

PACSOI - Patient-Centric Solid

Your health data close with you and ready for sharing



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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 Finally, after two years I receive the already outdated data."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

"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

"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

"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

"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

"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 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

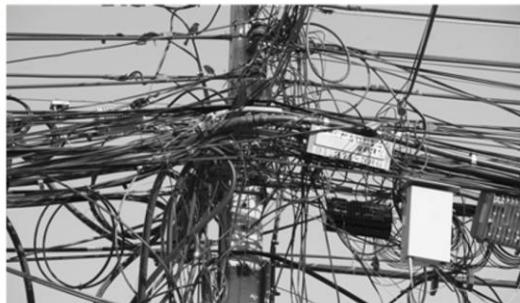
"I can't find a usable way to share my activity data and medication use with my physician"

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

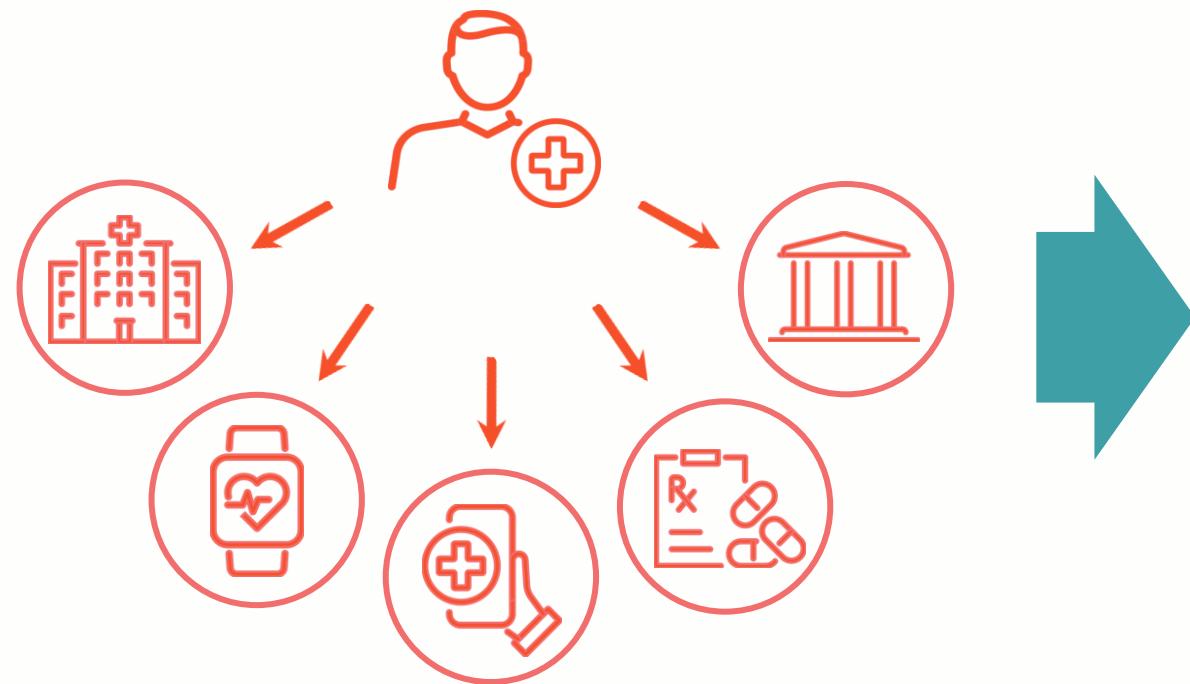


Data is stored in silos, unstructured, not linkable ... so
difficult to find, access, integrate or (re)use

