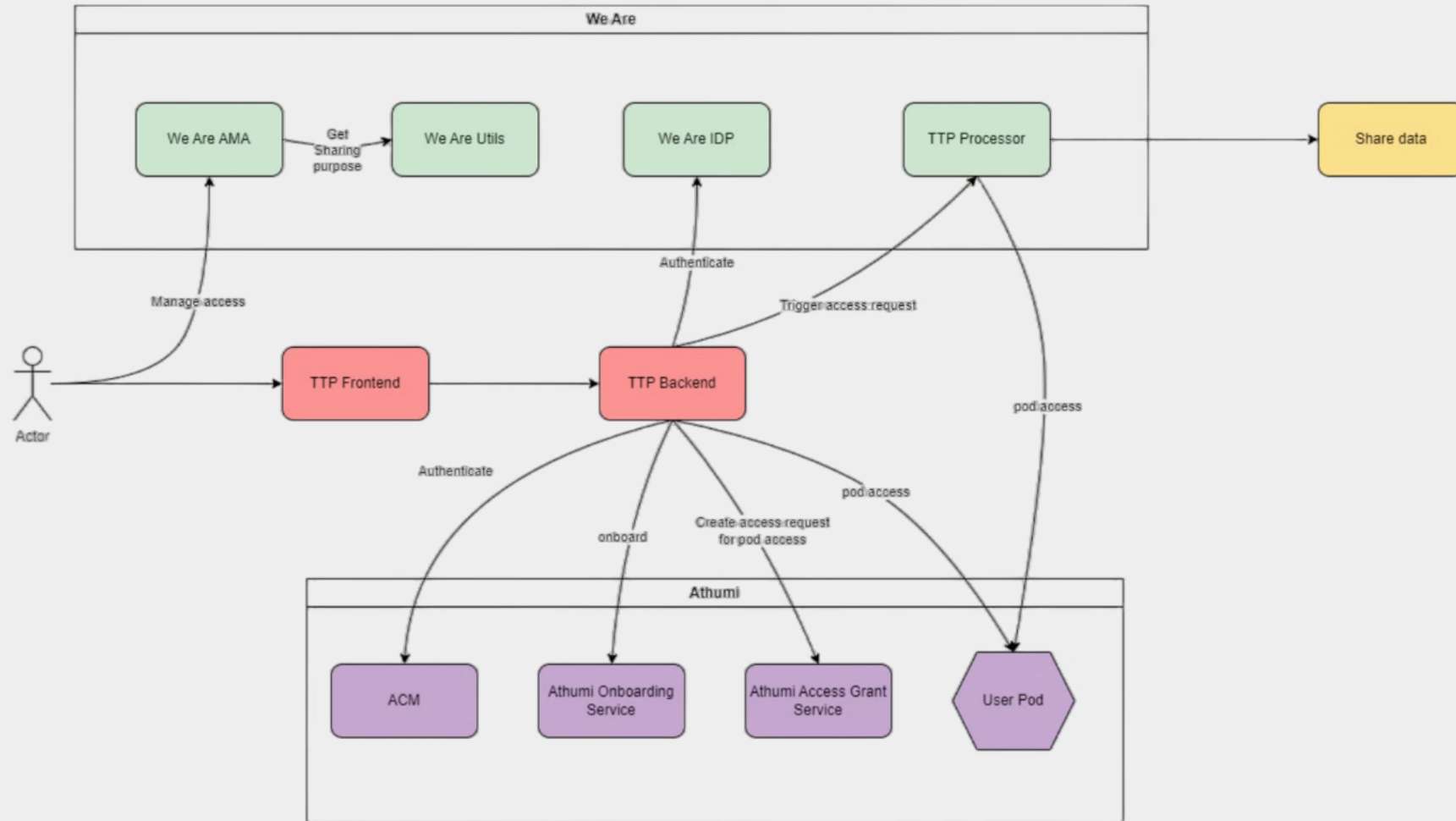
sanofi

UCLouvain

zenjoy



Application Architecture



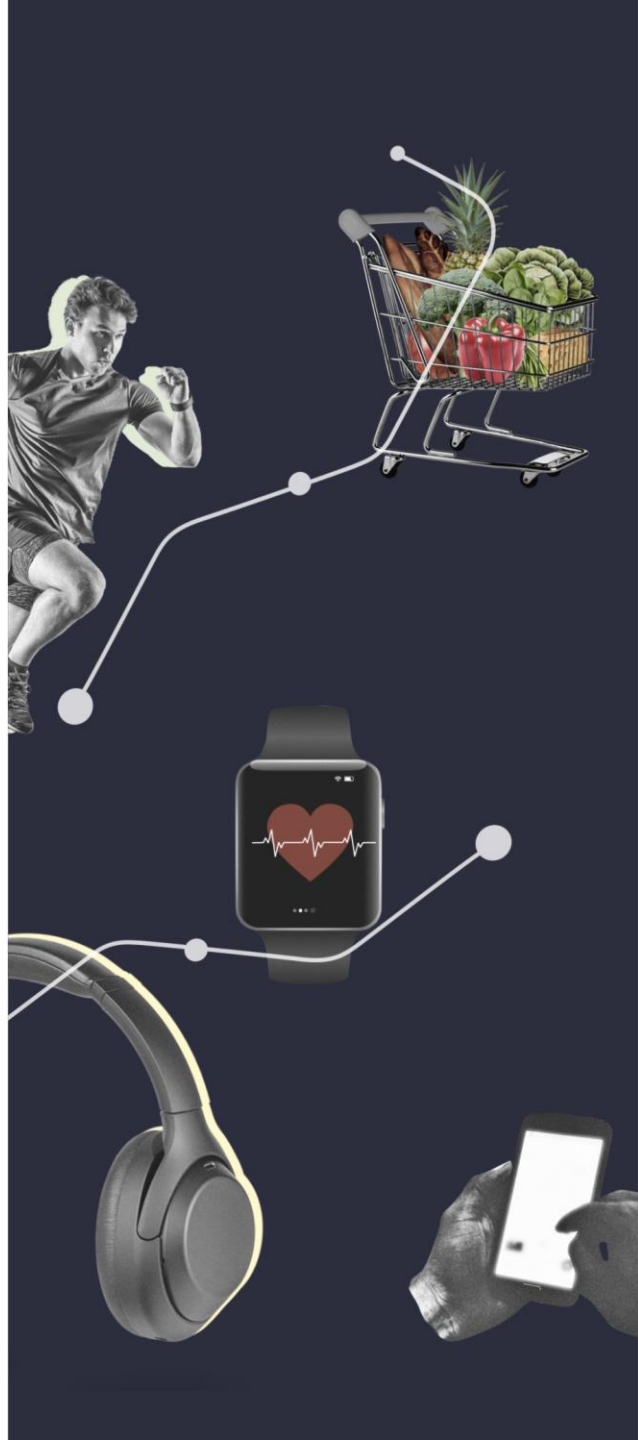
Reflection on TTP survey journey

Lessons learned

- Good communication in consortium
 - Survey questions
 - Communication strategy
 - Project planning
- Legal hiccups cause great delays
 - Getting consortium agreement in order
 - Getting security & legal GDPR assessment done
- Technical learnings
 - Pioneer: developer accessibility and unclear errors, server upgrades
 - Data structure: see Frederik
 - Building user trust



Vitalink Connector





We Are

vitalink
gegevens delen, aan elkaar binden

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 levenskwaliteit van mensen en individuen in hun dagelijkse leven. Het We Are

Toepassingen

Overzicht toepassingen



Koppeling Vitalink x SOLID

De brug tussen twee ecosystemen



Aanmelden

Kies hieronder de [digitale sleutel](#) waarmee u wenst aan te melden. Klik op "meer info" voor uitleg over die aanmeldmethode. Klik op de knop "hulp nodig bij aanmelden?" (rechts bovenaan) voor ondersteuning bij het aanmelden of neem contact op met het gratis nummer 1700.

[?](#) HULP NODIG BIJ AANMELDEN?

> eID en aangesloten kaartlezer

VEILIGSTE KEUZE



[Meer info](#) [?](#)

> itsme®



[Meer info](#) [?](#)

> Beveiligingscode via mobiele app

GEMAKKELIJKSTE KEUZE



Nog niet geactiveerd? [Activeer nu!](#) [Meer info](#) [?](#)

> eIDAS



[Meer info](#) [?](#)



Identificeer jezelf

Open de itsme®-app en tik op  om de QR-code te scannen.



