



# 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

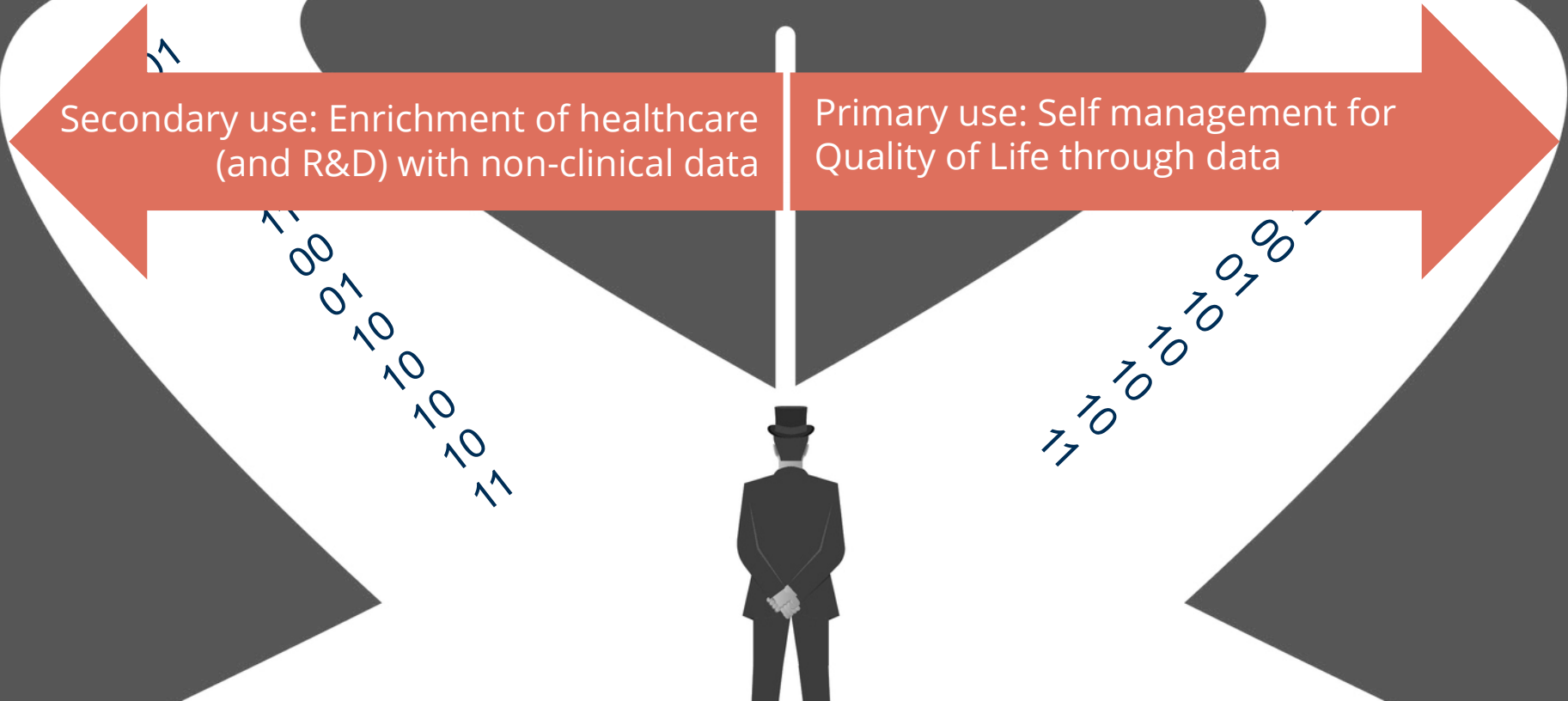


**Passive patient  
in disease-oriented care system**



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

# 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



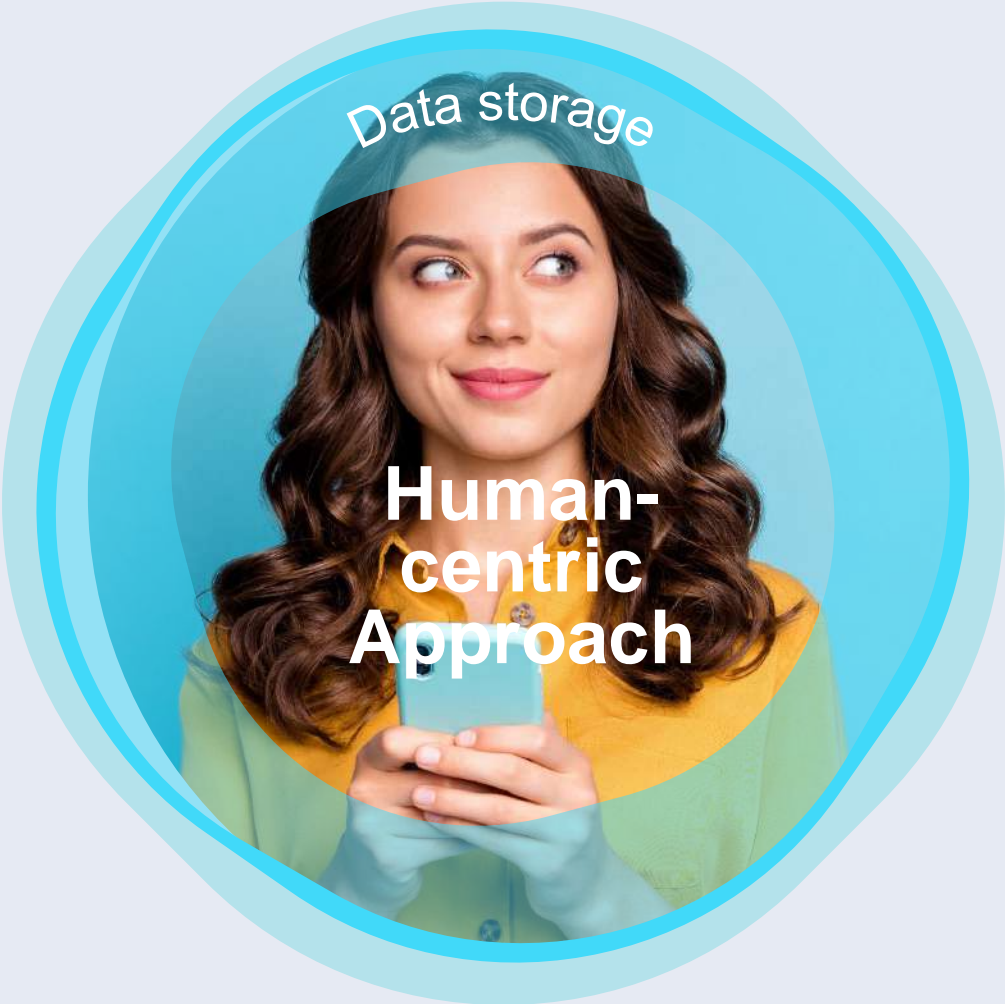
Reuse data across  
APPS



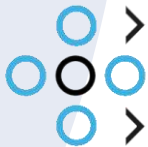
Connect with anyone



Select what you  
share precisely



# PERSONAL DATA SPACES




we are

# Roles and applications in the 'We Are' layers



Legal & Ethical framework

ACM/IDM  **itsme**  
Authentication and authorization



User Interfaces, e.g.  
- Consent mgmt app  
- Data formats / interop



Personal Digital Vaults  
-> architecture, infrastructure, requirements

Copyright principles: Fonds dr. Daniel De Coninck

# Flemish patient survey

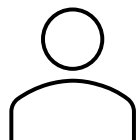
# Flemish patient survey

## 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

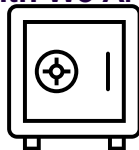
# PREM SURVEY FLOW

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



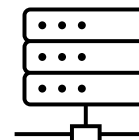
Patient gives consent to store the answers in his personal data vault (SOLID Athumi Pod)

Control over data in Athumi Pod with We Are AMA

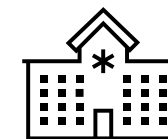


Patient gives consent to aggregate and pseudonymise the answers and share with VIKZ and the hospital

Extraction & data processing by VITO tool...