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

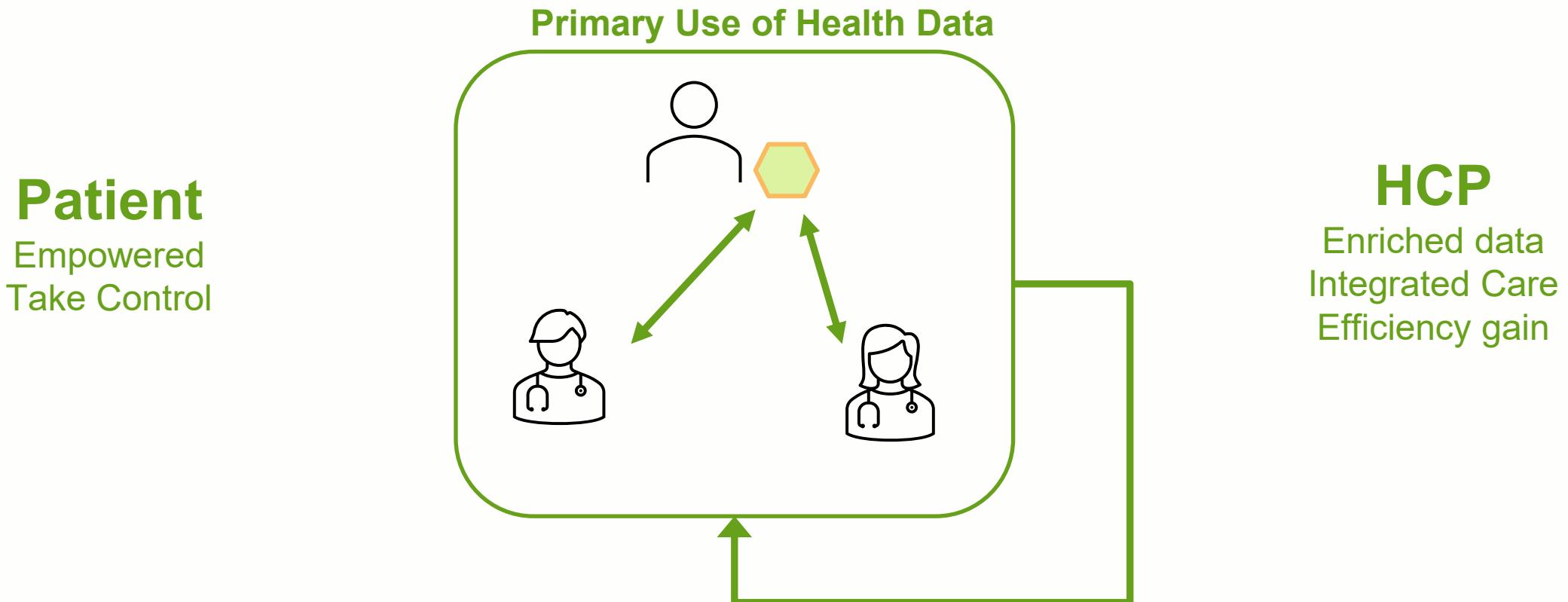
Unleash the potential of **personal health data** in a **safe, trustworthy and scalable manner**