Kun je de QR-code niet scannen? **Gebruik je telefoonnummer** >



Scan QR-code

Open de itsme®-app en tik op 

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

Log in & Access grant

Logged in to ACM as: <https://tni.webid.burgerprofiel.dev-vlaanderen.be/profiles/85372002-59bf-4430-a535-7f0103855783>
 Expiration date: 2024-12-19T09:12:35.000Z
 Pods: <https://storage.sandbox-pod.datanutsbedrijf.be/fadbcfc9-a419-4b7a-ab75-bc88128287f3/>
 Access grant: <https://vc.sandbox-pod.datanutsbedrijf.be/vc/87f47d25-e9cd-49eb-8b0b-df1510344ba8>
 Access grant expiration date: 2024-12-20T08:12:04.475Z

Bevolkingsonderzoek

```
[
  {
    "id": "e4bd38d6-0475-4632-a851-02479b79c010",
    "status": "ACTIVE",
    "containedName": "Centrum voor Kankeropsporing (CvKO)",
    "categoryDisplay": "Bevolkingsonderzoek Borstkanker",
    "periodStart": "2024",
    "appointmentReference": "Appointment/f4436661-6497-4280-b7e5-1d3121c3ae21"
  },
  {
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    "status": "ACTIVE",
    "containedName": "Centrum voor Kankeropsporing (CvKO)",
    "categoryDisplay": "Bevolkingsonderzoek Baarmoederhalskanker",
    "periodStart": "2024",
    "appointmentReference": "Appointment/8e1a3395-6f61-4daf-a401-8da0d9cd261b"
  }
]
```

Data in Vitalink



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

Garmin

120 gegevensrecords

Koppeling Vitalink x SOLID

Machine readable code
from the pod

Read turtle

```
@prefix acl: <http://www.w3.org/ns/auth/acl#>. @prefix acp: <http://www.w3.org/ns/solid/acp#>. @prefix cc: <http://creativecommons.org/ns#>. @prefix cert: <http://www.w3.org/ns/auth/cert#>. @prefix csvw: <http://www.w3.org/ns/csvw#>. @prefix current: <#>. @prefix dc: <http://purl.org/dc/terms>. @prefix dcam: <http://purl.org/dc/dcam>. @prefix dcat: <http://www.w3.org/ns/dcat>. @prefix dctype: <http://purl.org/dc/dcmitype>. @prefix foaf: <http://xmlns.com/foaf/0.1/>. @prefix ldap: <http://www.w3.org/ns/ldap#>. @prefix owl: <http://www.w3.org/2002/07/owl#>. @prefix posixstat: <http://www.w3.org/ns/posix/stat#>. @prefix rdf: <http://www.w3.org/1999/02/22-rdf-syntax-ns#>. @prefix rdfs: <http://www.w3.org/2000/01/rdf-schema#>. @prefix schema: <https://schema.org/>. @prefix shacl: <http://www.w3.org/ns/shacl#>. @prefix skos: <http://www.w3.org/2004/02/skos/core#>. @prefix skosxl: <http://www.w3.org/2008/05/skos-xl#>. @prefix solid: <http://www.w3.org/ns/solid/terms#>. @prefix swapdoc: <http://www.w3.org/2000/10/swap/pim/doc#>. @prefix ui: <http://www.w3.org/ns/ui#>. @prefix vann: <http://purl.org/vocab/vann/>. @prefix vcard: <http://www.w3.org/2006/vcard/ns#>. @prefix ws: <http://www.w3.org/ns/pim/space#>. @prefix xsd: <http://www.w3.org/2001/XMLSchema#>. <https://storage.sandbox-pod.datanutsbedrijf.be/fadbcfe9-a419-4b7a-ab75-bc88128287f3/careplans_index#e4bd38d6-0475-4632-a851-02479b79c010> <https://example.org/careplans#id> "e4bd38d6-0475-4632-a851-02479b79c010"; <https://example.org/careplans#status> "ACTIVE"; <https://example.org/careplans#containedName> "Centrum voor Kankeropsporing (CvKO)"; <https://example.org/careplans#categoryDisplay> "Bevolkingsonderzoek Borstkanker"; <https://example.org/careplans#periodStart> "2024"; <https://example.org/careplans#appointmentReference> "Appointment/f4436661-6497-4280-b7e5-1d3121c3ae21"; <https://storage.sandbox-pod.datanutsbedrijf.be/fadbcfe9-a419-4b7a-ab75-bc88128287f3/careplans_index#f73b59d6-05ff-4b40-91cd-616c286257b6> <https://example.org/careplans#id> "f73b59d6-05ff-4b40-91cd-616c286257b6"; <https://example.org/careplans#status> "ACTIVE"; <https://example.org/careplans#containedName> "Centrum voor Kankeropsporing (CvKO)"; <https://example.org/careplans#categoryDisplay> "Bevolkingsonderzoek Baarmoederhalskanker"; <https://example.org/careplans#periodStart> "2024"; <https://example.org/careplans#appointmentReference> "Appointment/8e1a3395-6ff61-4daf-a401-8da0d9cd261b".
```



Koppeling Vitalink x SOLID



1 item

 Zoeken ...

