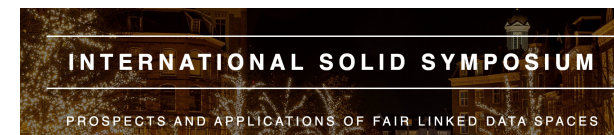




Privacy, ethics & data governance for health data with Solid & FAIR data



Filip Pattyn
FAQIR Ecosystem

<https://www.linkedin.com/in/filippattyn/>
+32 486 739 129

Filip.pattyn@faqir.eu
Filip.pattyn@faqir.org

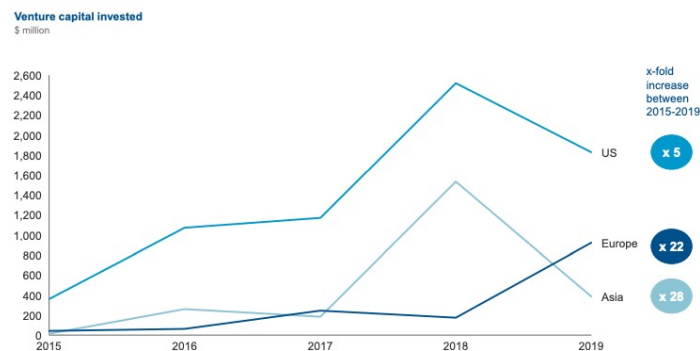
Filip.pattyn@ugent.be

2025-04-24



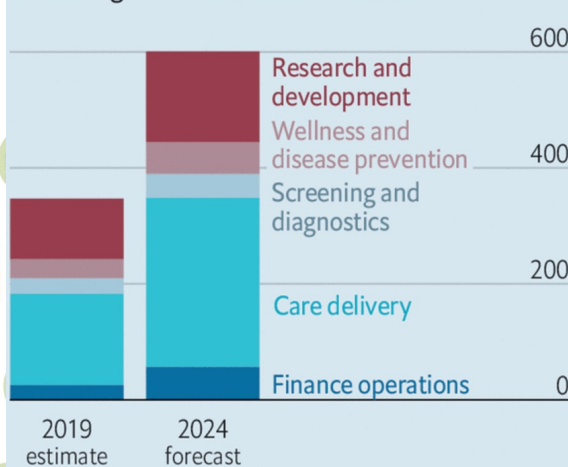
McKinsey estimates that global digital-health revenues—from telemedicine, online pharmacies, wearable devices and so on—will rise from \$350bn last year to \$600bn in 2024 (see chart 1). Swathes of America's \$3.6trn health-care market are in for a digital makeover. The same is happening in China, Europe and most other places where doctors ply their trade.

Exhibit 2.3 – The venture capital invested in AI companies in healthcare has grown significantly since 2015



1 Healthy growth

Global digital health, market size, \$bn



The Economist

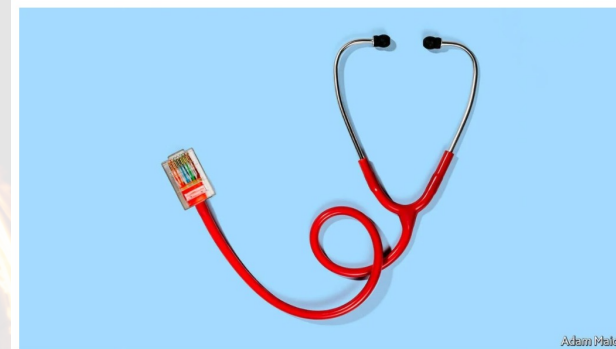
Business

Dec 3rd 2020 edition >

Health care and technology

The dawn of digital medicine

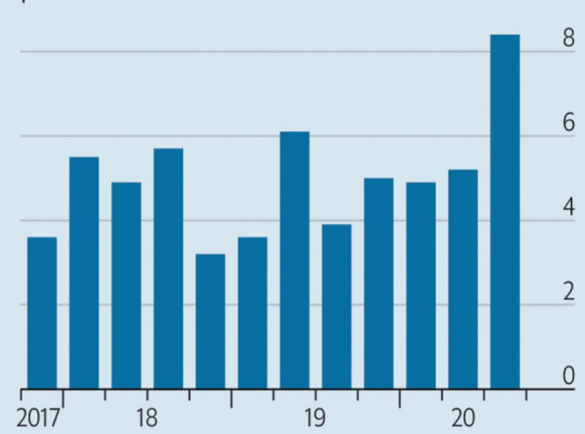
The pandemic is ushering in the next trillion-dollar industry



Adam Phillips

2 Hypertension

Global digital health equity funding to private firms, \$bn



The Economist



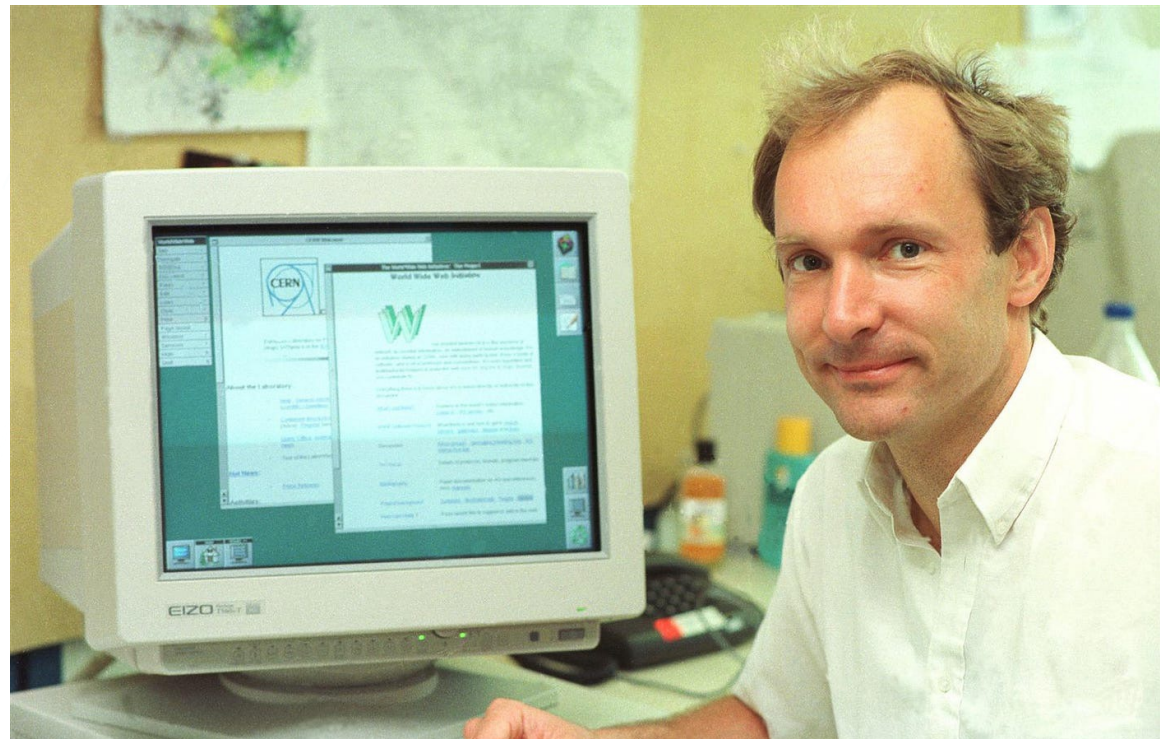
Technology Evolutions



1: World Wide Web in 1989

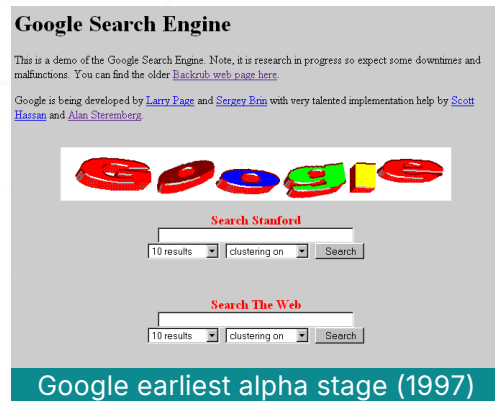


1994: Yahoo
Directory Launches
3.000 websites
rowse categories
Manually curated





2: Google is Founded in 1998



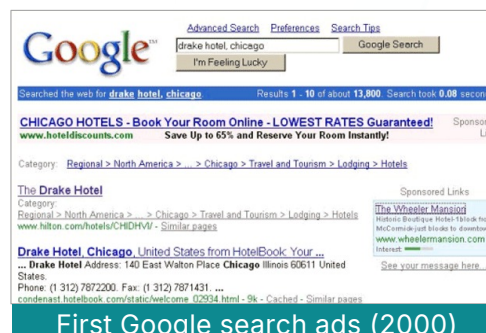
Google earliest alpha stage (1997)



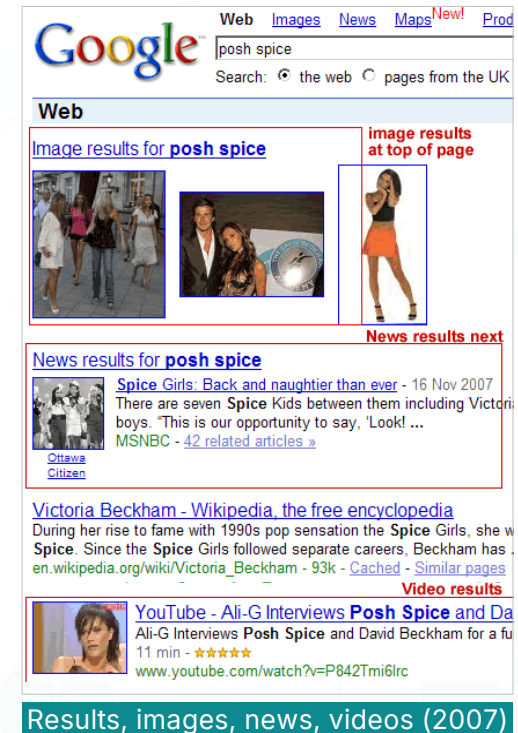
Google Beta homepage (1998)



Google Beta homepage (1998)



First Google search ads (2000)



Results, images, news, videos (2007)



3: Knowledge Graph in 2012

Google Search results for "matt groening" (About 4,670,000 results (0.34 seconds)).