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

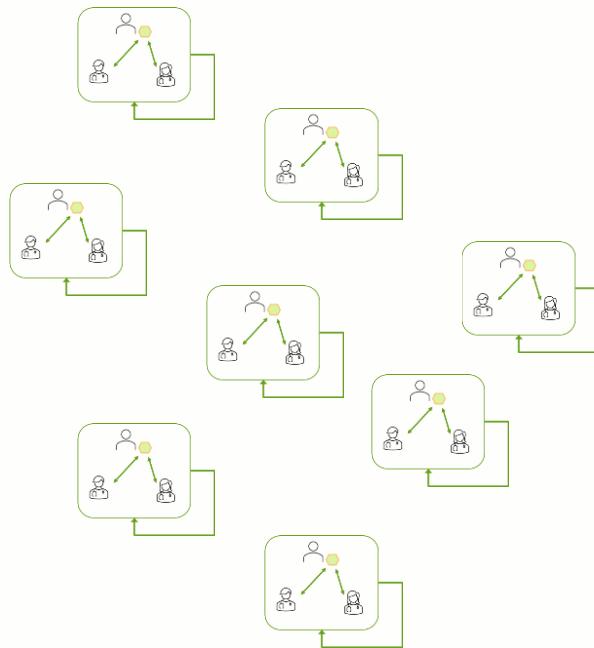




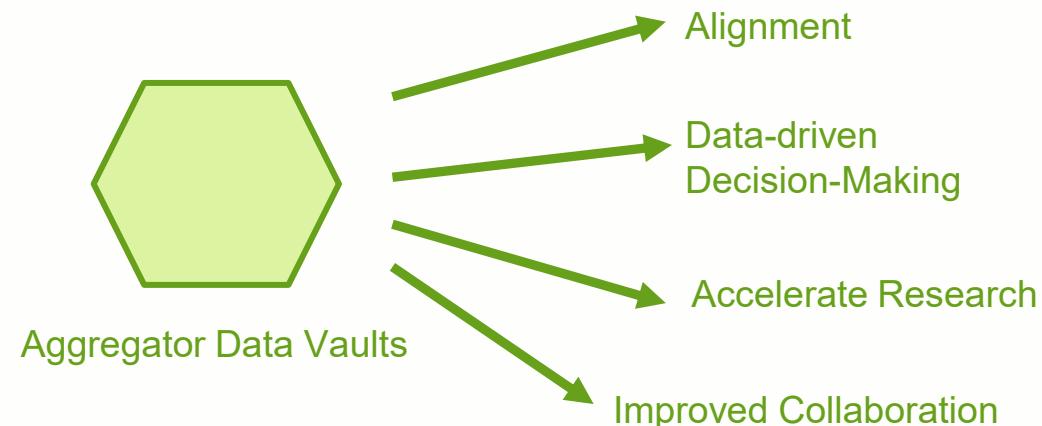
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Primary Use of Health Data