 Filter

Gegevensbeschrijving

Gedeeld met

[Bevolkingsonderzoek](#)

3 okt 2024

Bekijken

< Resultaten Bevolkingsonderzoek



Bevolkingsonderzoek Borstkanker

Datum deelname aan het bevolkingsonderzoek	1/2/2022
Verdere opvolging	Geen
Datum volgende onderzoeksuitnodiging	13/4/2027

Bevolkingsonderzoek Baarmoederhalskanker

Datum deelname aan het bevolkingsonderzoek	1/3/2024
Verdere opvolging	Jaarlijkse terugkomst
Datum volgende onderzoeksuitnodiging	1/1/2025

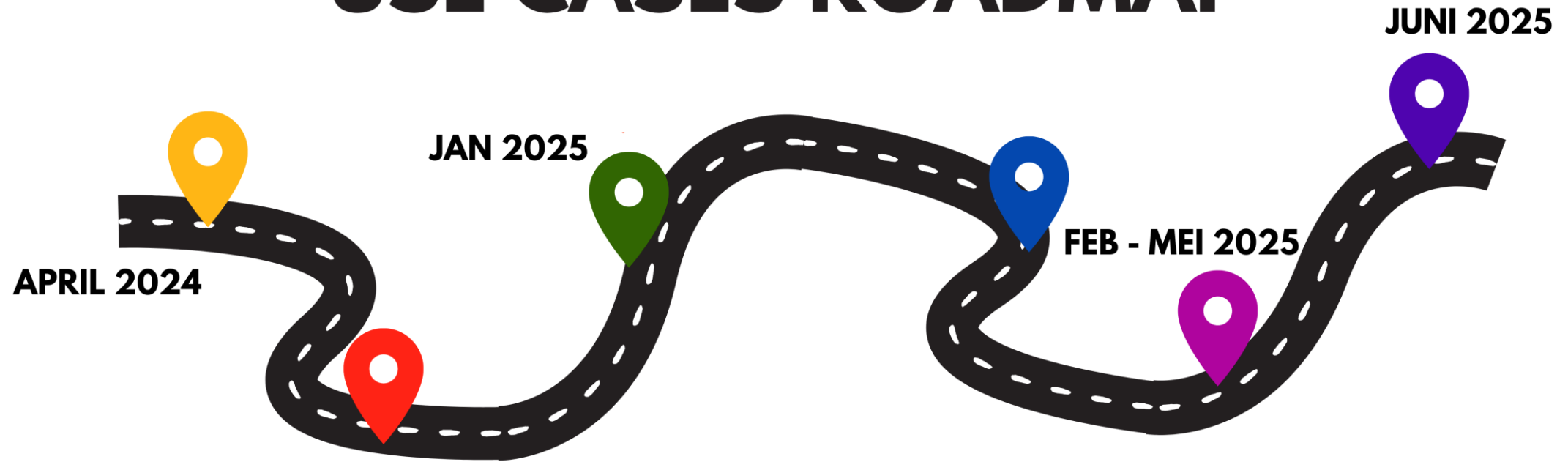
SOLID4Health



Goal SOLID4HEALTH

- Unlock personal health- and lifestyle data for the development, validation and valorisation of health applications for preventive health
 - Knowledge sharing on data sharing and data reuse
 - Application of SOLID-technology & interaction with non-SOLID systems

