

# PACSOI - Patient-Centric Solid

Your health data close with you and ready for sharing



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Filip Pattyn

# Underuse of data in advanced healthcare



"For every research project I have to go through the same process of reaching out to multiple parties with different policies and not-aligned data. Finally, after two years I receive the already outdated data."

A researcher in a pharmaceutical company

"We're always playing catch-up, and no one is happy to see us coming when we ask to contribute to yet another registry."

A staff member of a governmental department

"If we use data more effectively, we can save a lot of costs and also reduce the pressure on healthcare providers by avoiding duplicate tests and finding data more quickly."

"For my daughter, a specialist can only really have a proper consultation once they've read the 100 pages to see what has already happened with the patient."

Karlien Hollanders, mother of a rare disease patient

"Sometimes it takes half an hour before we can find the necessary information in the maze of documents to help an unconscious patient"

An emergency doctor

"I realize that my data is being stored in different places but I have little knowledge of it. What informed consent have I given and who has access and for what purpose?"

Hemophilia patient

"I often waste valuable time trying to prove through the available medical information that the patient has been obese for a long time."

A bariatric surgeon

"If the doctor can see the data remotely, we might be able to skip 2 of the 4 annual consultations."

"With the help of data, we can redesign the care pathway to make it patient-centric. Because that's what it's all about—how can you help that individual in the best possible way?"

Valerie Storms, a cystic fibrosis patient

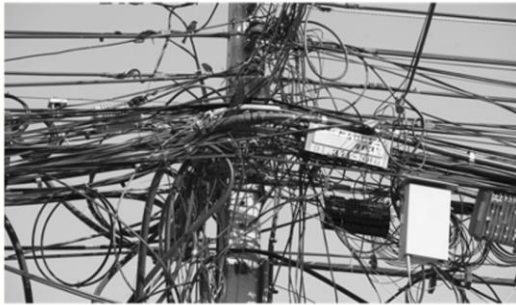
"I can't find a usable way to share my activity data and medication use with my physician"

A person with diabetes



# Hurdles

An avalanche of health data is available  
... but **hard to use, not interoperable**



Innovative or personalised therapies require **integrated patient data**



Challenge to deal with **data generated by the patient** outside 'the system'.



The **patient wants to be involved** in his/her own health



**Health data standards** exist but need to be used and combined

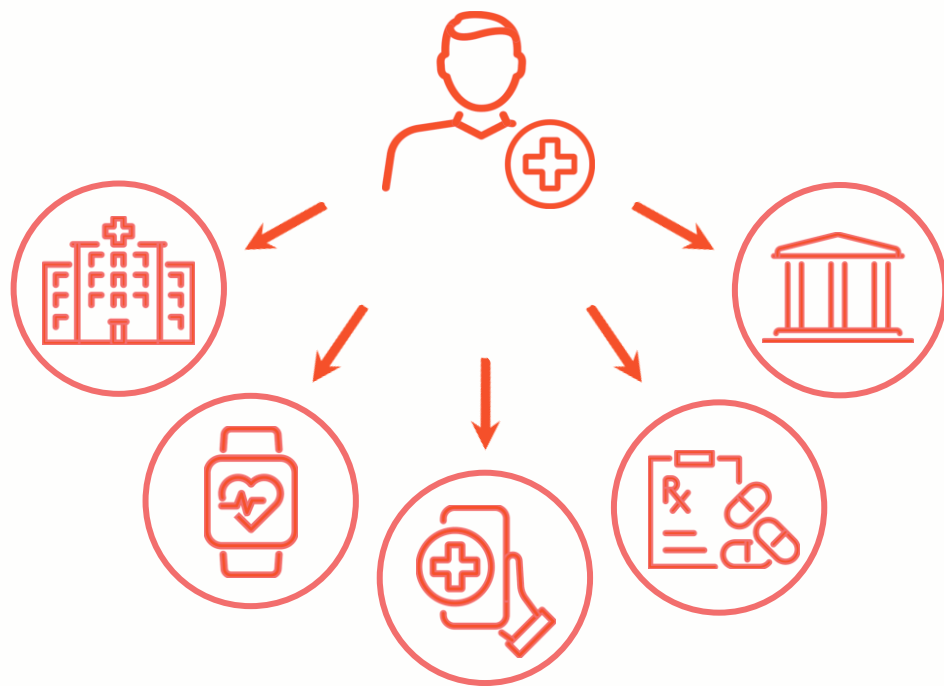


Data is stored in silos, unstructured, not linkable ... so **difficult to find, access, integrate or (re)use**