Secondary Use of Health Data



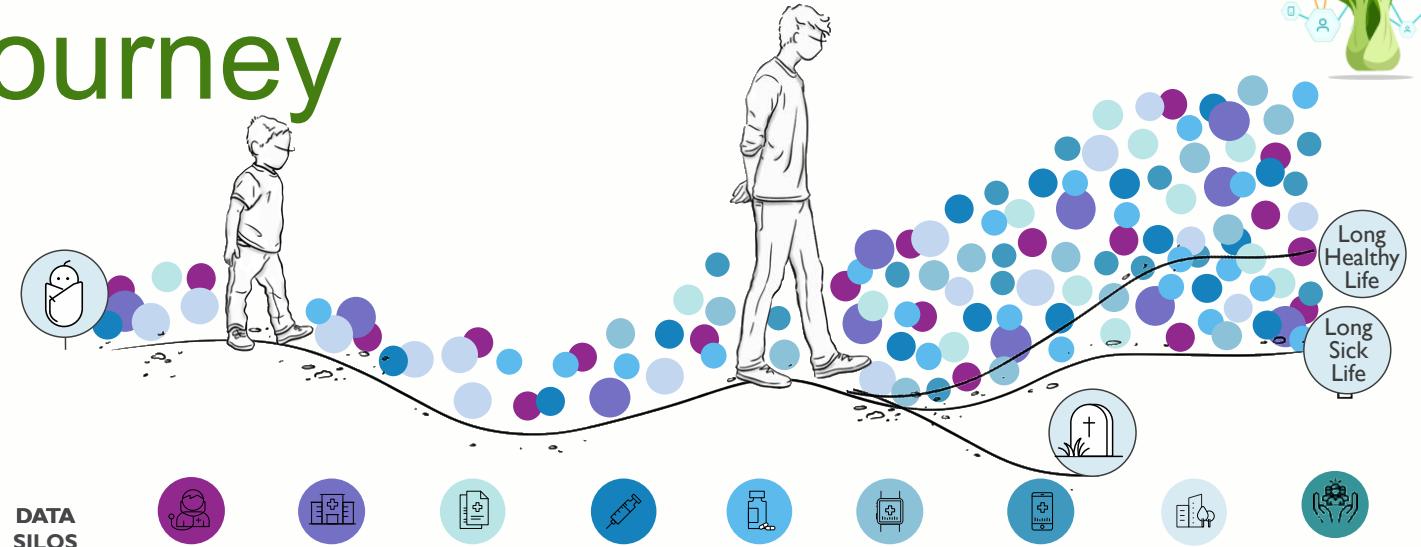
Policy Maker

Researcher

Obesity patient journey

Fully combined patient history

- Lifestyle
- Medications
- Interventions
- Conditions



Bariatric surgery requirements

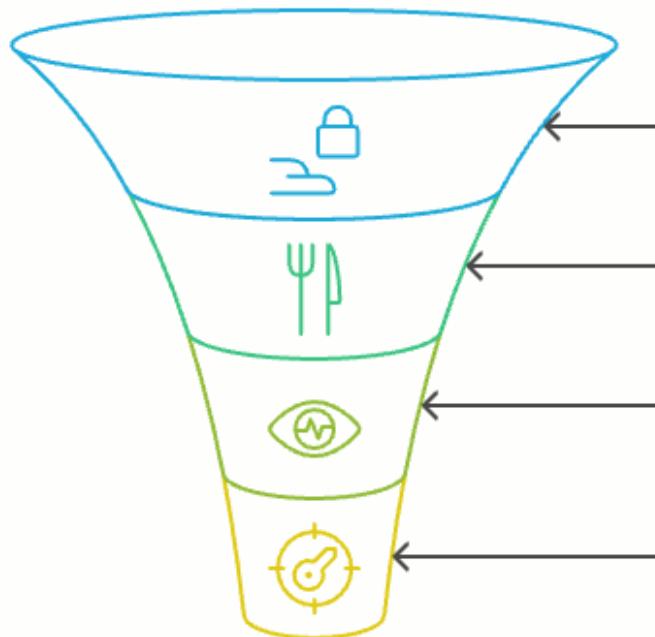
- BMI > 40
- BMI 35-40 + one obesity related disease
- Documented attempts of conservative treatment of 6 months
- Psychological clearance
- Between 18-65 years old