Everything

- Images
- Maps
- Videos
- News
- Shopping
- More

Mountain View, CA
Change location

Show search tools

Matt Groening - Wikipedia, the free encyclopedia
en.wikipedia.org/wiki/Matt_Groening
Matthew Abram "Matt" Groening [1] is an American cartoonist, screenwriter, and producer. He is the creator of the comic strip Life in Hell (1978-present) as well ...
→ Early life - Career - Awards - Personal life

Images for matt groening - Report images

Matt Groening - IMDb
www.imdb.com/name/nm0004981/
Matt Groening, Writer: The Simpsons. Growing up in Portland, Oregon, **Matt Groening** did not particularly like school, which is what originally turned him towards ...

Matt Groening Biography - Facts, Birthday, Life Story - Biography.com
www.biography.com › People
Visit Biography.com and learn about the life and humor of **Matt Groening**, cartoonist, satirist and creator of cultural phenomenon, The Simpsons.

Interview with Matt Groening - The AV Club
www.avclub.com/content/node/47771

"The Simpsons" creator Matt Groening reveals location of Springfield ...
www.cbsnews.com/.../the-simpsons-creator-matt-groening-reveals-lo-...
Apr 10, 2012 – **Matt Groening** tells Smithsonian magazine that Homer, Marge, Bart, Lisa and Maggie reside in Springfield, Oregon Read more by Jessica ...

Matt Groening reveals inspiration behind 'Simpsons' Springfield ...
www.washingtonpost.com/.../matt-groening.../giQA37TLAT_blog.ht...
Apr 11, 2012 – Also in the morning mix: Alec Baldwin goes on a Twitter rant.

Matt Groening
Matthew Abram "Matt" Groening is an American cartoonist, screenwriter, and producer. He is the creator of the comic strip Life in Hell as well as two successful television series, The Simpsons and ... Wikipedia

Born: February 15, 1954 (age 58), Portland
Education: Lincoln High School, The Evergreen State College
Parents: Margaret Groening
Siblings: Lisa Groening
Awards: Reuben Award for Cartoonist of the Year

Books

- The Simpsons Library... 2004
- Bart Simpson's Guide to... 1993
- The Simpsons: A Comp... 1997
- The Simpsons Uncens... 1991
- The Simpsons Forever...

People also search for

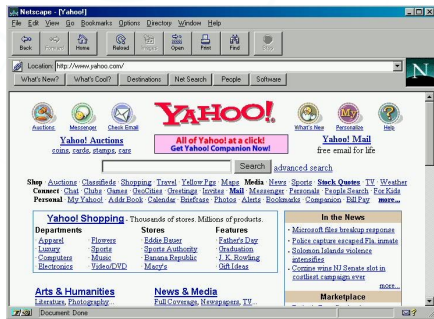
- Seth MacFarlane
- David X. Cohen
- James L. Brooks
- Dan Castellaneta
- Nancy Cartwright

Report a problem

Parents: Margaret Groening, Homer Groening
Siblings: Lisa Groening



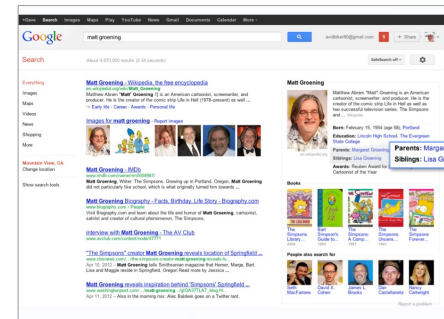
4: Conversations with Data in 2024



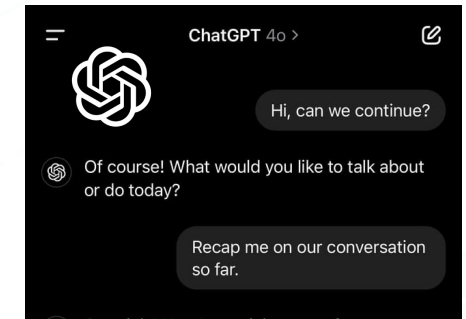
1994: Yahoo Directory Launches
~3.000 Websites
Browse categories
Manually curated