... and shared with VIKZ and the hospital



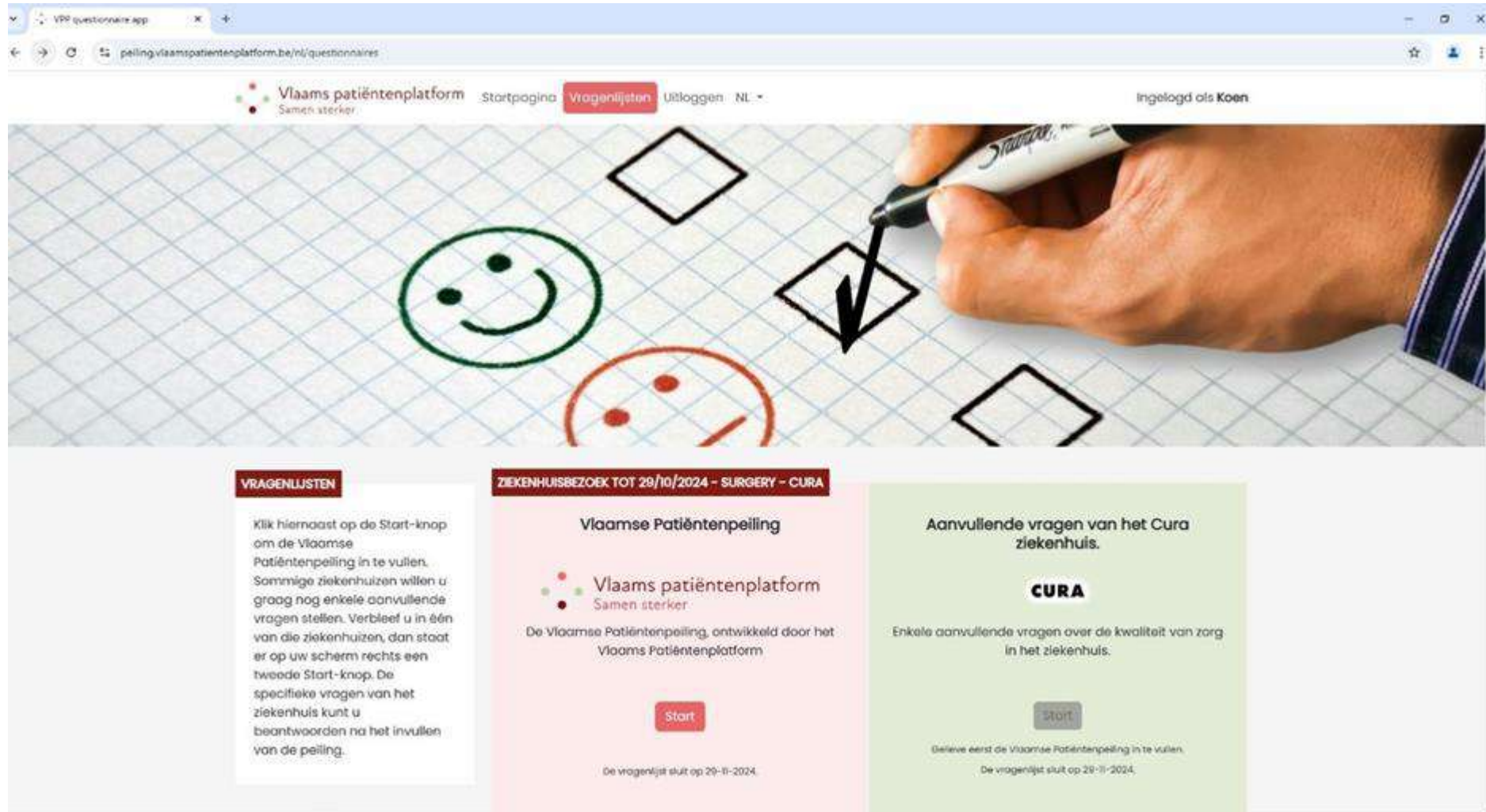
Hospital



VIKZ

# Technologie

## A view on the application



The screenshot shows a web browser window displaying the 'VPP questionnaire app'. The browser's address bar shows the URL 'pelling.vlaamspatiëntenplatform.be/nl/questionnaires'. The page header includes the logo for 'Vlaams patiëntenplatform' with the tagline 'Samen sterker', navigation links for 'Startpagina', 'Vragenlijsten', and 'Uitloggen', and the text 'Ingelogd als Koen'. The main content area features a large image of a hand drawing a smiley face and a sad face on a grid background. Below this image are three main sections:

- VRAGENLIJSTEN**: A white box containing instructions: 'Klik hiernaast op de Start-knop om de Vlaamse Patiëntenpeiling in te vullen. Sommige ziekenhuizen willen u graag nog enkele aanvullende vragen stellen. Verbleef u in één van die ziekenhuizen, dan staat er op uw scherm rechts een tweede Start-knop. De specifieke vragen van het ziekenhuis kunt u beantwoorden na het invullen van de peiling.'
- ZIEKENHUISBEZOEK TOT 29/10/2024 - SURGERY - CURA**: A pink box titled 'Vlaamse Patiëntenpeiling' with the Vlaams patiëntenplatform logo. It states: 'De Vlaamse Patiëntenpeiling, ontwikkeld door het Vlaams Patiëntenplatform'. A red 'Start' button is visible, and a note at the bottom says 'De vragenlijst sluit op 29-10-2024.'
- Aanvullende vragen van het Cura ziekenhuis.**: A green box titled 'CURA' with the text: 'Enkele aanvullende vragen over de kwaliteit van zorg in het ziekenhuis.' A grey 'Start' button is visible, and a note at the bottom says 'De vragenlijst sluit op 29-10-2024.'

## 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

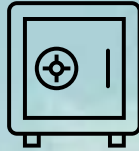
# TTP SURVEY JOURNEY

- 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...



... 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



ALLES WAT U WILT WETEN OVER TROMBOTISCHE TROMBOCYTOPENISCHE PURPURA

KU LEUVEN

UCLouvain



sanofi

zenjoy

ttp-api.zenjoy.dev/en

NL EN FR

## Survey for people living with TTP

This national patient survey aims to map different aspects of thrombotic thrombocytopenic purpura (TTP) from the Belgian patient's perspective. It investigates **how individuals experience this disease, what impact it has on daily life, and how it was diagnosed and treated**. The survey was developed by a research consortium of Belgian partners, including the TTP community (patient association), VITO (a scientific institute), academic professors from KU Leuven and UCLouvain, and the pharmaceutical companies Takeda and Sanofi.