Patient Journey – empowerment & control

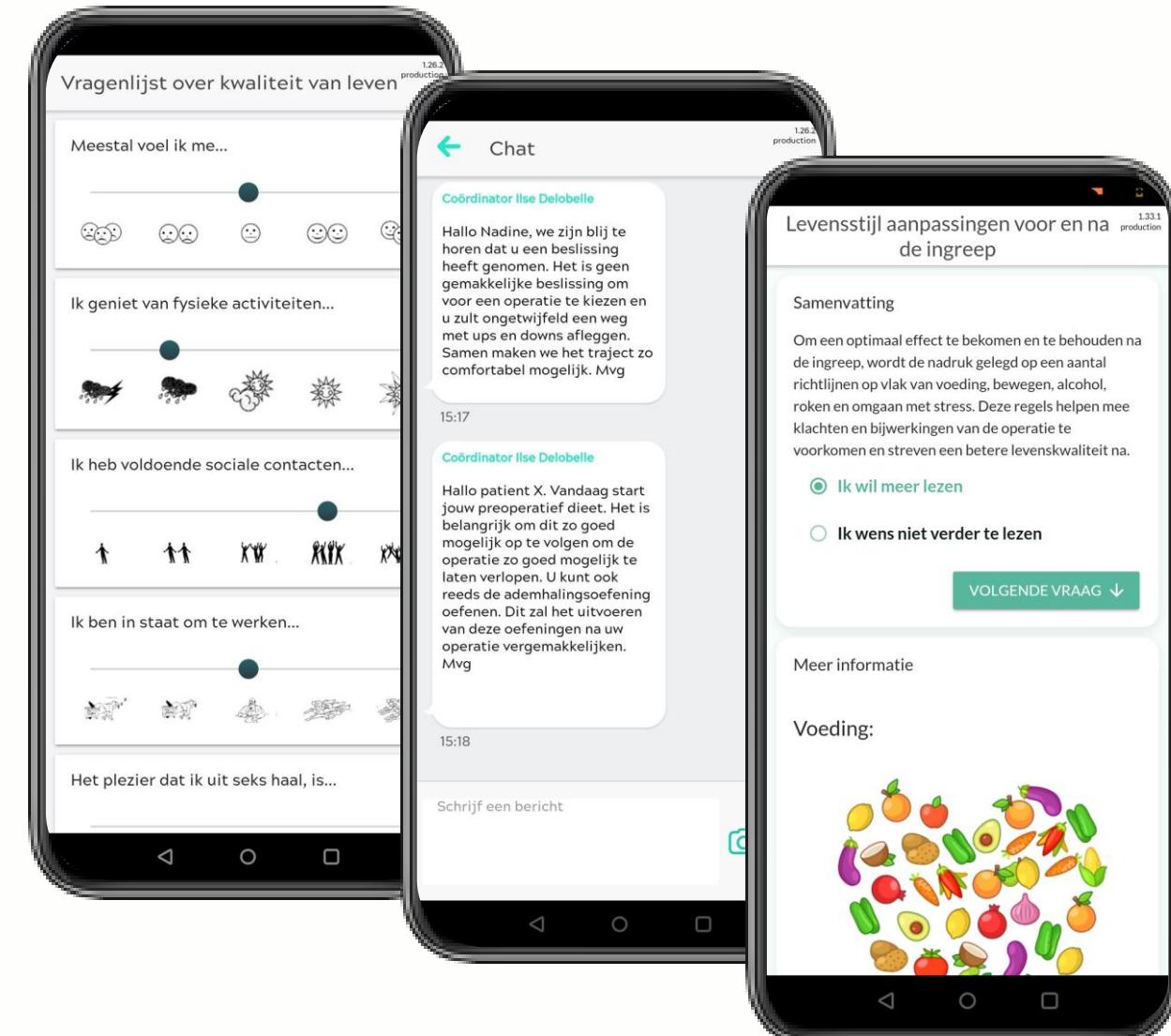


Pre-Surgery Preparation Process

Patient Data Collection



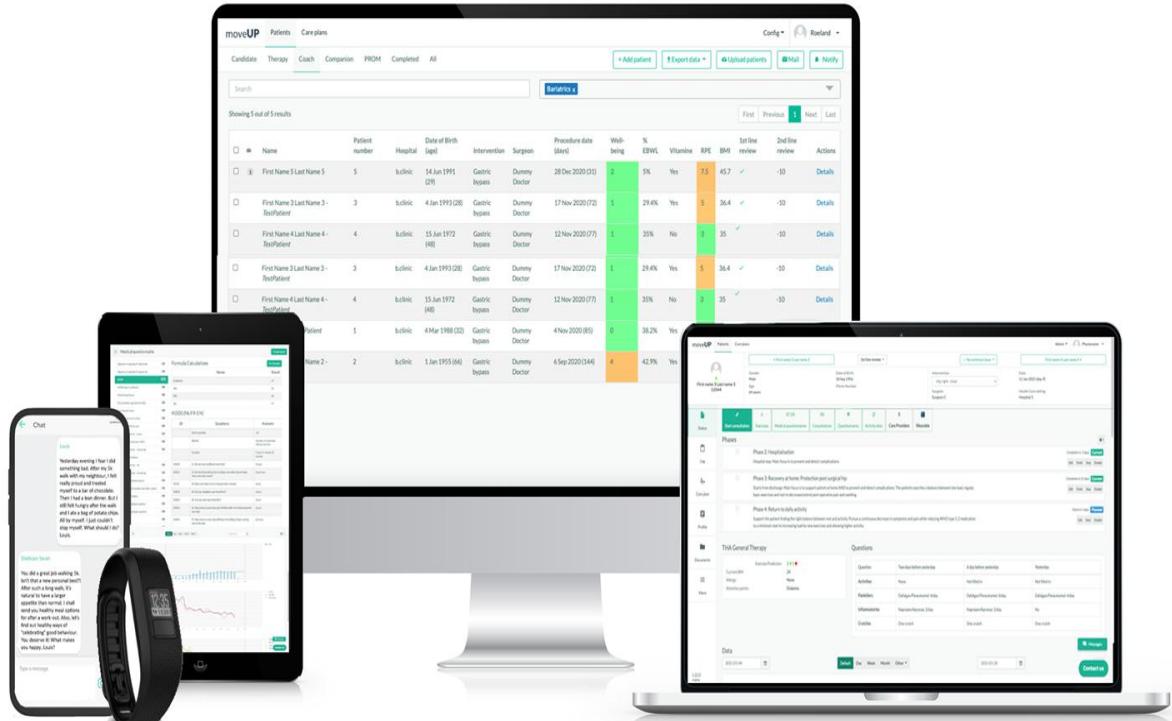
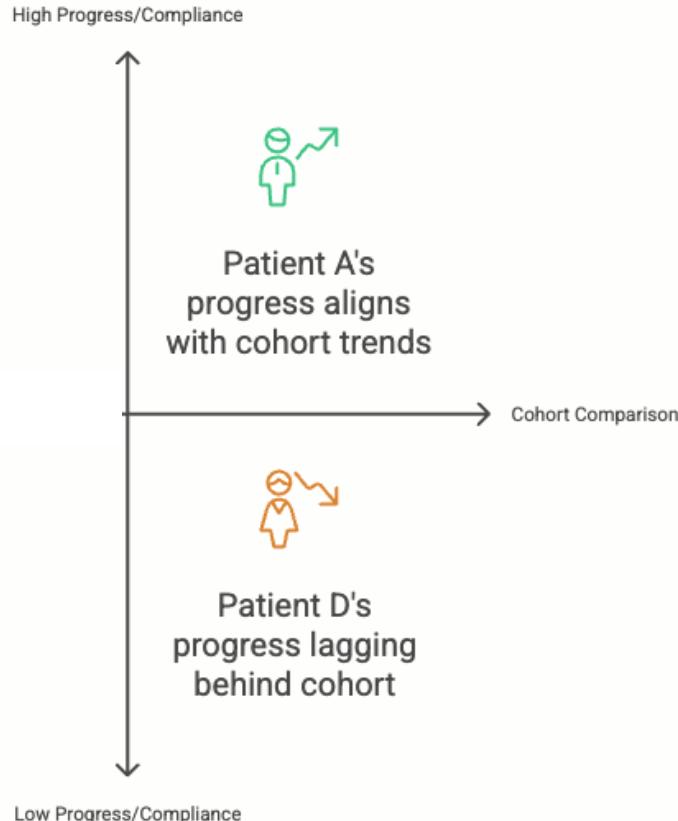
Preparedness for Surgery