# Separate data from applications

**From Fragmented Data**



**to Personal Data Vaults**



# What if ALL your health data generated inside and outside the healthcare system is within reach?





# Objective PACSOI

Unleash the potential of **personal health data** in a **safe, trustworthy and scalable manner**

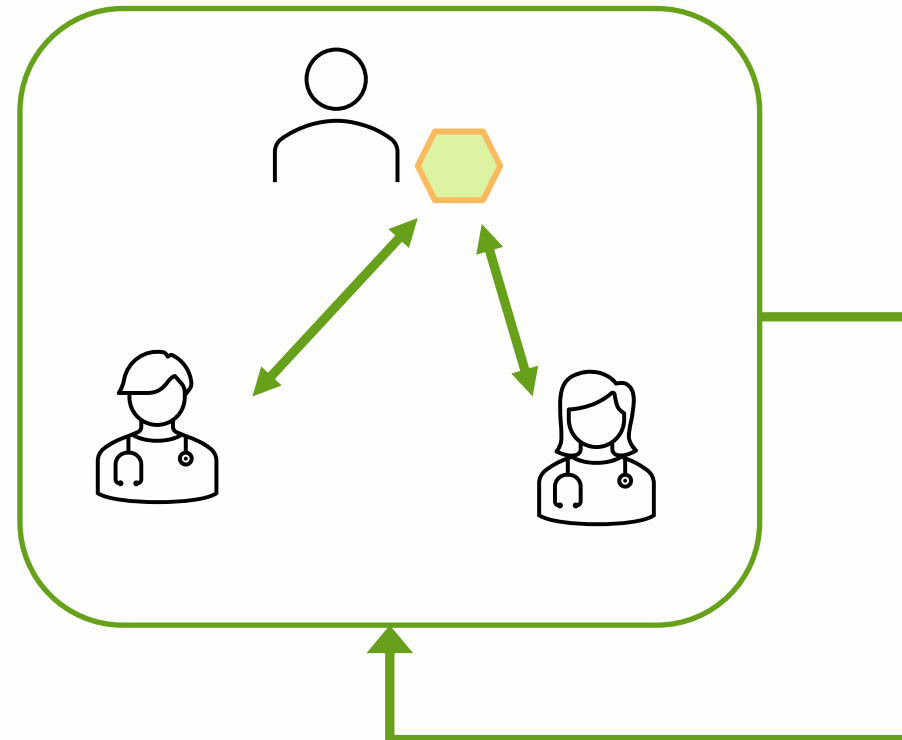
Employ **Solid** to realize **decentralized patient-centric data storage** to break through the barriers set up by data silos resulting from healthcare and monitoring tools to improve patient care and secondary use of data.



# PACSOI's focus: data that works for you

Generate data once, use multiple times

## Primary Use of Health Data



**Patient**  
Empowered  
Take Control

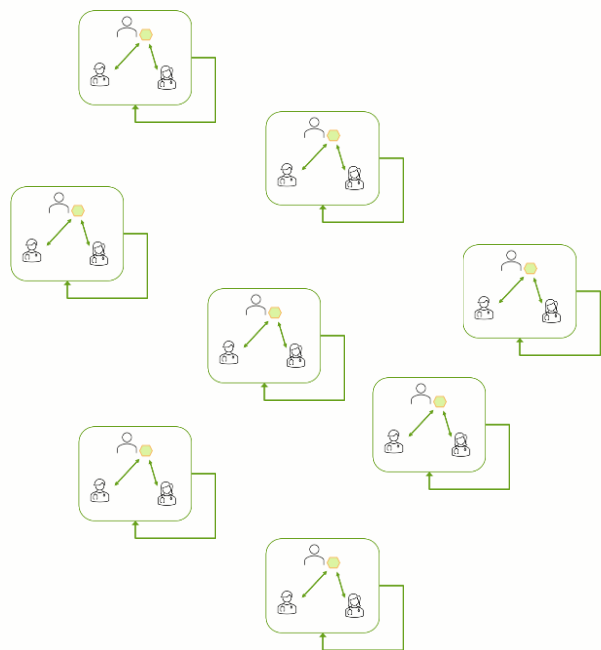
**HCP**  
Enriched data  
Integrated Care  
Efficiency gain