1998: Google is Founded
~2,4M Websites
Intelligent crawling
Indexing



2012: Google's Knowledge Graph
~634M Websites
More semantic
Knowledge Graph



2024: ChatGPT DeepSeek & Grok
~1,1B Websites
AI-driven Search
Conversations



EU Legislation



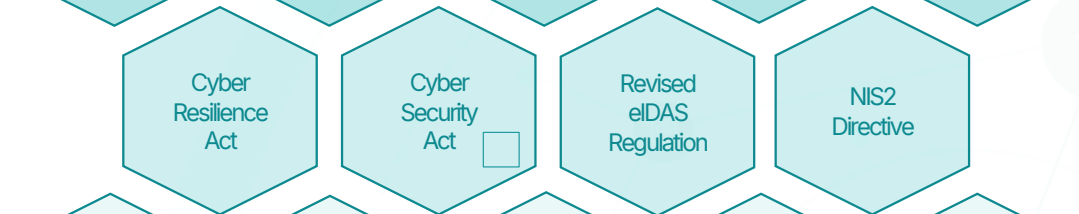
Secure Regulatory Framework



Data Availability & Sharing



Security & Trust



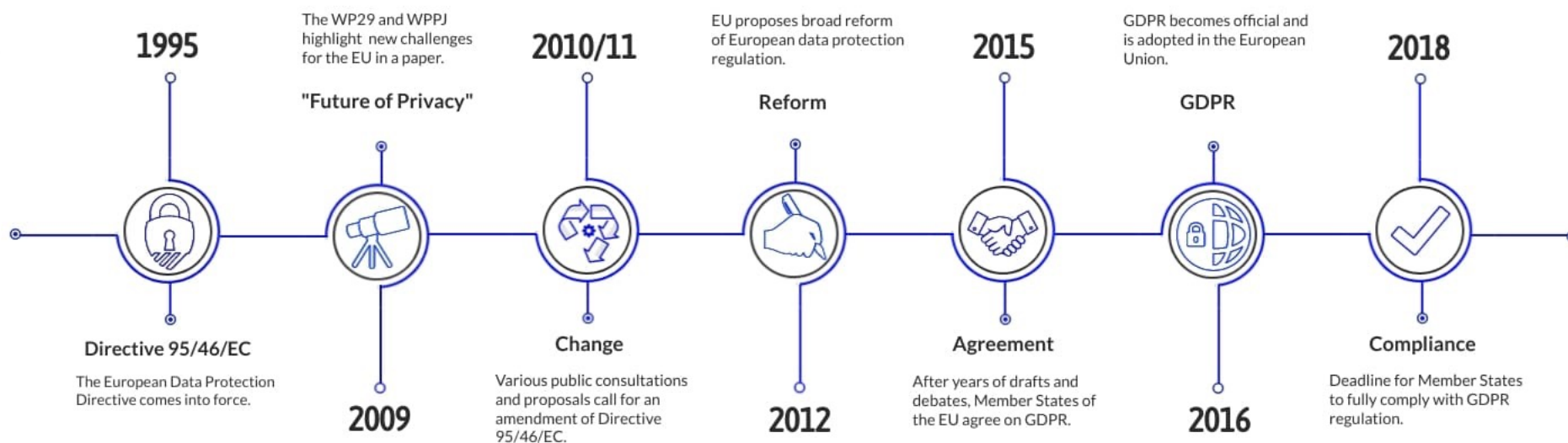
Robustness & Safety





A brief history of GDPR

A Brief History of GDPR



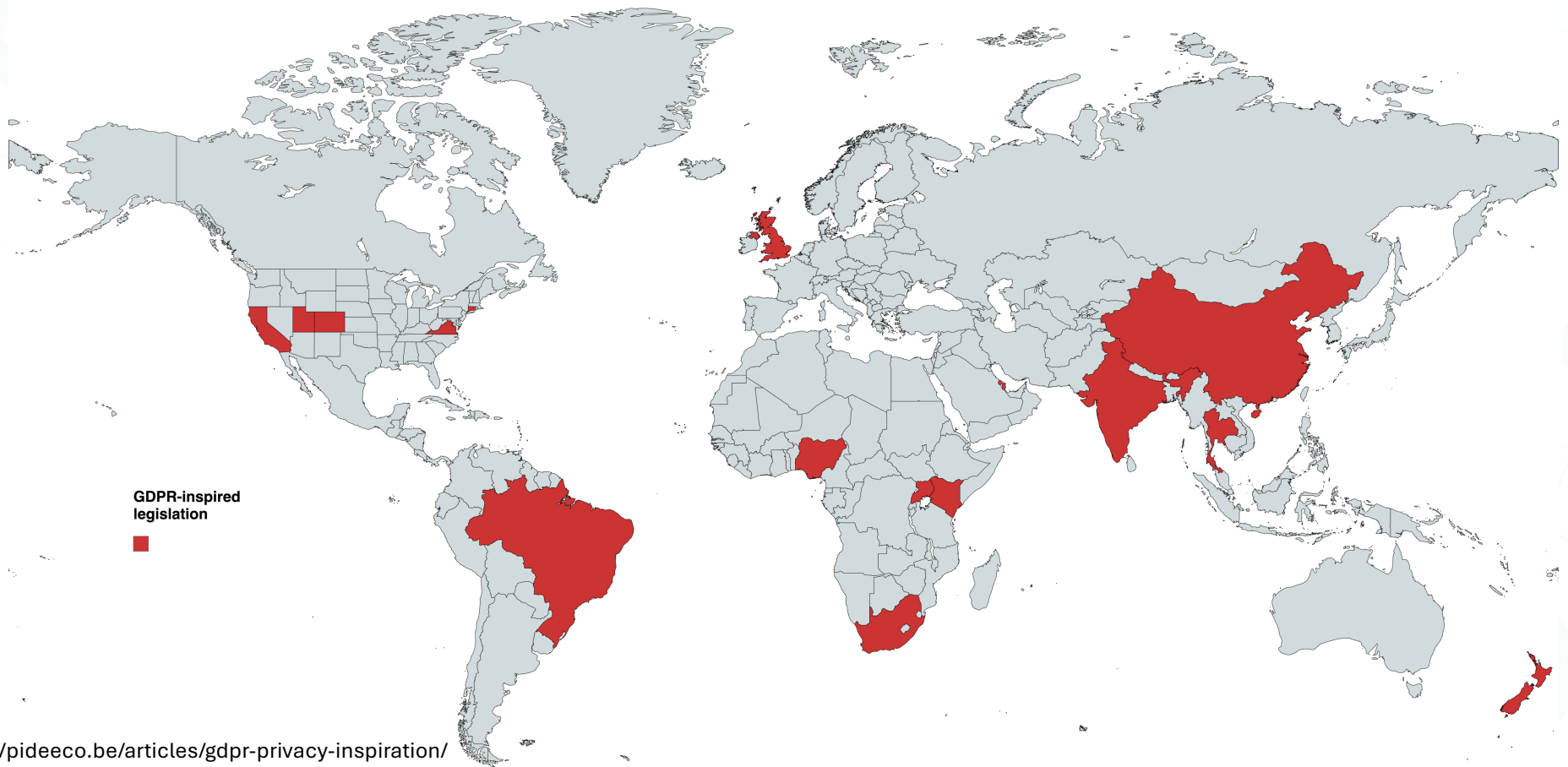
Source: <https://pideeco.be/articles/gdpr-privacy-inspiration/>

FAQIR Confidential

info@faqir.org



GDPR-inspired legislation



Source: <https://pideeco.be/articles/gdpr-privacy-inspiration/>

FAQIR Confidential

Created with mapchart.net

faqir.org

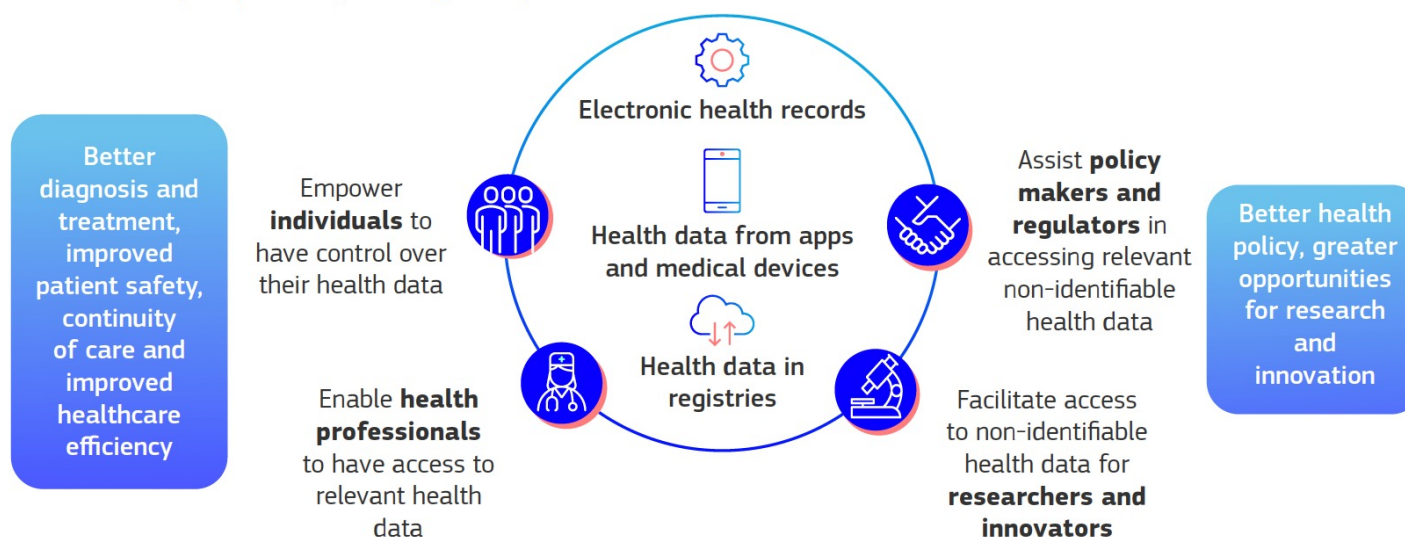


EUROPEAN HEALTH DATA SPACE

#EUDigitalHealth

OBJECTIVES

- ✓ **Empower individuals** through better digital access to their personal health data; support free movement by ensuring that health data follow people;
- ✓ **Unleash the data economy** by fostering a genuine single market for digital health services and products;
- ✓ Set up **strict rules** for the use of individual's non-identifiable health data for research, innovation, policy-making and regulatory activities.