**Step 1 - Identify yourself**

By consenting to participate in this patient survey, you agree that the academic partners of this consortium can analyze your data anonymously and in aggregate with data from all participants.

**Step 2 - Fill in the questionnaire**

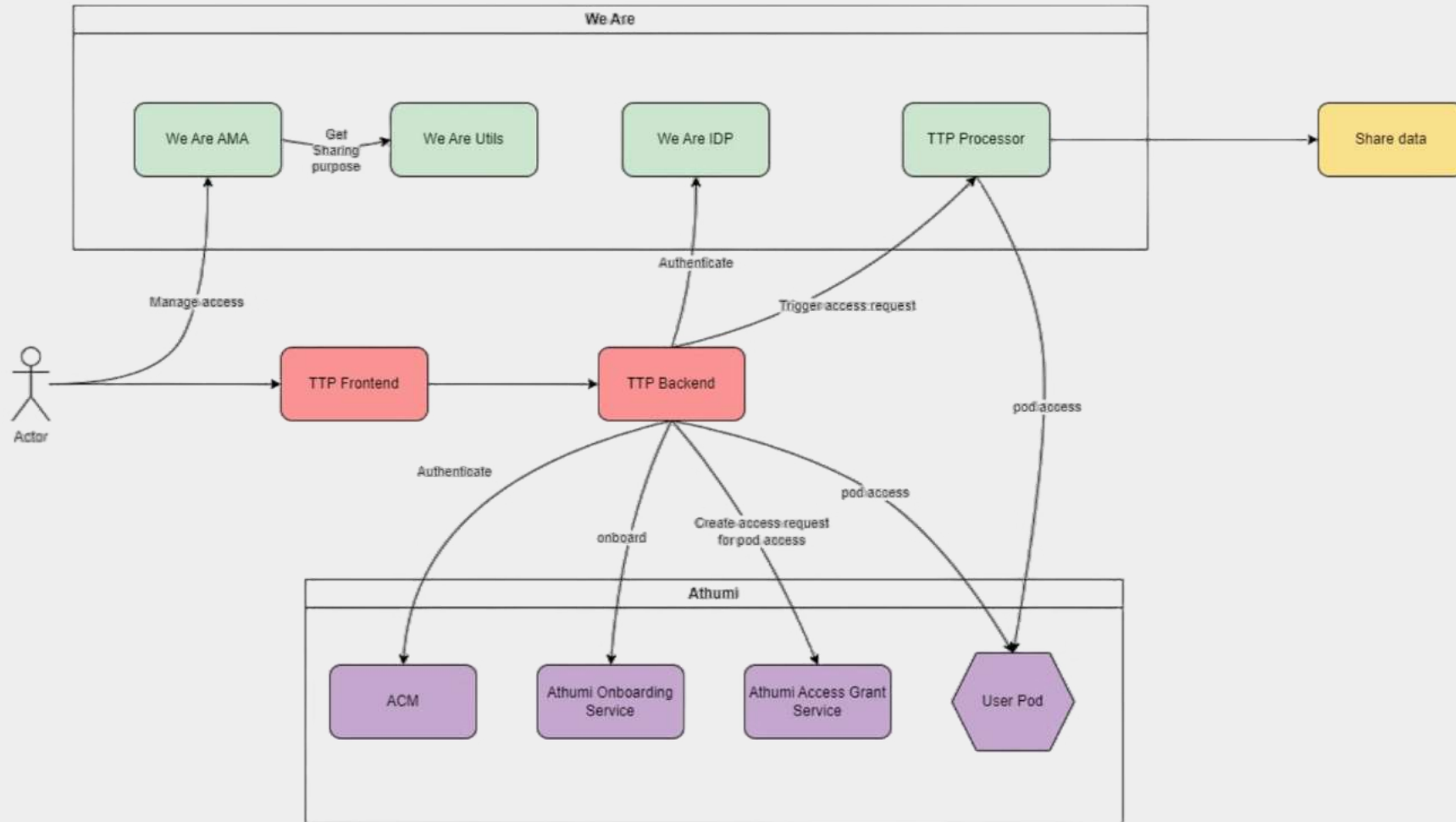
By agreeing to participate in this patient survey, you agree that the consortium may publish the results of this survey. It takes approximately 15 minutes to complete the questionnaire.

**Step 3 - Be informed**

By participating in this survey, the consortium commits to reporting the results back to you. You will have access to these results through the TTP community website.