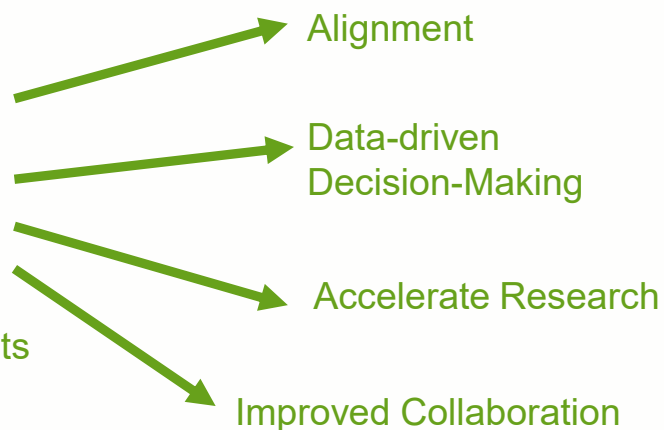
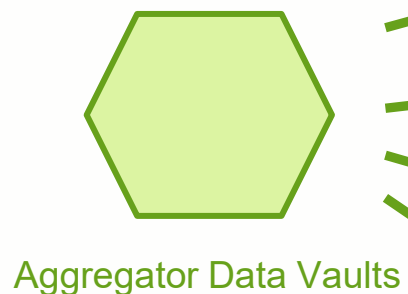
# PACSOI's focus: data that works for you

Generate data once, use multiple times

## Primary Use of Health Data



## Secondary Use of Health Data



**Policy Maker**

**Researcher**



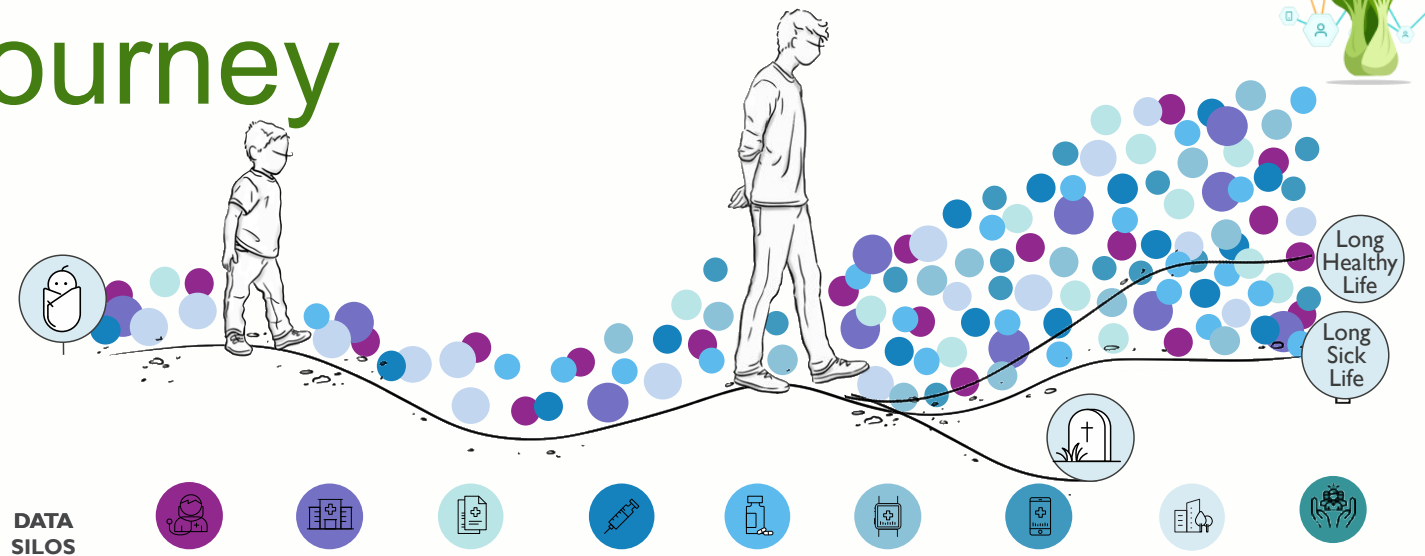
# Obesity patient journey

## Fully combined patient history

- Lifestyle
- Medications
- Interventions
- Conditions

## Bariatric surgery requirements

- BMI > 40
- BMI 35-40 + one obesity related disease
- Documented attempts of conservative treatment of 6 months
- Psychological clearance
- Between 18-65 years old