EHDS: challenges

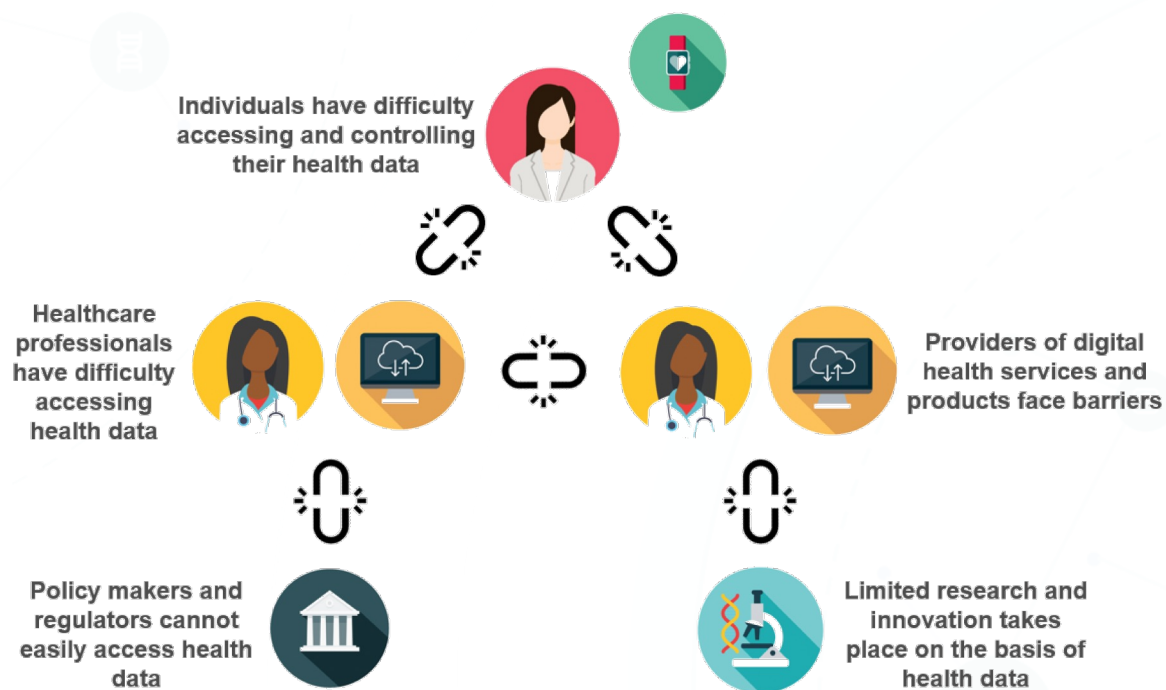


Figure 2 - Problems in controlling, using and sharing health data



EHDS: Benefits

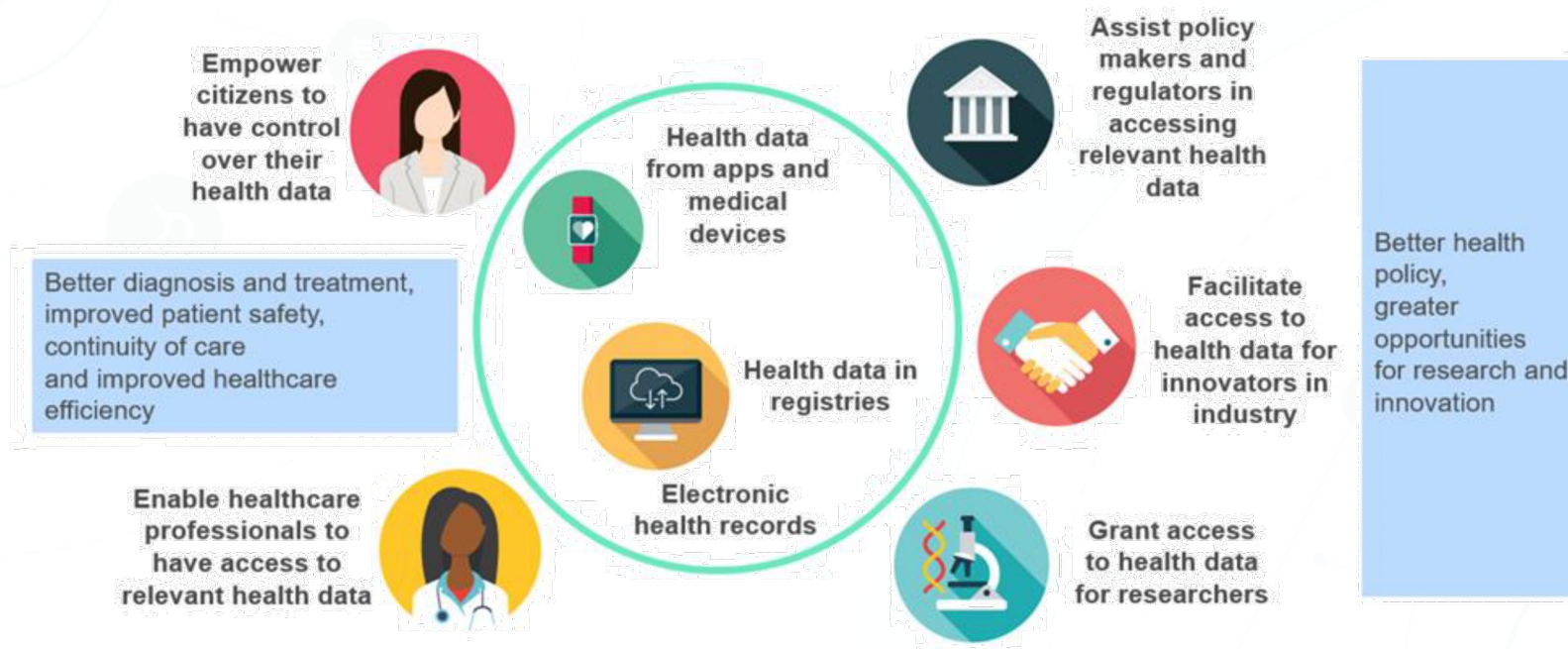


Figure 4. Benefits for users of European Health Data Space



EHDS

Formal signing and publication
in Official Journal on 21 February 2025

Belgian Presidency of the Council of the EU 2024
@EU2024BE

Confirmed: a healthy space for your data!

Ambassadors just confirmed the provisional agreement on the regulation for a European Health Data Space (#EHDS).

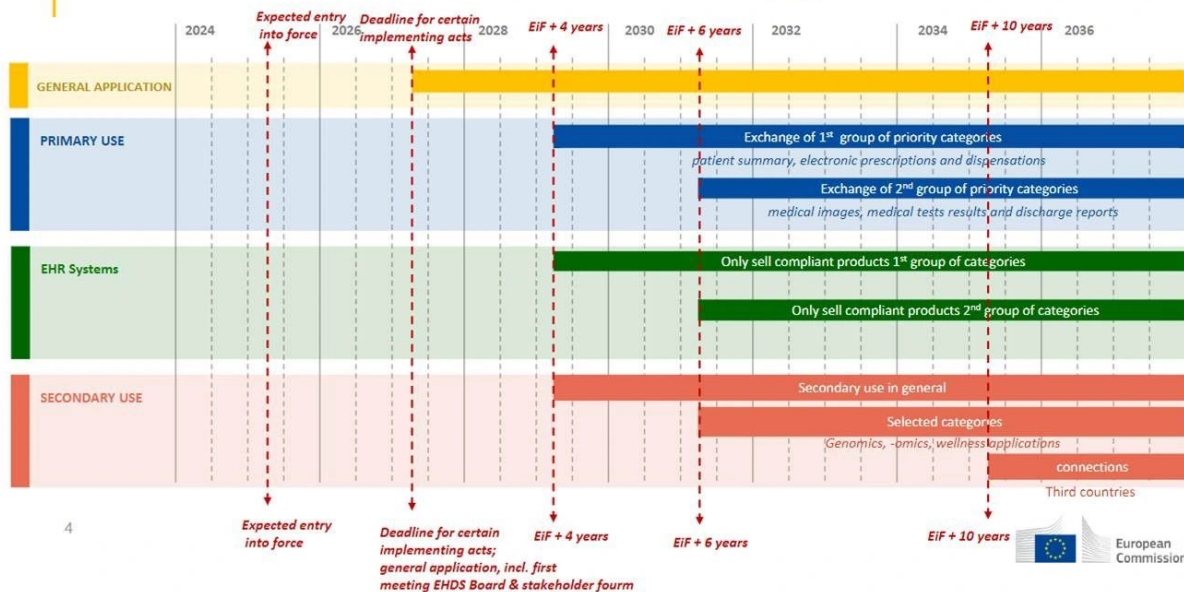
Soon, you'll have faster & easier access to electronic health data, whether at home or in another member state.



Pierre Cartuyvels and 6 others

5:46 PM · Mar 22, 2024 · 9,154 Views

EHDS – Overall timeline for application





EHDS timeline

Key milestones towards full implementation

- **March 2025:** The EHDS Regulation enters into force, marking the beginning of the transition period.
- **March 2027:** Deadline for the Commission to adopt several key implementing acts, providing detailed rules for the regulation operationalisation
- **March 2029:** Key parts of the EHDS Regulation will enter **into application**, including, for **primary use**, the exchange of the first group of priority categories of health data (Patient Summaries, ePrescriptions/eDispensations) in all EU Member States. **Rules on secondary use** will also start to apply for most data categories (e.g. data from electronic health records).
- **March 2031:** For primary use, the exchange of the **second group of priority categories of health data** (medical images, lab results, and hospital discharge reports) should be operational in all EU Member States. Rules on secondary use will also start to apply for the remaining data categories (e.g. genomic data).
- **March 2034:** **Third countries and international organisations** will be able to apply to join HealthData@EU, for the secondary use.



Criticism





Digital In Health Today



Today, planning a trip is a piece of cake



Booking flight, hotel, ..

5-10 min



Fast and safe payments

1-3 min



Digital boarding pass

30 sec



An absurd situation

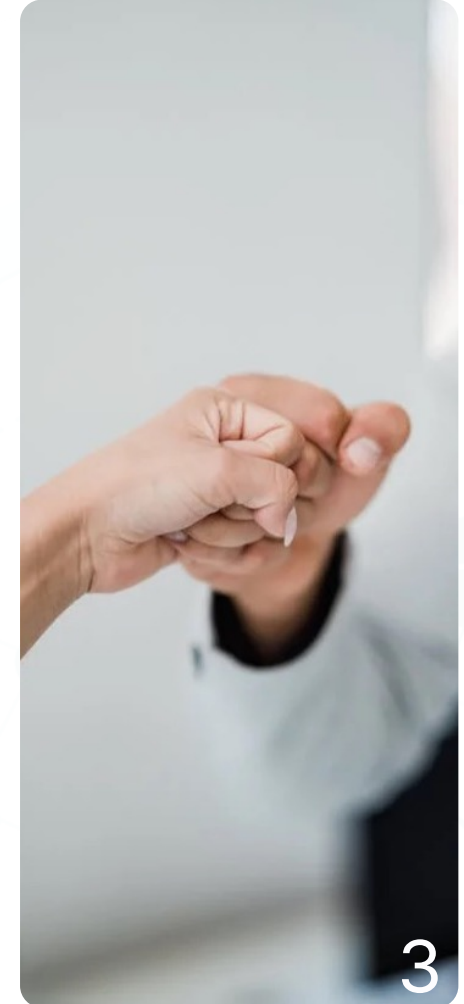


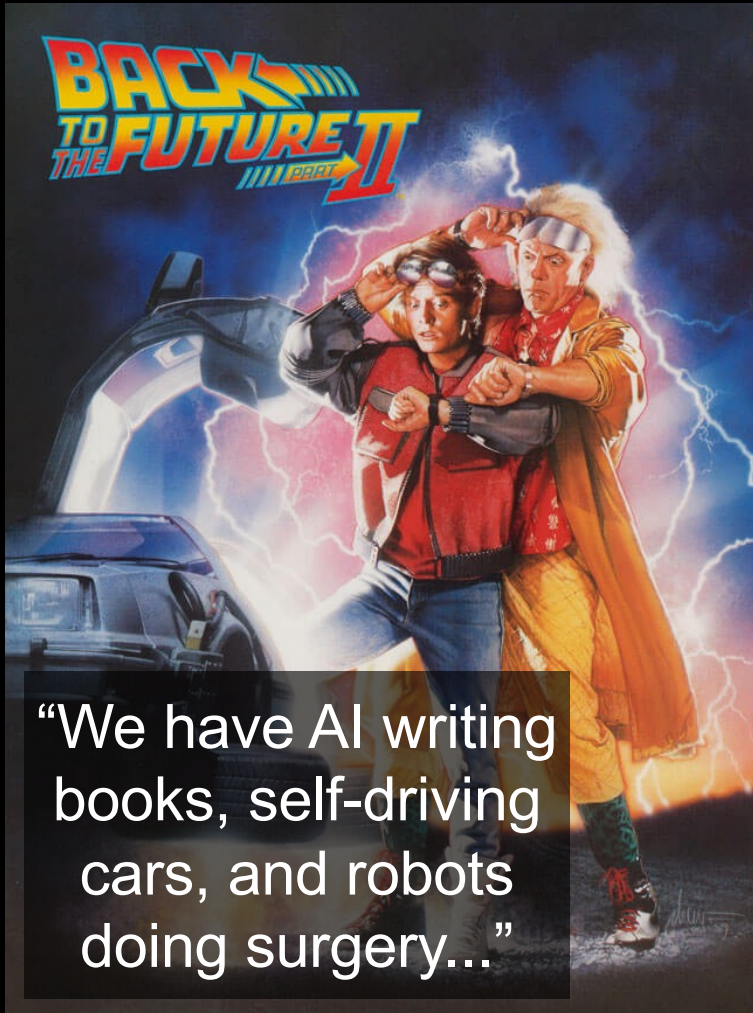
In this age of fast digital progress
the health sector is lagging behind.