# 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

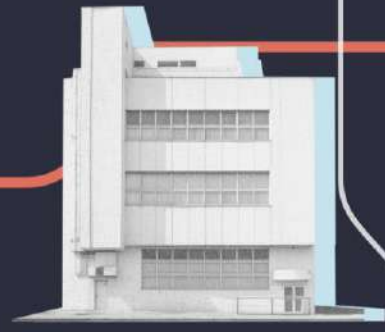


# Vitalink Connector





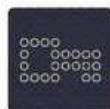
**We Are**



# 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](#)

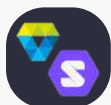
## Wat we doen

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. Met 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<sup>®</sup>-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<sup>®</sup>-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/](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"  
  },  
  {  
    "id": "f73b59d6-05ff-4b40-91cd-616c286257b6",  
    "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

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 5e1a3395-6f61-4daf-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

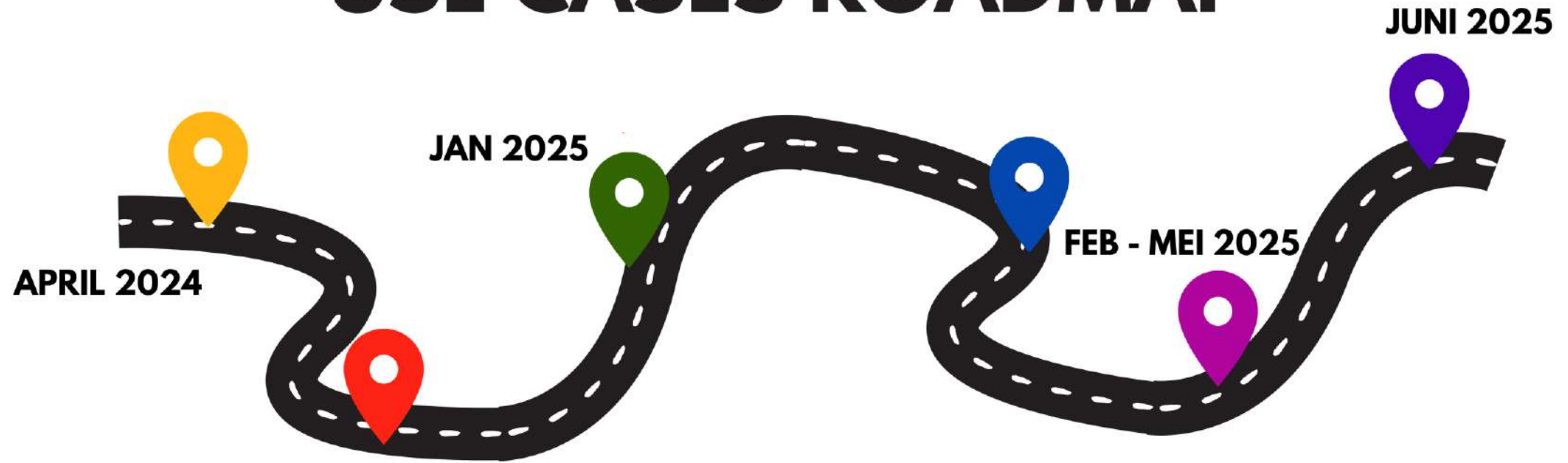
# SOLID4Health



# Goal SOLID4HEALTH

- Unlock personal health- and lifestyle data for the development, validation and valorisation of health applications for preventive health
  - Knowledge sharing on datasharing 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

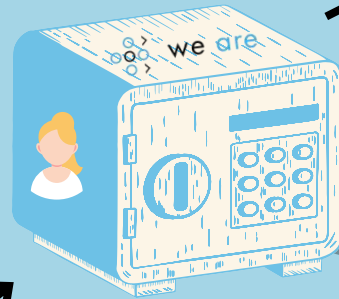
# USE CASE: MENTAL WELLBEING



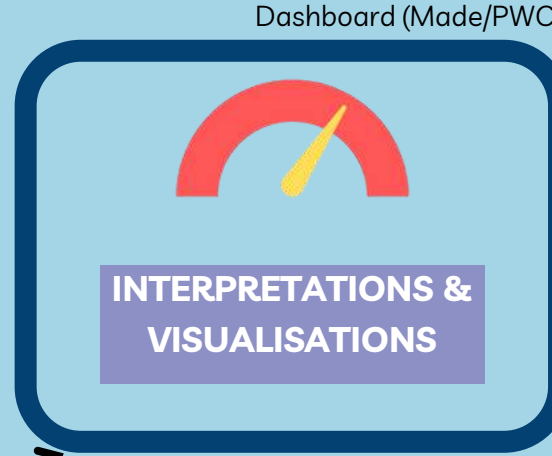
Health insurers  
CM & Helan: Demographic  
data, reactive data



Platforms/apps  
IDlab (app monitors mobile  
data use),  
Gezond Leven (Geluksmaat  
survey),  
Helan (Welwijzer)



Technical infrastructure and data  
standards  
(Solidlab, PwC, Imec, VITO)



Referral to partner  
platforms v(Helan, CM,  
Gezond leven...) + others  
*from other use cases?*