USE CASES ROADMAP



1

BRAINSTORM

Samenkomst Mechelen

- doelgroep
- idee platform
- samenwerking en bijdrage partners

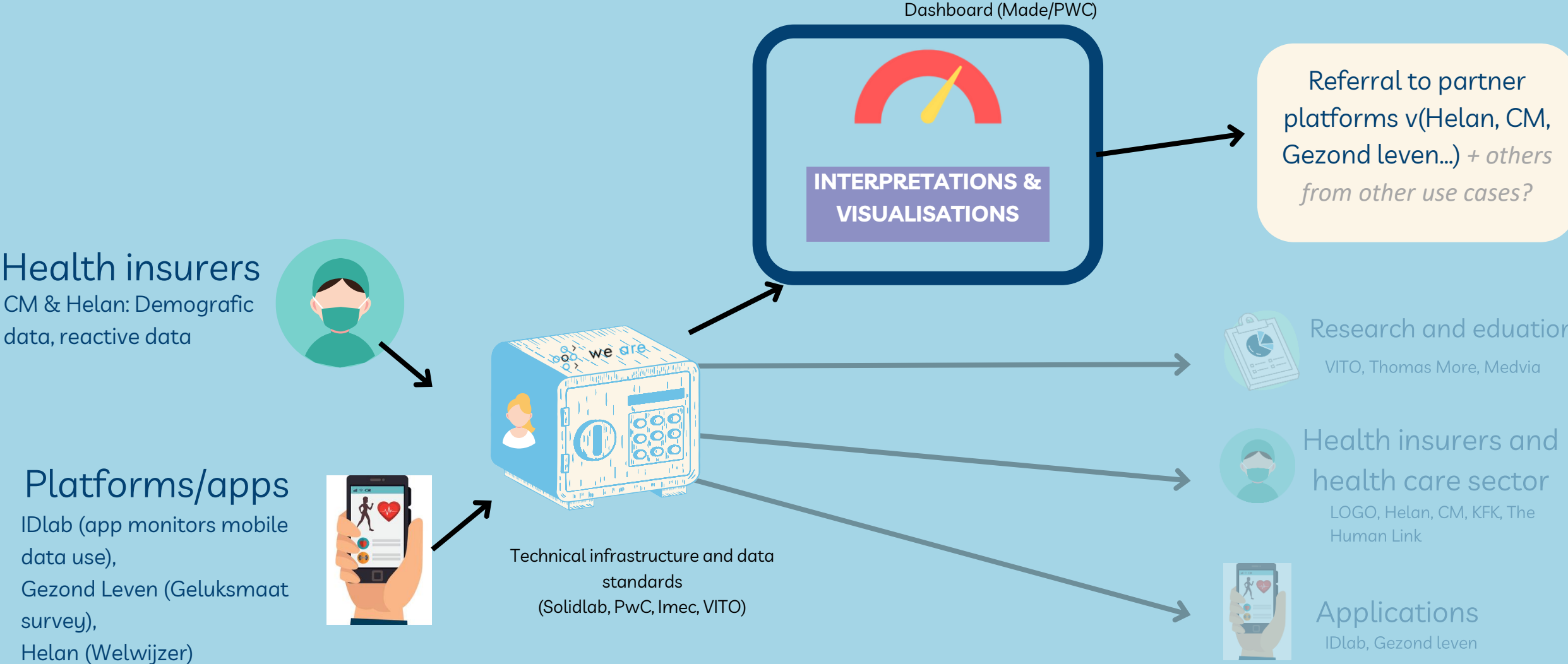
2

CONCEPT

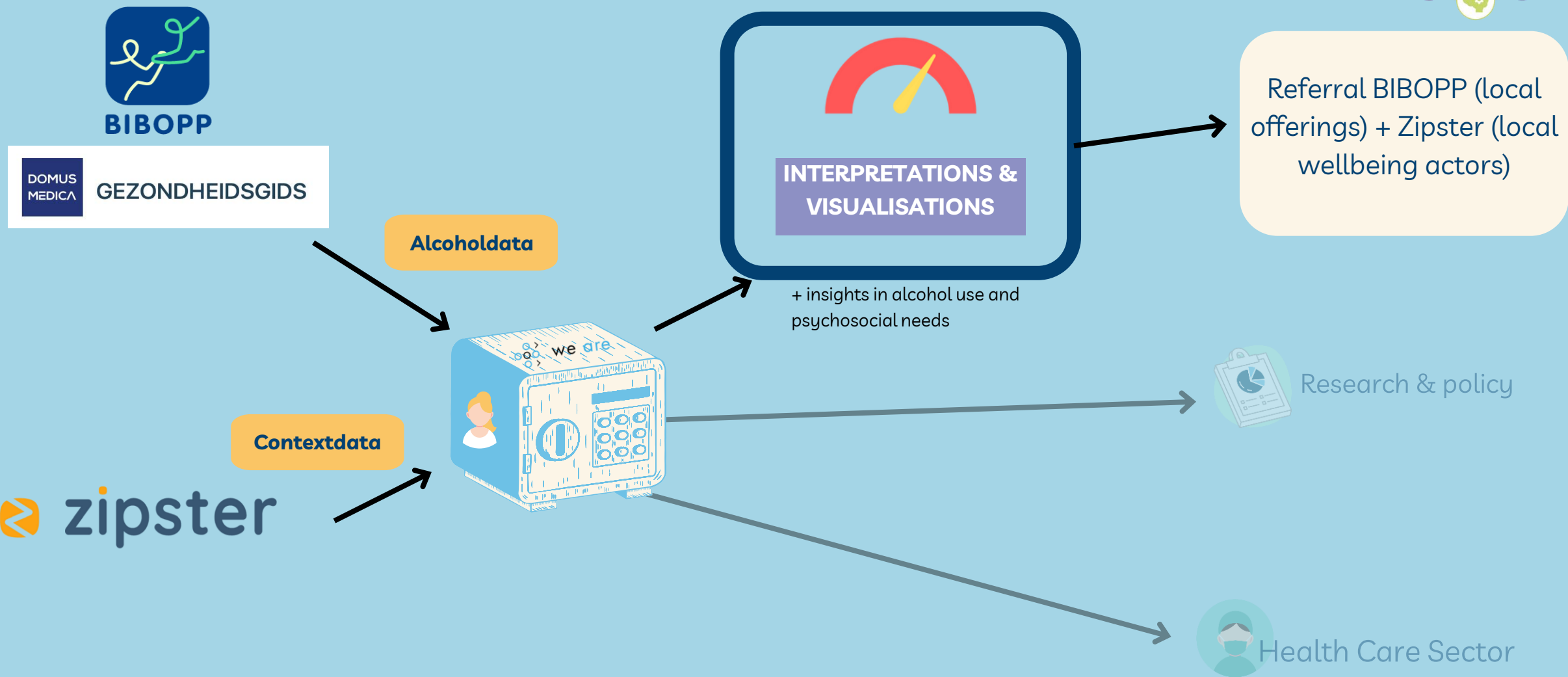
Uitwerken

- 1-1 gesprekken noden & wensen partners
- opvraging beschikbare data bij partners
- technische werkgroep

USE CASE: MENTAL WELLBEING



USE CASE: ONLINE PREVENTION PLATFORM

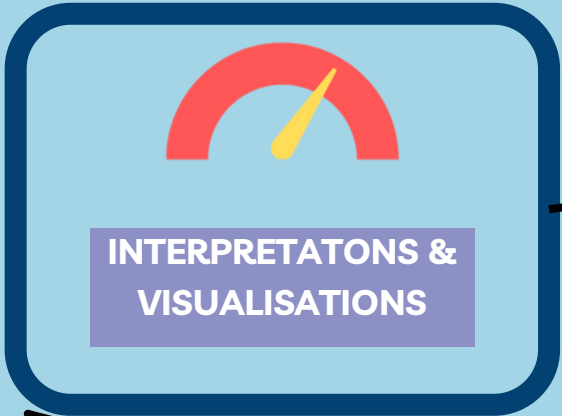
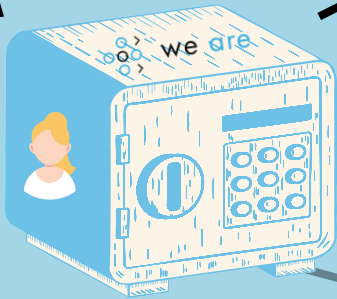


USE CASE: FOOD



Surveys

Healthy Habits
Golazo
Gezondheidsgids



- Insights in eating patterns, history & evolution in food preferences for citizens and HCP

Referral to partner platforms (Bibopp, apps hospital) + *andere uit use cases?*



Research and policy



Supermarkets



Health Care Sector

USE CASE: 1E-2E LINE



Hospitals

Obesity surveys



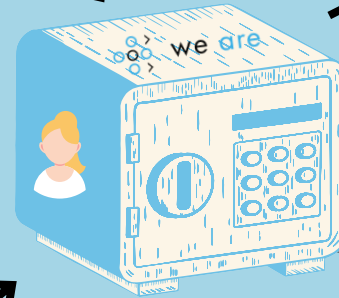
First Line

Gezondheidsgids?