Challenges:

1. Finding information
2. Structure
3. Safe sharing





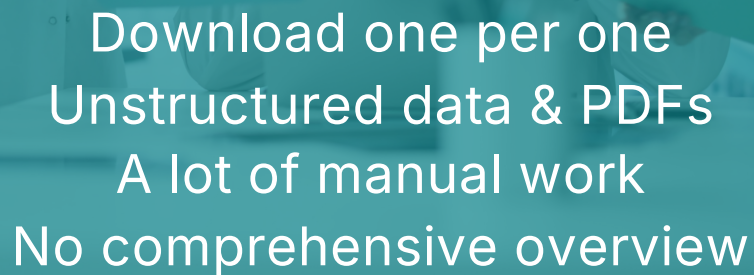
“We have AI writing books, self-driving cars, and robots doing surgery...”





Emergency doctors have **just 10-20 minutes per patient** but **need 40 minutes to 2 hours** to **find, review, and analyze data** across multiple systems.

This slows down care and puts both doctors and patients at a disadvantage.



FAQIR Confidential



... or a patient population?





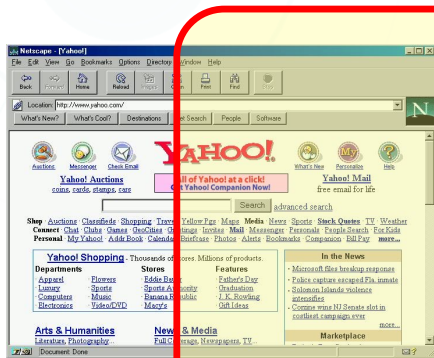
Geneticists & rare disease specialists

- Data is critical in a holistic approach
- Data from the medical history
- Data sharing & interdisciplinary collaboration
- Data interpretation & management
- The patient's data input

Data is a bottleneck in rare disease care and research



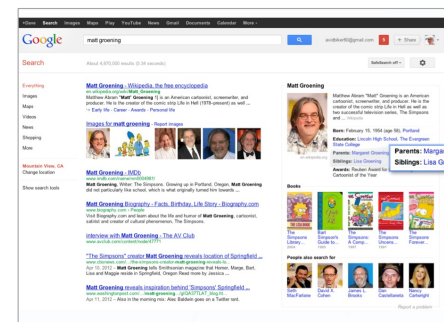
Human-Data Interaction? In HealthCare?



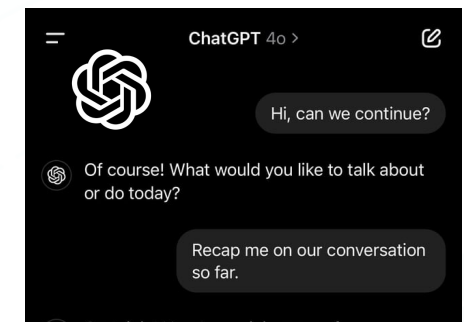
1994: Yahoo Directory Launches
~3.000 Websites
Browse categories
Manually curated



1998: Google is Founded
~2,4M Websites
Intelligent crawling
Indexing



2012: Google's Knowledge Graph
~634M Websites
More semantic
Knowledge Graph



2024: ChatGPT DeepSeek & Grok
~1,1B Websites
AI-driven Search
Conversations



Handling health data is
challenging due to
fragmented sources,
privacy laws, and
inconsistent standards,
making **integration and
secure sharing difficult** for
research and policy.



Researchers & Policy Makers

Disconnected Data



Data Interoperability



Data Avalanche





Researchers & Policy Makers

Small-scale
registries
€500K-
€1M

18 - 36
months

Larger
registries
€1M- €5M

1. Initial Planning & Stakeholder Engagement: 3–6 months
2. Regulatory Approval and Ethical Clearances: 6–12 months
3. Technical Development (Infrastructure & Data Systems): 6–18 months
4. Pilot Testing and Data Collection: 3–12 months



Personal Data Vaults



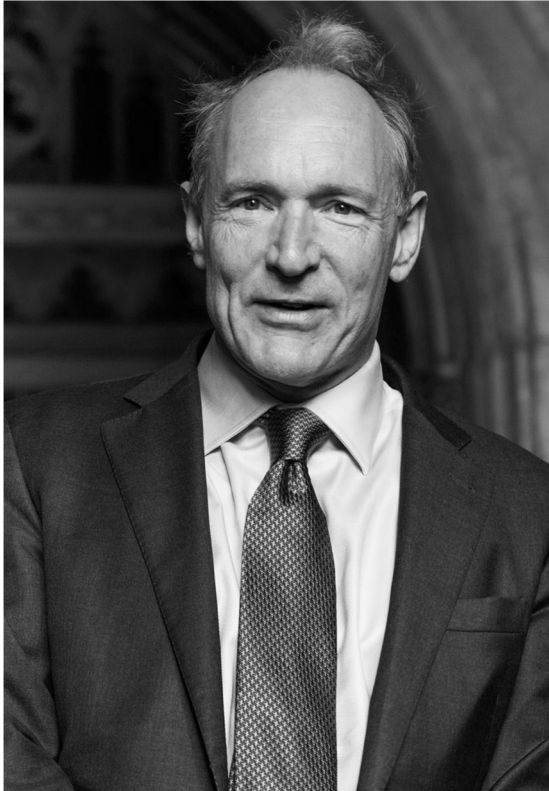
Patients

Patients often lack control over their sensitive medical information, facing **challenges in understanding and managing their health data.**



Caregivers

During illness, these barriers leave them **feeling vulnerable and powerless.**



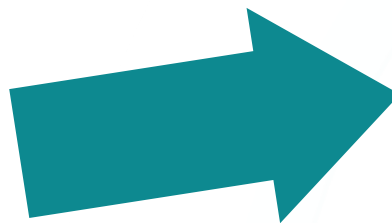
SOLID aims to
restore choice
by separating
data from apps.

Sir Tim Berners-Lee



Separating Data from Apps

From unstructured &
fragmented data with
NO CONTROL



EMPOWERED

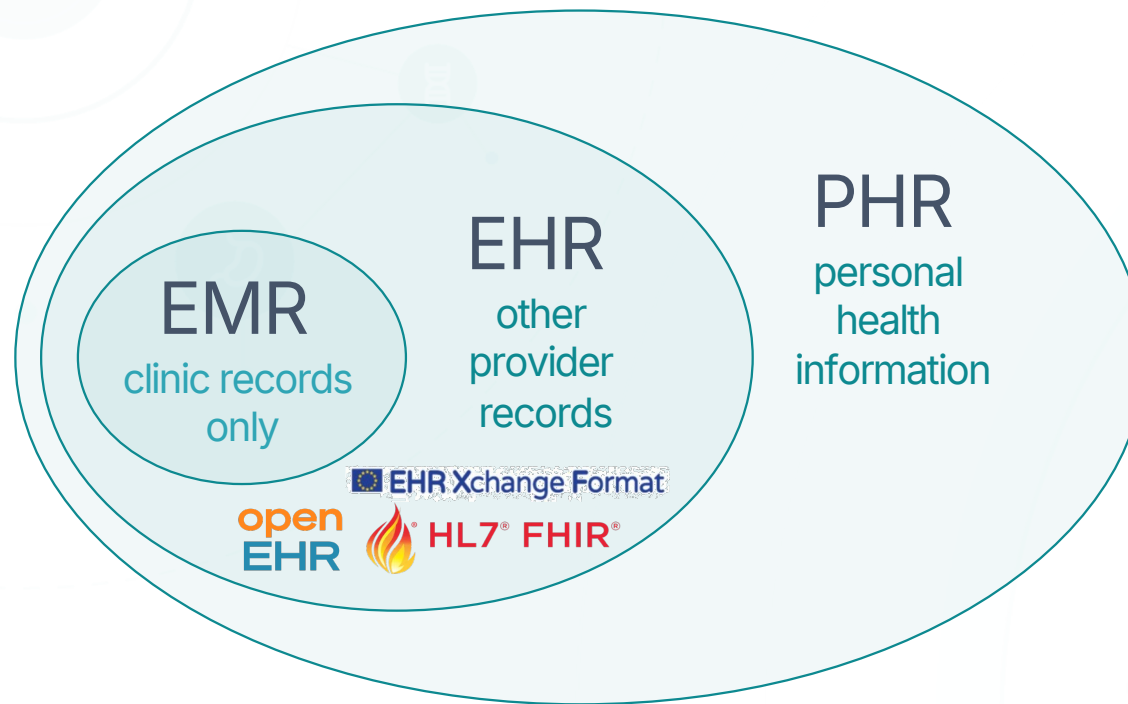
towards structured &
hyper-connected data