Research and education  
VITO, Thomas More, Medvia

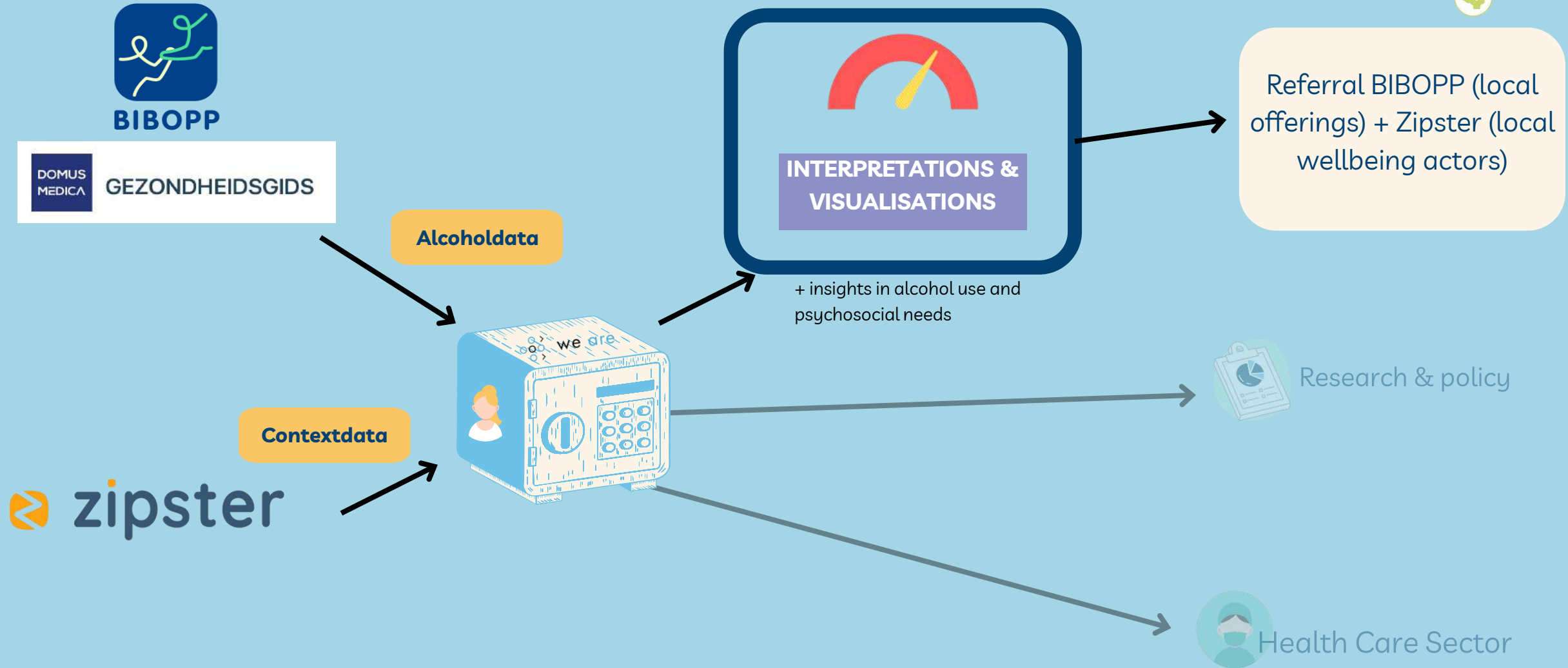


Health insurers and  
health care sector  
LOGO, Helan, CM, KFK, The  
Human Link

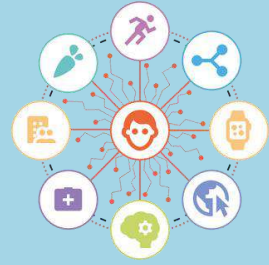


Applications  
IDlab, Gezond leven

# USE CASE: ONLINE PREVENTION PLATFORM



# USE CASE: FOOD

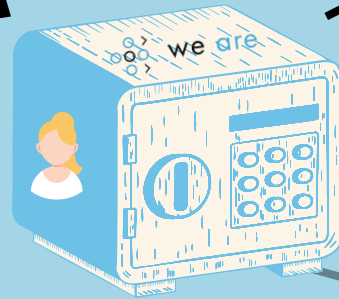


## Surveys

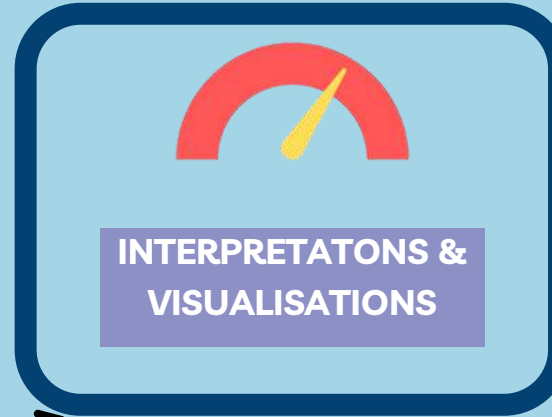
Healthy Habits

Golazo

Gezondheidsgids



### Dashboard



- 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



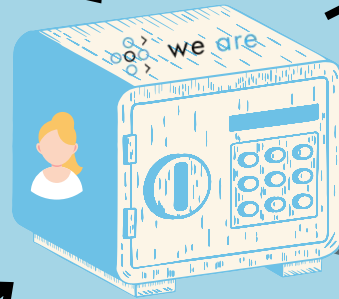
First Line

Gezondheidsgids?