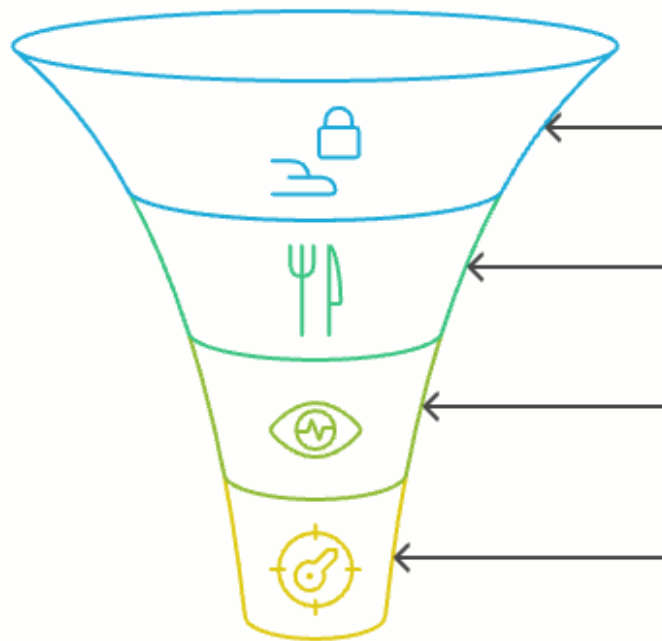


# Patient Journey – empowerment & control

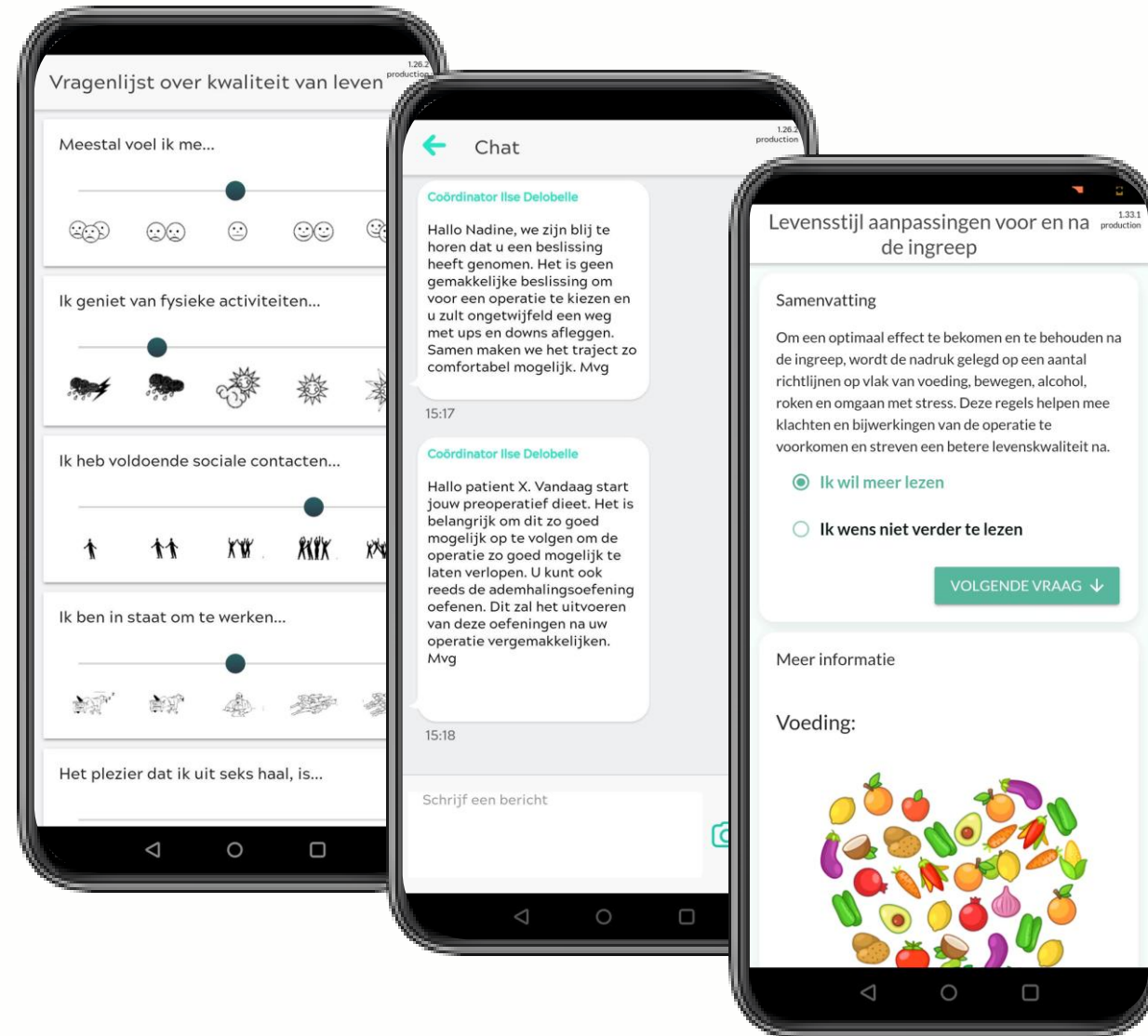


## Pre-Surgery Preparation