Patient Journey – better care & more insights through data sharing



Patient Progress and Cohort Comparison



I have a dream ...



Health Applications

Data Sharing

Ecosystem Governance
Data Vaults
Health Data Model

FAQIR
INSTITUTE

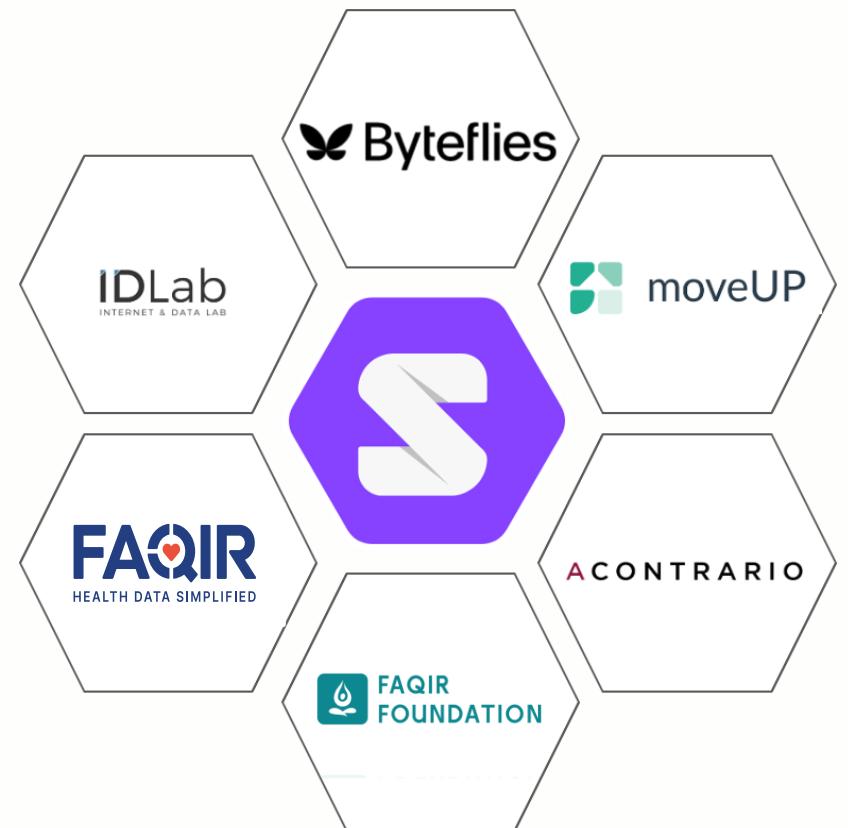
FAQIR
FOUNDATION

Industry-proof
Trust

Is becoming a reality...



Thank you
SolidLab
&
PACSOI Consortium
Members!





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