Platforms/apps

- Beweeginformatie uit smartwatch (zelf te simuleren obv Garmin data)



Dashboard



- Visualisation for HCP: hospital, GP, physio
- Visualisation for the citizen

Referral to partnerplatforms (Bibopp, apps hospital) + *others from use cases*



Research & Policy

VITO, Sport Vlaanderen



Health Care Sector

Ziekenhuizen



Applications

Bingli: decision support

Mental Wellbeing

- App GSM usage
- Geluksmaat/Welwijzer (vragenlijst)

Obesitas (1e-2e lijn)

- GG voeding & beweging
- Vragenlijst ziekenhuis
- Beweeginfo wearables

1 platform

*Demonstrator-level = 'the story'
= minimum wireframes*

Food

- Survey Golazo, Healthy Habits, Gezondheidsgids

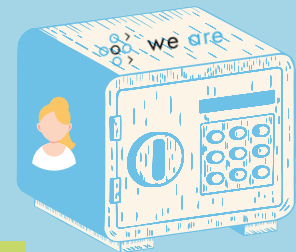
Alcohol use

- Gezondheidsgids
- Zipster survey

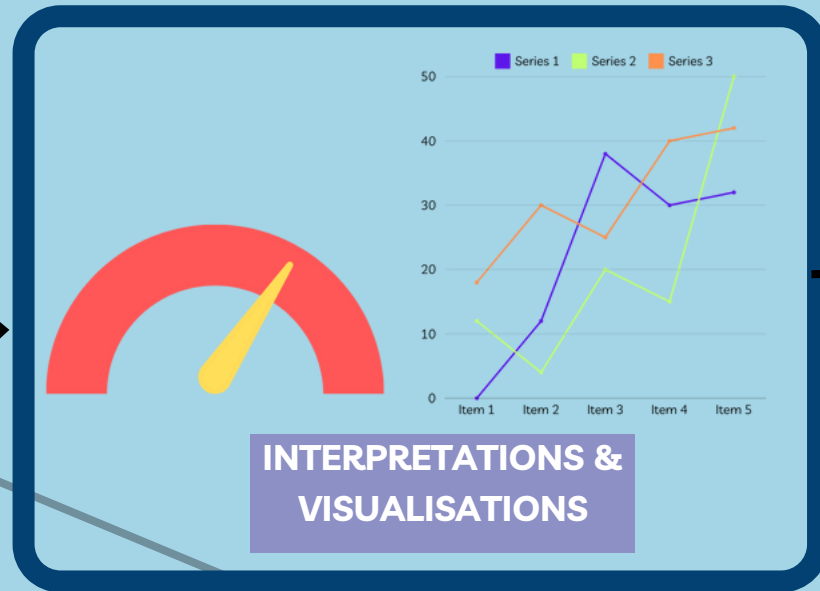
SCREENING DATA

SCREENING DATA

SCREENING DATA



DASHBOARD



ADVICE

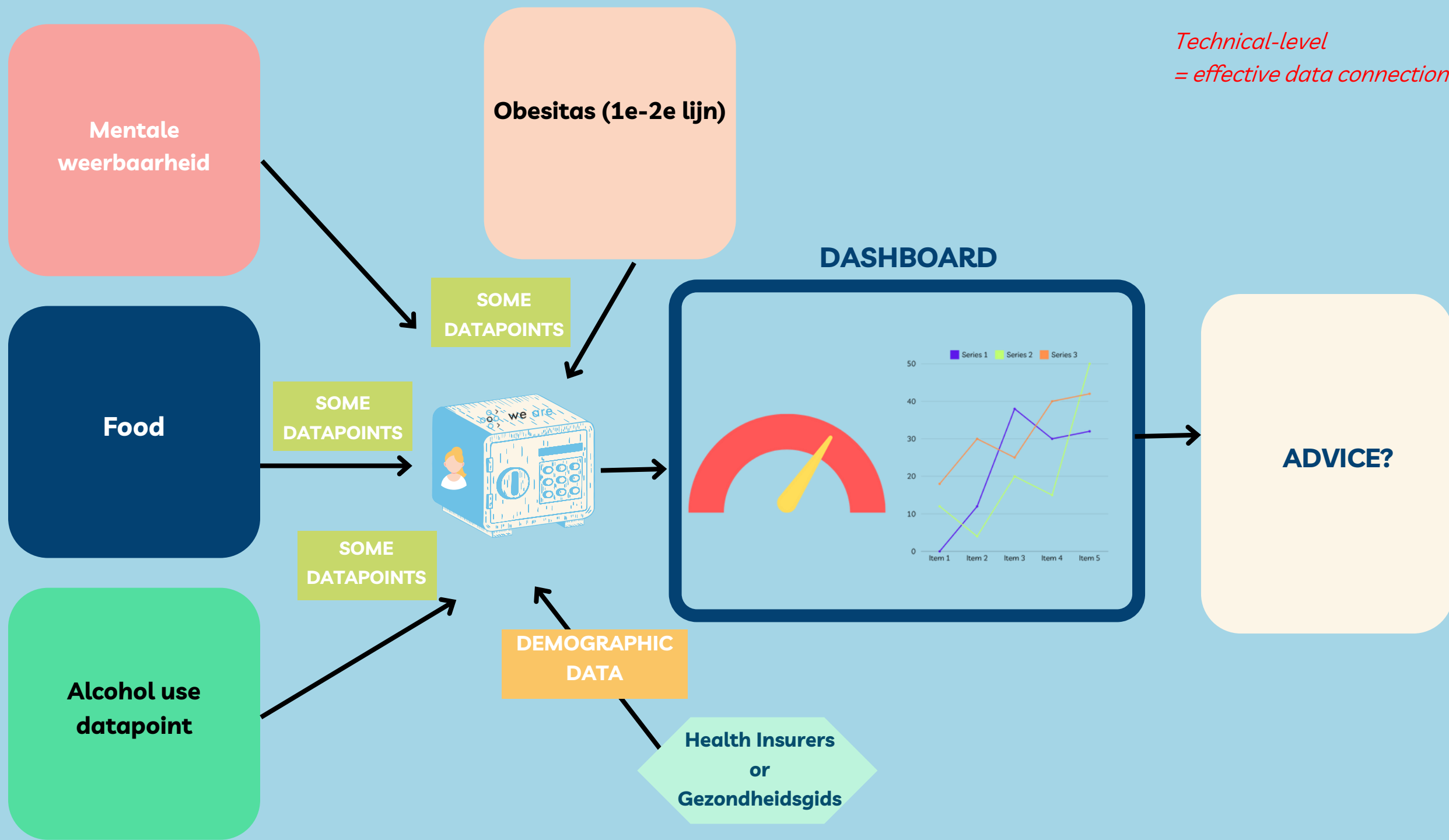
- ZIPSTER
- Uit in Vlaanderen + Sociale kaart (BiBopp)
- Partnerplatforms (Helan, CM, Gezond leven...)