From Strings to Things



Include Personal Health Data



INTERNATIONAL
STANDARDS

COMMON
DATA MODELS

PERSONAL HEALTH
RECORDS

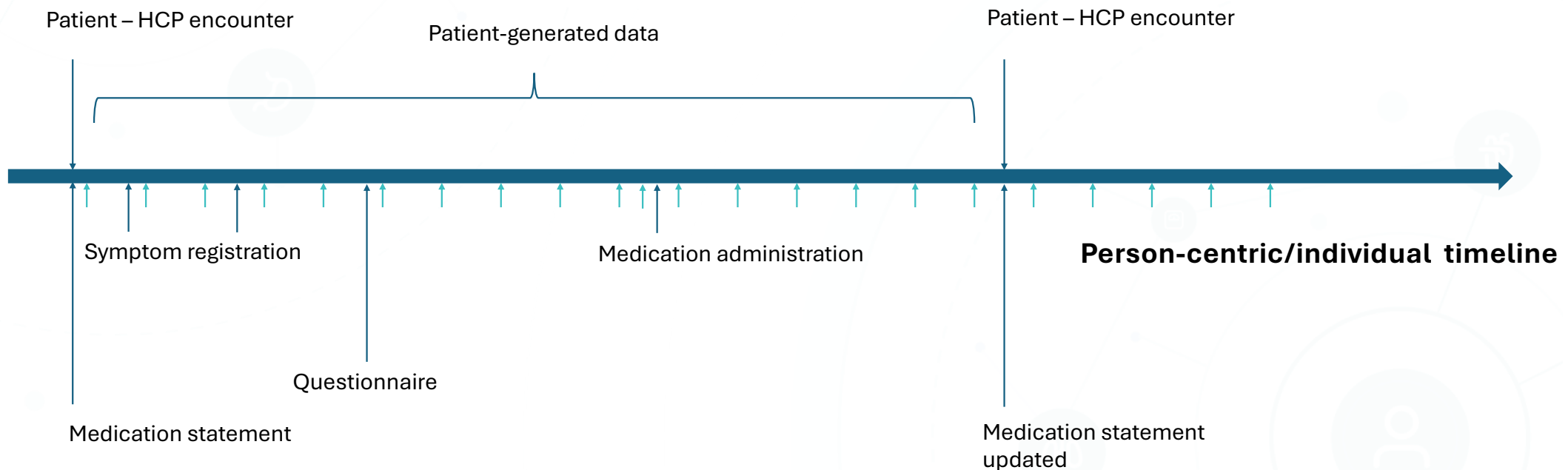


LOINC[®]
from Regenstrief

Leading healthcare
terminology, worldwide



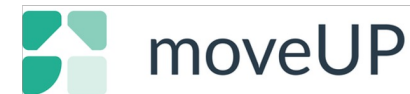
Personal Health Record Data Model





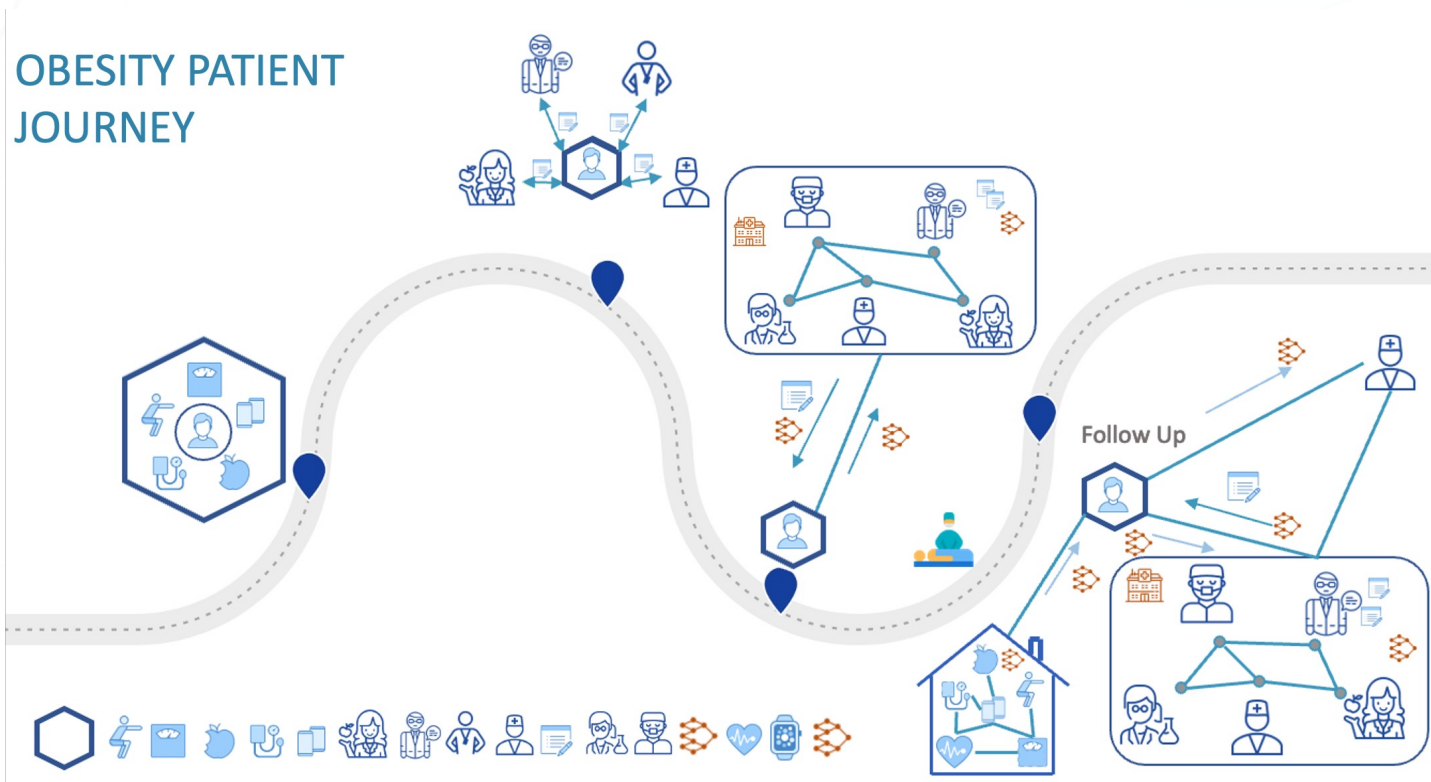
PACSOI

PATIENT CENTRIC SOLID



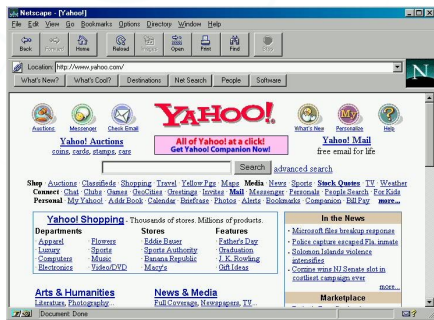


PACSOI: Patient Centric Solid





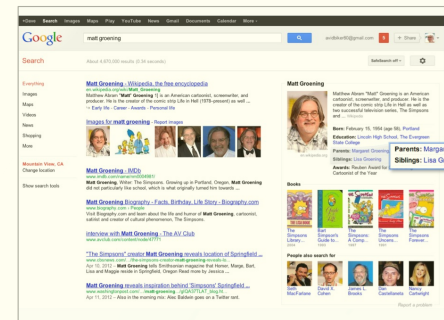
Knowledge Graphs in HealthCare



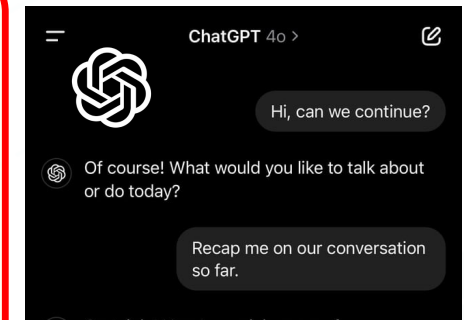
1994: Yahoo Directory Launches
~3.000 Websites
Browse categories
Manually curated



1998: Google is Founded
~2,4M Websites
Intelligent crawling
Indexing



2012: Google's Knowledge Graph
~634M Websites
More semantic
Knowledge Graph



2024: ChatGPT DeepSeek & Grok
~1,1B Websites
AI-driven Search
Conversations



GenAI, LLM, RAG ...

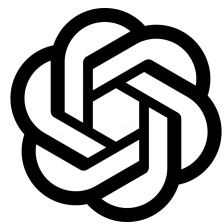


Generative AI

Generative artificial intelligence is a subset of artificial intelligence that uses generative models to produce text, images, videos, or other forms of data.

These models learn the underlying patterns and structures of their training data and use them to produce new data based on the input, which often comes in the form of natural language prompts.

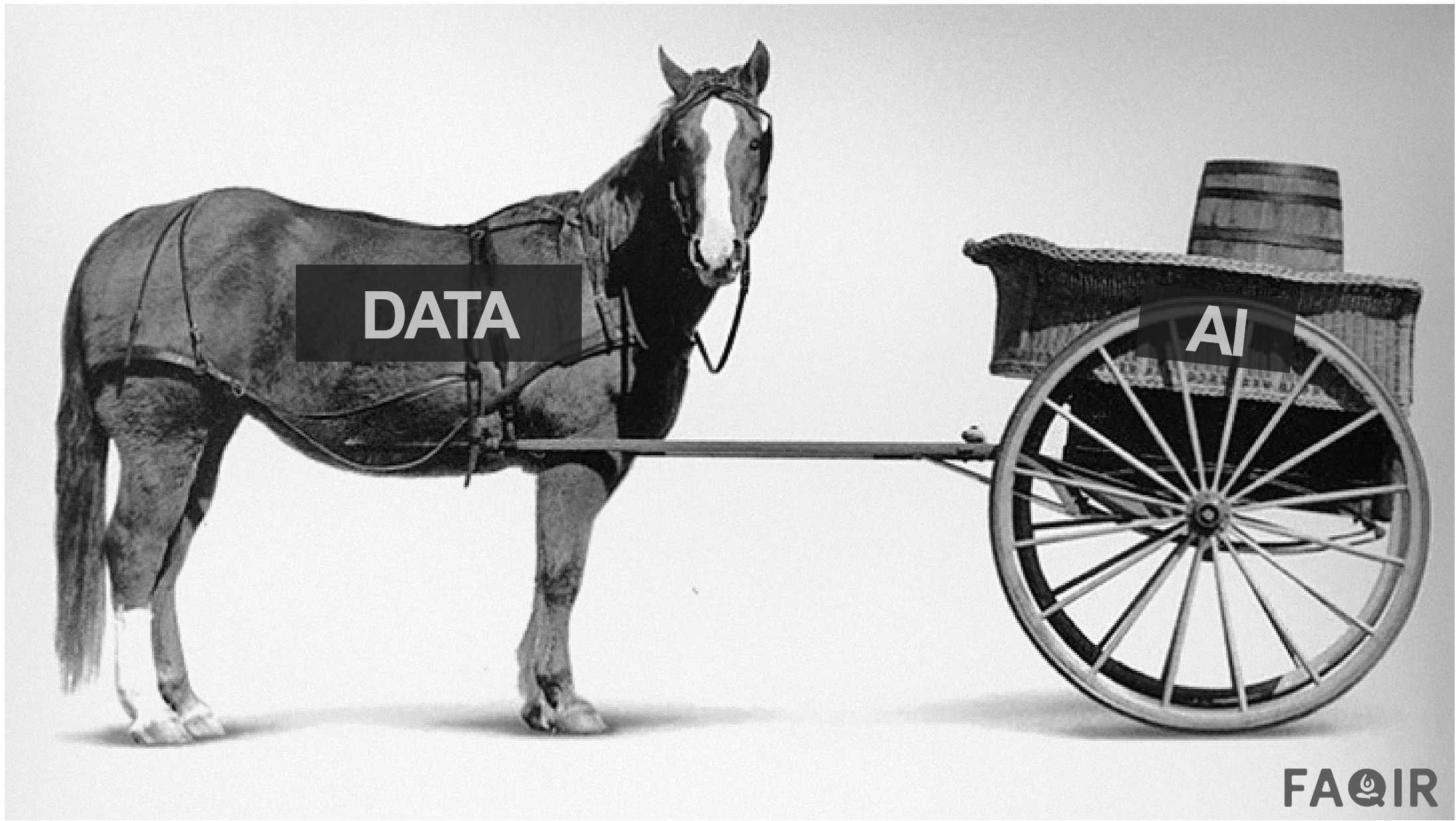
[wikipedia]