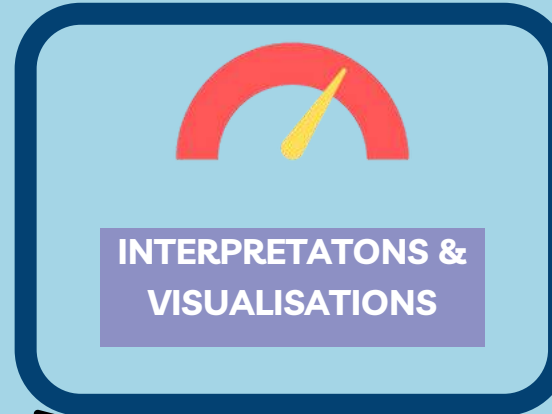


Platforms/apps

- Beweginformatie 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

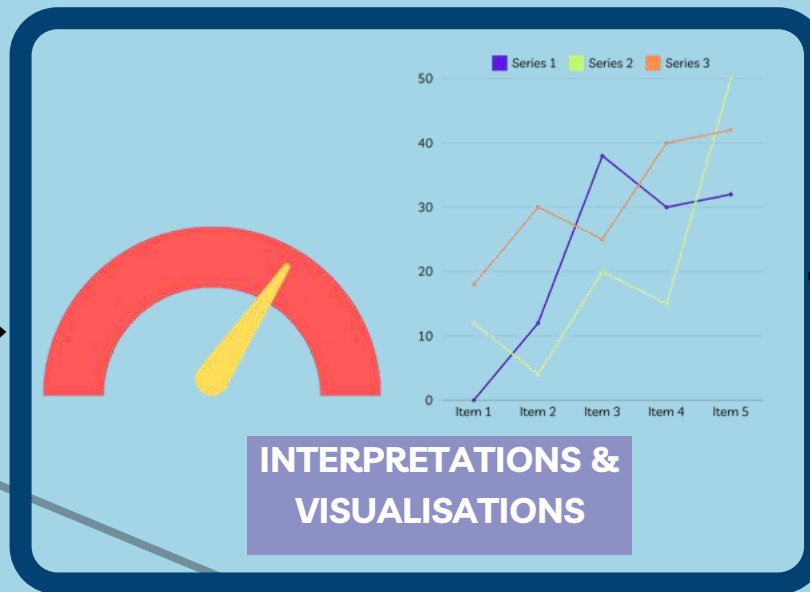
SCREENING DATA

SCREENING DATA

DEMOGRAPHIC &  
REACTIVE DATA

Health  
insurers

## DASHBOARD

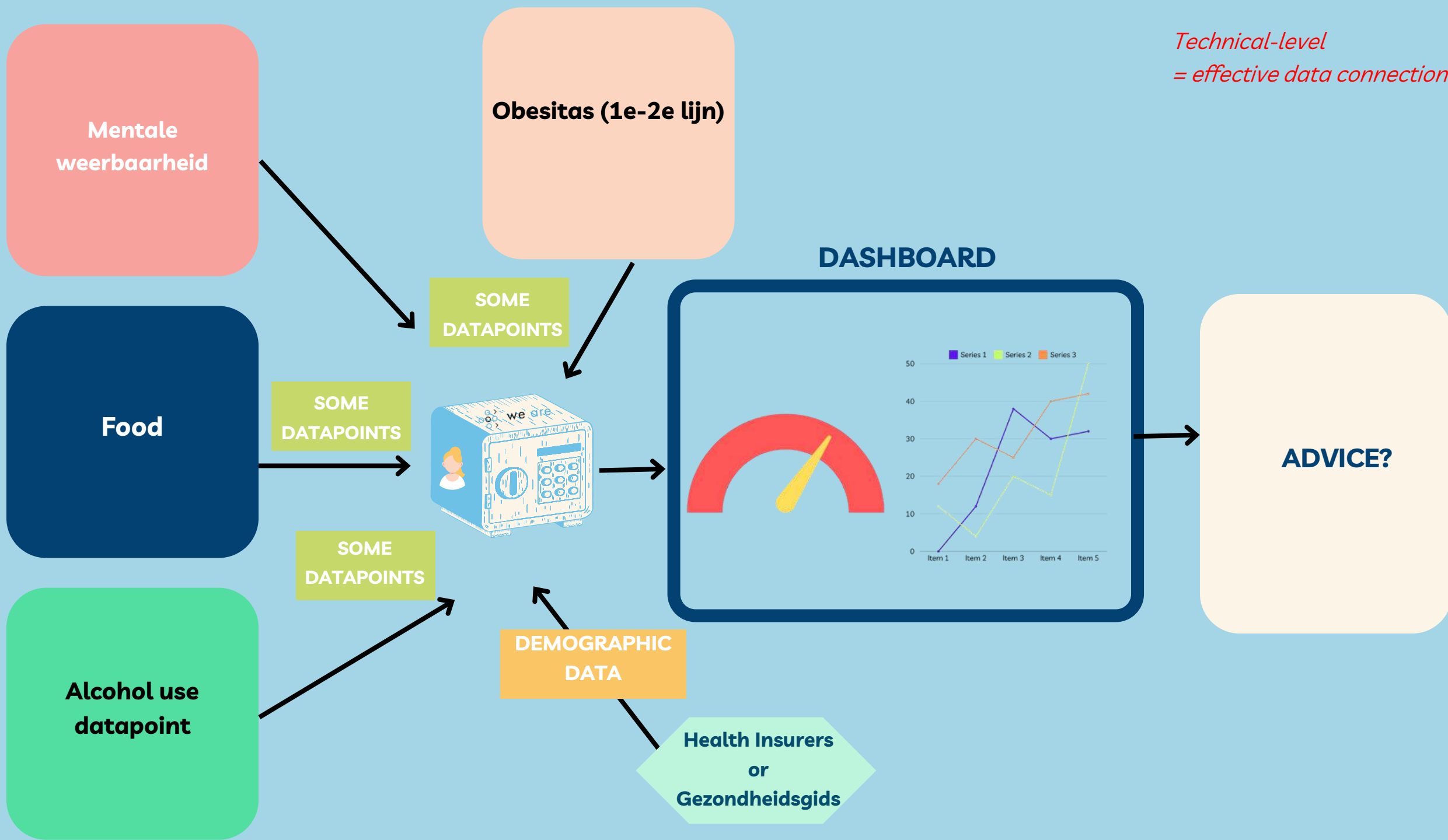


## ADVICE

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

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

*Technical-level  
= effective data connection*



Mentale  
weerbaarheid

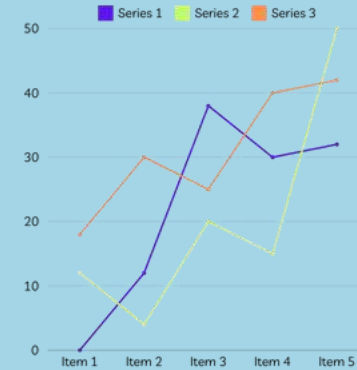
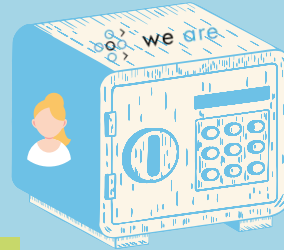
Obesitas (1e-2e lijn)

SOME  
DATAPOINTS

DASHBOARD

Food

SOME  
DATAPOINTS



ADVICE?

SOME  
DATAPOINTS

DEMOGRAPHIC  