DEMOGRAPHIC & REACTIVE DATA

Health insurers

SECONDARY USE
(Healthcare, policy, R&D, business)

*Technical-level
= effective data connection*



WellData

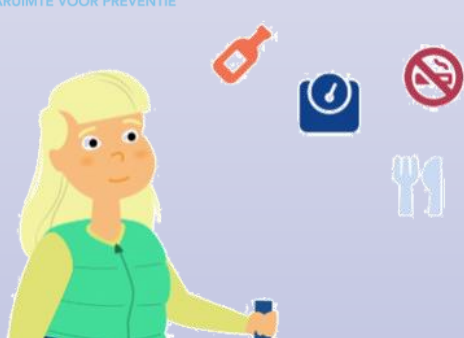
Interreg VL-Ned: Welldata

Designing and building a prevention health data space



Meet the partners





WP3: Variables for prevention

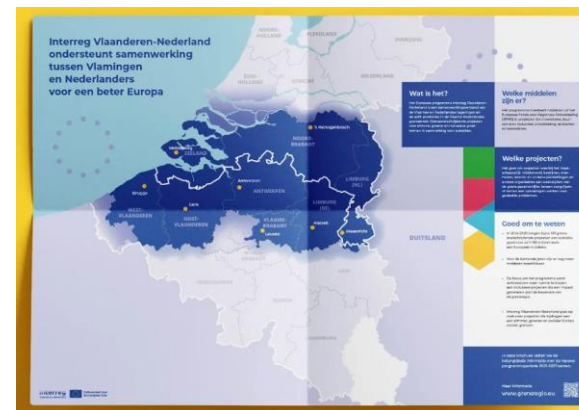
- **Which** are these, and how do we **standardize** these?
- Which **ethical, legal and societal boundary conditions** to let the citizen capture and share these?
- In which language do we need to store them?

The work plan



WP4: Demonstrator in field labs

- **Building** a platform with **interoperable preventive applications** in Flanders and the Netherlands in line with the boundary conditions
- **Testing** this together with citizens in their care community



WP5: Data space for preventive care by exchanging data and knowledge

- **Scalability and knowledge sharing**
 - In the care community
 - in the border region
- **Action plan** for datadriven prevention in line with EHDS

Use case challenges

- Interoperability of applications
 - FHIR – OMOP – RDF
- Re-use of data across applications
 - E.g. weight
- Cross-border SOLID sharing
 - IDPs
- Cross-application consent
 - User friendliness vs security

THANK YOU

For more information:

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

Elfi.Goesaert@vito.be



Vlaamse
overheid



next
gen
EU