Grok



deepseek





Garbage In - Garbage Out

HEALTH TECH Experts say IBM Watson's flaws are rooted in data collection and interoperability

By Evan Sweeney · Sep 6, 2017 2:04pm

Poor data quality is enemy number one to the widespread, profitable use of machine learning. While the caustic observation, "garbage-in, garbage-out" has plagued analytics and decision-making for generations, it carries a special warning for machine learning. The quality demands of machine learning are steep, and bad data can rear its ugly head twice — first in the historical data used to train the predictive model and second in the new data used by that model to make future decisions.

Analytics And Data Science

If Your Data Is Bad, Your Machine Learning Tools Are Useless

by Thomas C. Redman

April 2, 2018

But first, the industry will have to tackle a [significant hurdle](#) in making patient data more accessible and available in [real time](#). As Chen and Asch point out, clinical data for predictive purposes has a shelf life of about four months.

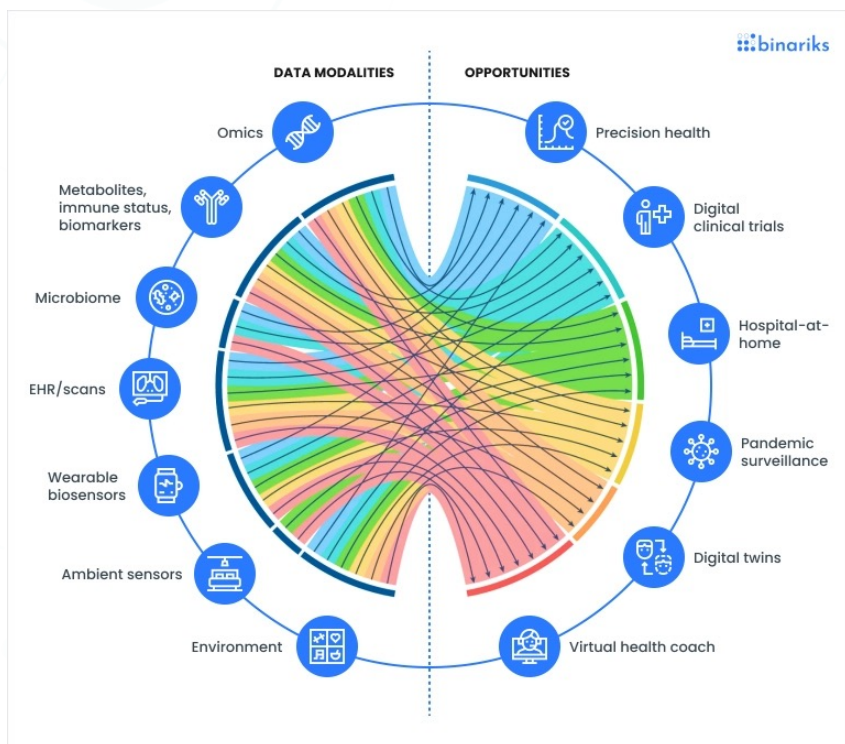


Challenges in AI adoption

StageZero identifies three main challenges that face companies that want to innovate within AI: data scarcity, data quality, and regulatory compliance. A lack of data, especially quality data, stands out as the most significant issue in developing successful AI models.



Growing Amounts of Multimodal Data



Multimodal biomedical AI

[Julián N. Acosta](#), [Guido J. Falcone](#), [Pranav Rajpurkar](#) & [Eric J. Topol](#)

Nature Medicine **28**, 1773–1784 (2022) | [Cite this article](#)

143k Accesses | 412 Altmetric | [Metrics](#)

Abstract

The increasing availability of biomedical data from large biobanks, electronic health records, medical imaging, wearable and ambient biosensors, and the lower cost of genome and microbiome sequencing have set the stage for the development of multimodal artificial intelligence solutions that capture the complexity of human health and disease. In this Review, we outline the key applications enabled, along with the technical and analytical challenges. We explore opportunities in personalized medicine, digital clinical trials, remote monitoring and care, pandemic surveillance, digital twin technology and virtual health assistants. Further, we survey the data, modeling and privacy challenges that must be overcome to realize the full potential of multimodal artificial intelligence in health.

ON THE PURSUIT OF 'HEALTH DATA' HAPPYNESS



Cut corners & win fast,
but lose trust just as quickly.

Slower & painfull, but
integrity builds trust.





Privacy & Ethics



Data Governance & Provenance

NY Times copyright suit wants OpenAI to delete all GPT instances

Shows evidence that GPT-based systems will reproduce Times articles if asked.

JOHN TIMMER - 27 DEC 2023 20:05 543

That's also strongly implied by a [comment](#) that investment firm Andreessen Horowitz filed with the US Copyright Office in late 2023 ([PDF](#)) in which the firm argued that treating AI model training as copyright infringement "would upset at least a decade's worth of investment-backed expectations." Also known as a16z, Andreessen Horowitz is an OpenAI investor, and founder Marc Andreessen is a prominent AI booster.

TECHNOLOGY

Clearview AI fined \$33.7 million by Dutch data protection watchdog over 'illegal database' of faces



World Business Markets Sustainability More

My News

US appeals court rejects copyrights for AI-generated art lacking 'human' creator

By Blake Brittain

March 18, 2025 7:05 PM GMT+1 · Updated 12 days ago



Data contracts

Consent Management

'Availability' of data?

Accessibility:
free, paid ... ?



Subjective Data Crucial Role in Healthcare

Martha's rule having 'transformative effect', NHS England data shows

Mother of girl who died in 2021 reveals figures on Today programme that are welcomed by national medical director



📷 Martha Mills died after doctors failed to move her to an intensive care unit despite her parents voicing serious concerns about her health. Photograph: Mills/Laity family photograph/PA

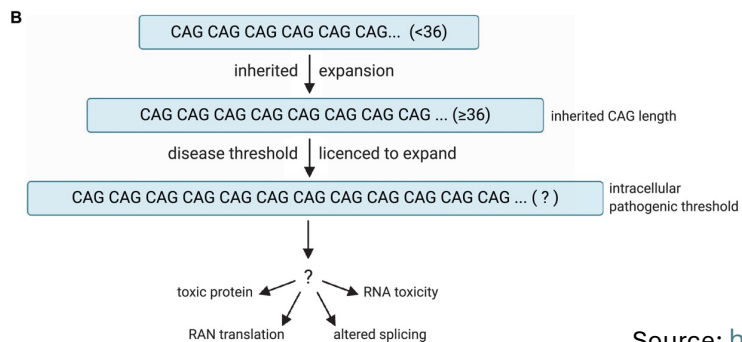
Patients have been moved to intensive care or received potentially life-saving treatment such as oxygen as a direct result of hospitals adopting Martha's rule, **NHS** data shows.