DATA

Alcohol use  
datapoint

Health Insurers  
or  
Gezondheidsgids

# WellData

# Interreg VL-Ned: Welldata

Designing and building a prevention health data space



**NSX**  
NORMALIZED SYSTEMS



Selfcare™  
take good care of yourself

**SPORT.**  
VLAANDEREN

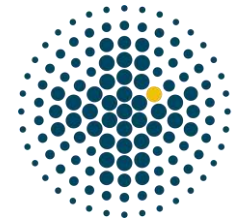


**TU/e**

THOMAS  
**MORE**

**TNO**

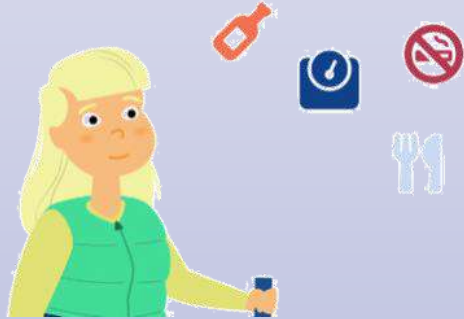
**van**  
vlaams apothekers netwerk



**mijn data**  
onze gezondheid

Meet the partners

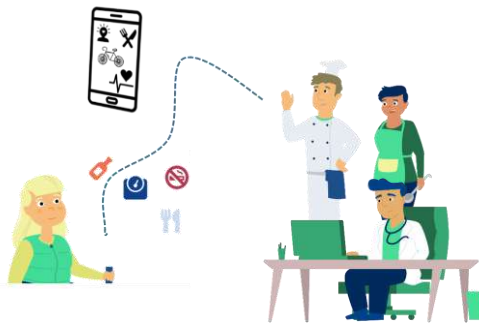




### WP3: Variables for prevention

- **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>

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Vlaamse  
overheid



next  
gen  
EU