Process

### Patient Data Collection



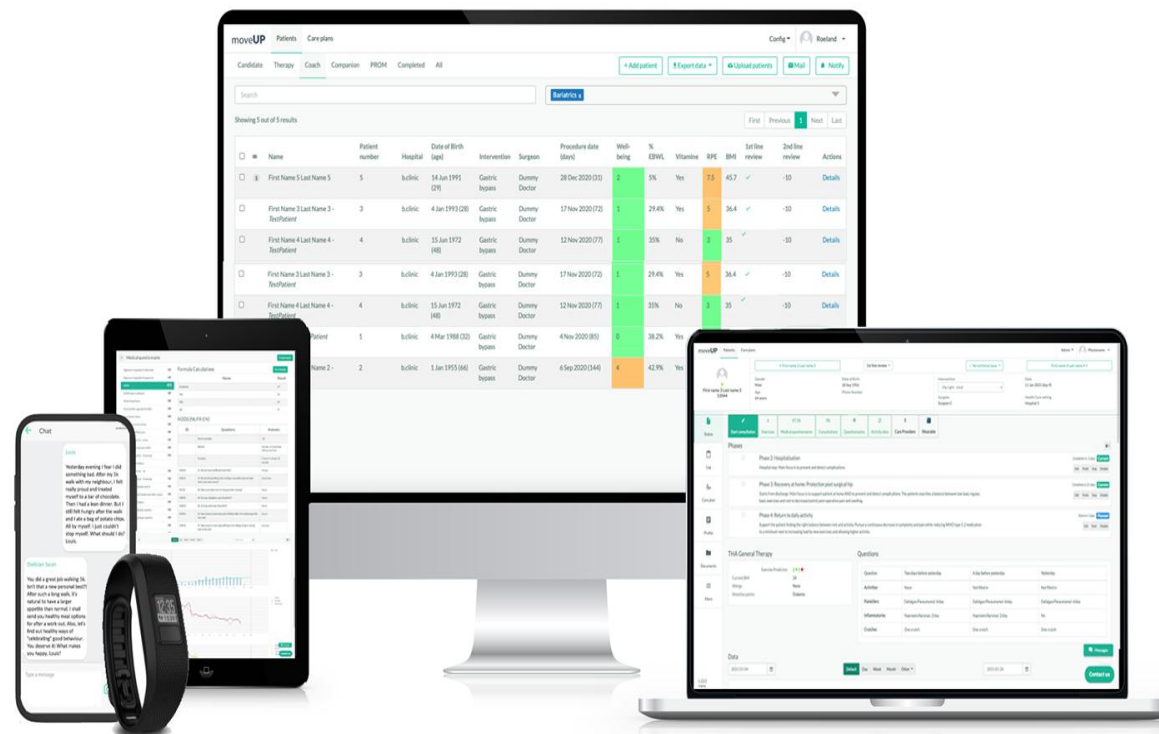
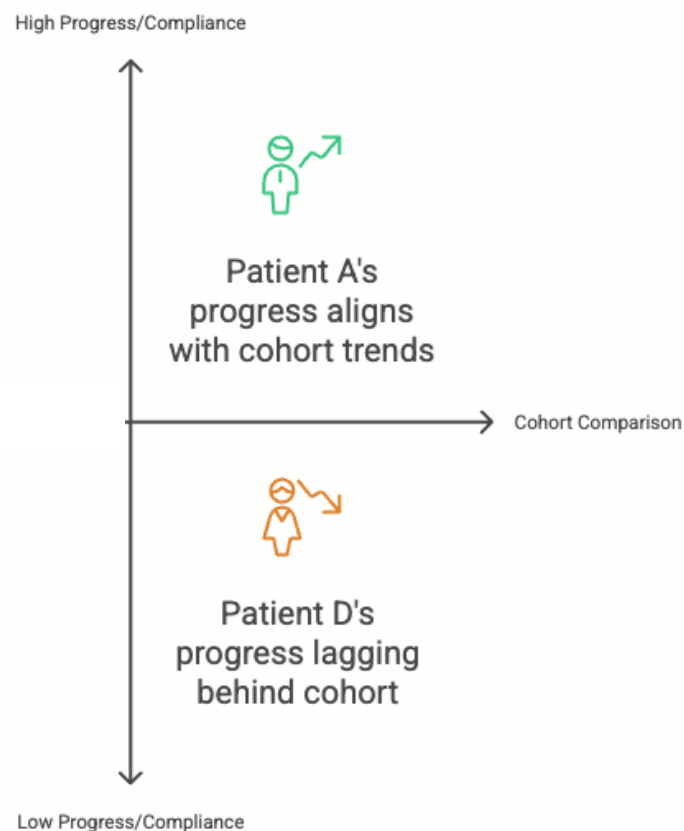
Preparedness for Surgery





# Patient Journey – better care & more insights through data sharing

## Patient Progress and Cohort Comparison



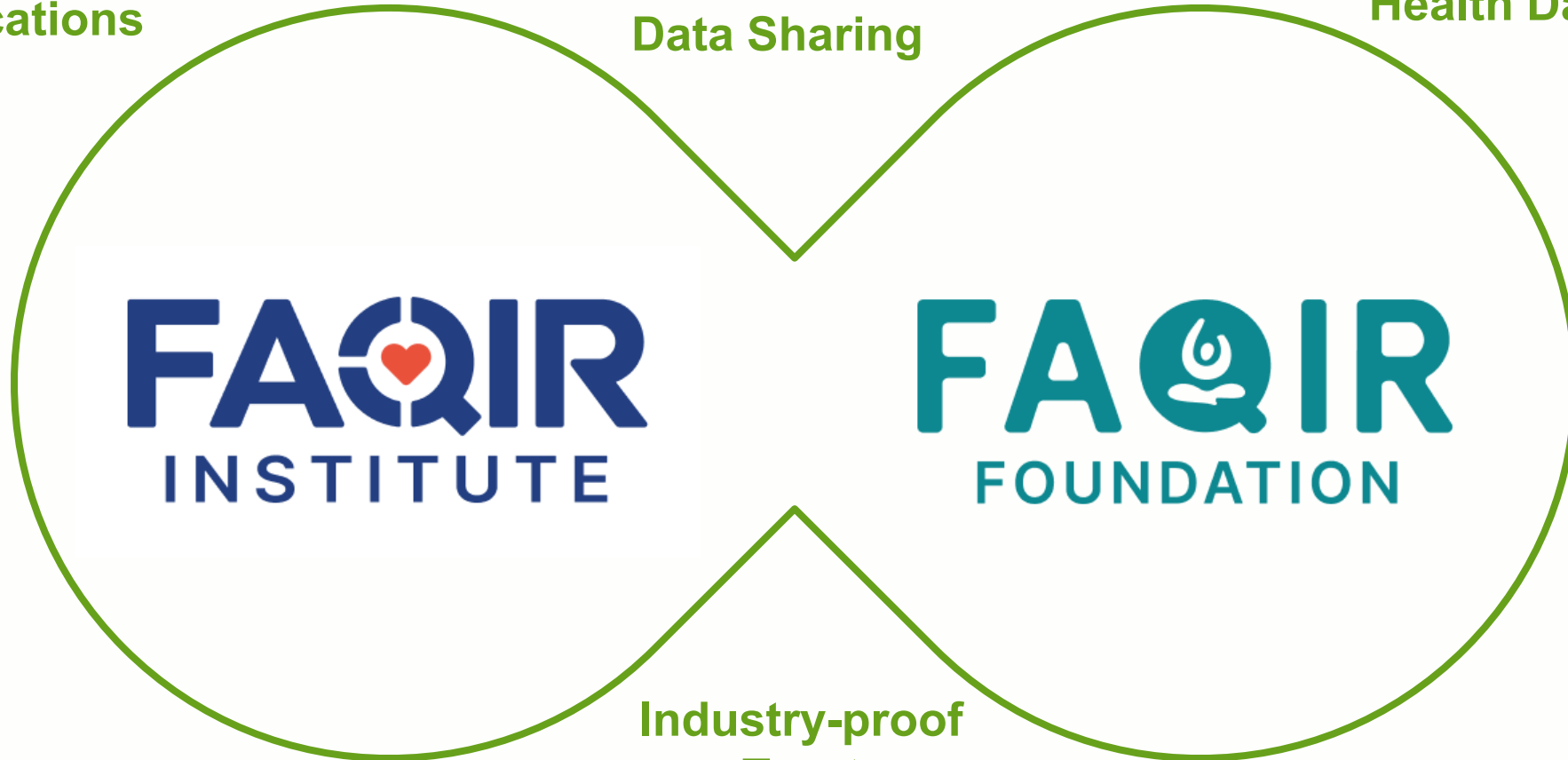
# I have a dream ...



**Ecosystem Governance**  
**Data Vaults**  
**Health Data Model**

**Health Applications**

**Data Sharing**

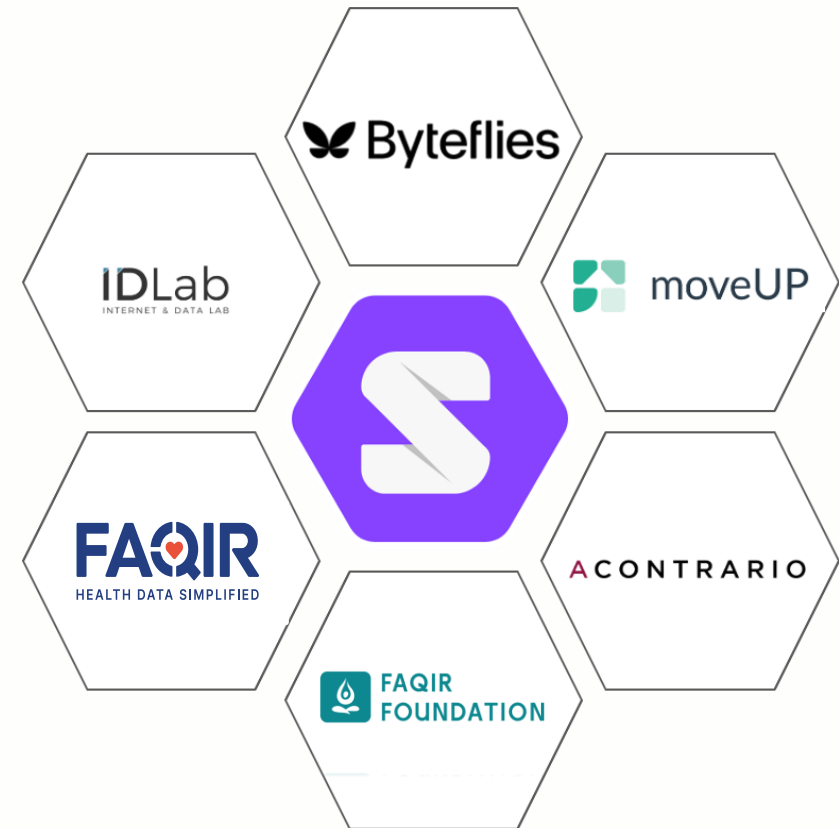


**Industry-proof  
Trust**

Is becoming a reality...



**Thank you  
SolidLab  
&  
PACSOI Consortium  
Members!**





# PACSOI

<https://pacsoi.org>

## Filip Pattyn

FAQIR Institute, [faqir.eu](http://faqir.eu)  
FAQIR Foundation, [faqir.org](http://faqir.org)  
Ghent University  
+32 486 739 129