Networked devices help head off medical woes and speed recovery

Digital technologies are helping to guide early clinical interventions and assessments of treatment



A device designed by Impedimed, an Australian technology supplier, that can detect if someone is at risk of lymphoedema — a common and debilitating side effect of cancer treatment

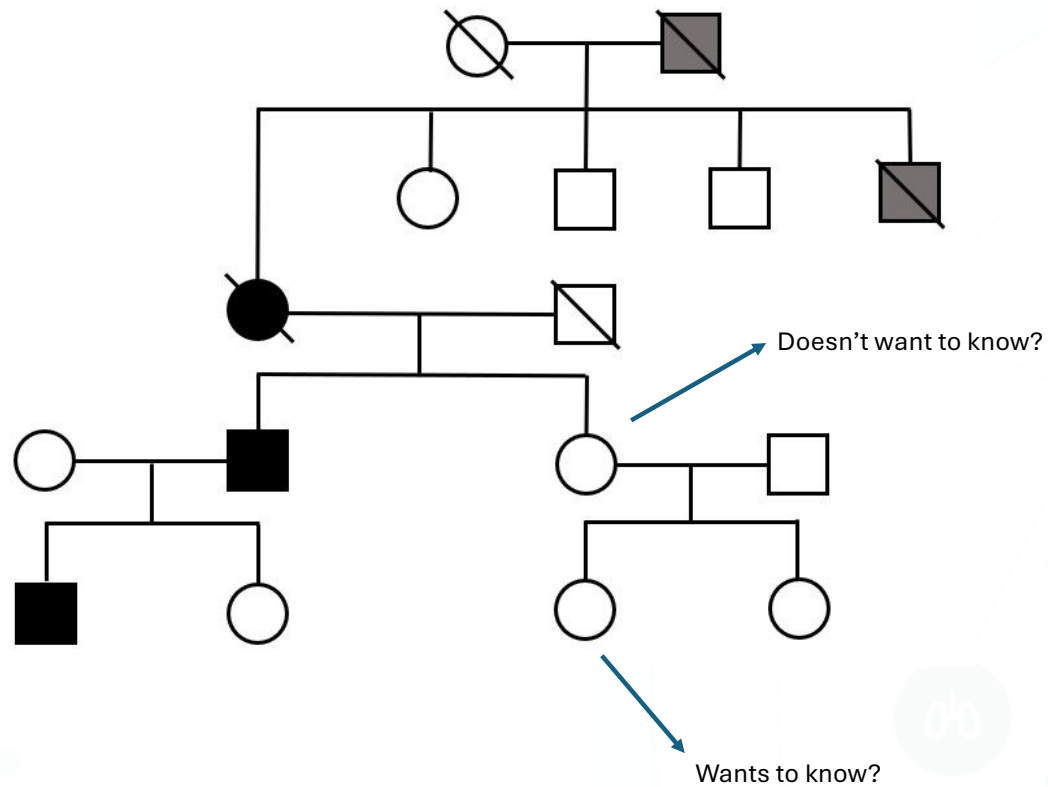


Slurred Speech

info@faqir.org 50



The right to know or not?



[illegible]

1 / 2
-
100%
+

DOSSIER GEGEVENS LABO

voorschrift: 16/11/23
staalnaam: 16/11/23
ref: **819.232.455**
ontvangst: 16/11/23 13:19

DOSSIER INFO

patiënt:
uw ref.:
print: 26/03/24 09:52
status: Volledig

PATIENT

HERFOT4
HERFOT3
HERFOT19

819.232.455
16/11/23

Eenheid

Referentie


Hematologie

Bezetting na 1 uur*
Erytrocyten
Hemoglobine
Hematocriet
MCV

2
6.13
16.3
40.0
87.7

mm
x10⁹/µL
g/dL
L
fL

<20
4.35 - 5.61
13.4 - 16.5
39.7 - 49.3
82.2 - 96.5



Resultaten van

18 PERSONEN (1000000) VRIJGEZONDEN (1000000) INGEVANGEN (1000000)

PLAAT	DATUM	VTC	OPMERKINGEN	D	TYPE	ZONDERVRIJGEZONDEN	INTELLING	DOORST
	24/05/2024	✓	Labo verstuig	Labo		laboratorium		
	24/05/2024	✓	Labo verstuig	Labo		laboratorium		
	23/05/2024	✓	Labo verstuig	Labo		laboratorium		
	23/05/2024	✓	Labo verstuig	Labo		laboratorium		
	22/05/2024	✓	Labo verstuig	Labo		laboratorium		
	22/05/2024	✓	Labo verstuig	Labo		laboratorium		
	22/05/2024	✓	Labo verstuig	Labo		laboratorium		
	22/05/2024	✓	Labo verstuig	Labo		laboratorium		
	22/05/2024	✓	Labo verstuig	Labo		laboratorium		
	22/05/2024	✓	Labo verstuig	Labo		laboratorium		
	21/05/2024	✓	COVID-19 PCR Test	Labo		LAB		
	21/05/2024	✓	bevestigend Ziektehuus ontsteking	Ontsteking		Intensieve zorg		
	21/05/2024	✓	bevestigend Ziektehuus ontsteking	Ontsteking		Intensieve zorg		
	21/05/2024	✓	INCL. B. THOMAS AAN BED	Externe ink		Medische bes...		
	21/05/2024	✓	bevestigend Riet Thoma	Verstrij Med...		Medische bes...		

18 personen

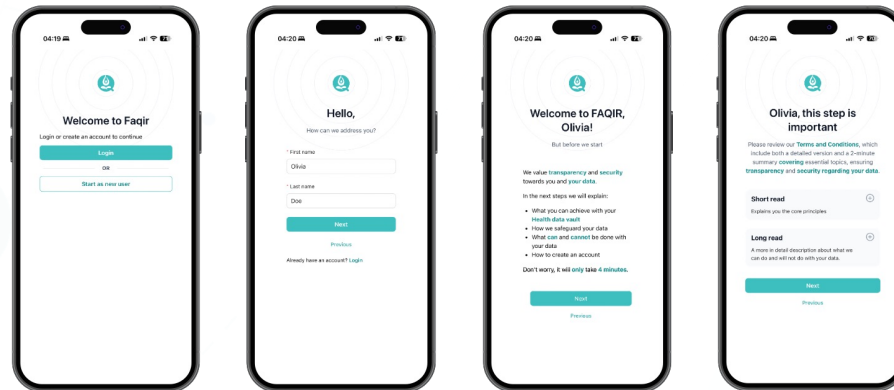


How Does it Work?

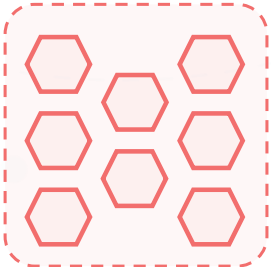


FAQIR Ecosystem

1



Create personal
data vaults



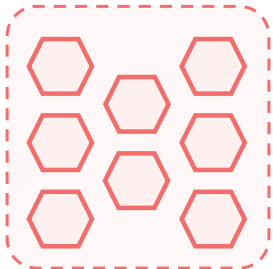


FAQIR Ecosystem

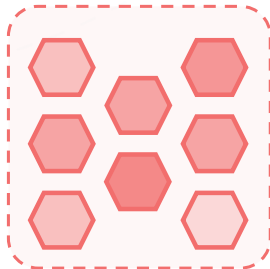
1

2

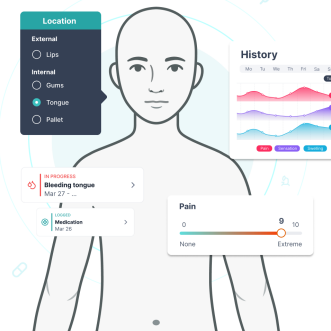
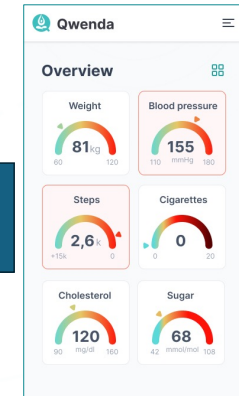
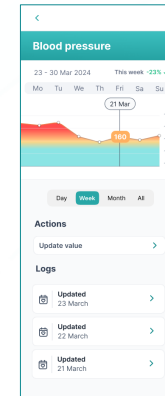
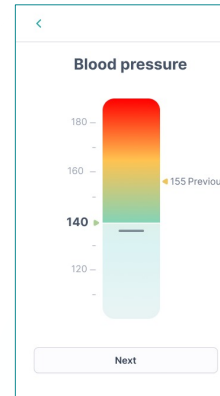
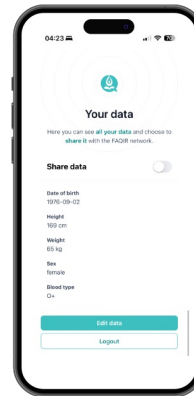
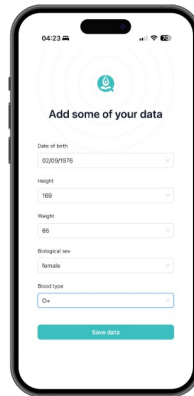
Create personal
data vaults



Initialize
test data



Automatic or manual
entry of health events,
medical encounters,
medications, QOLs ...





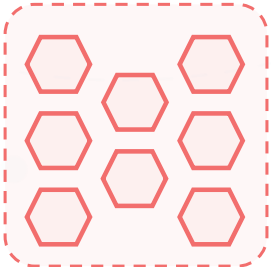
FAQIR Ecosystem

1

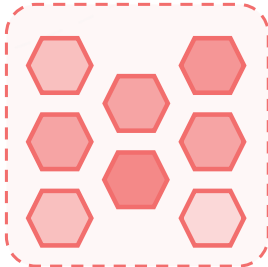
2

3

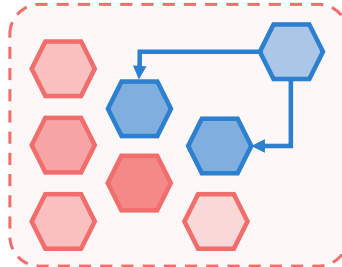
Create personal
data vaults



Initialize
test data



Enable for primary use
for care givers

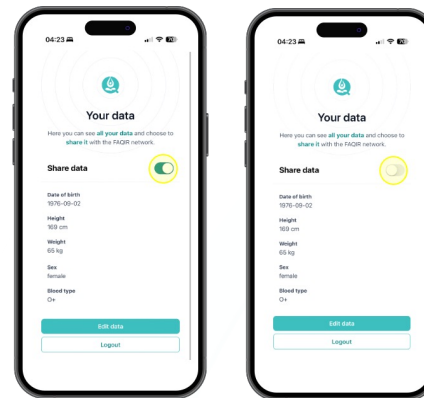


Web application for
healthcare professionals
for data dashboarding of
individuals and groups

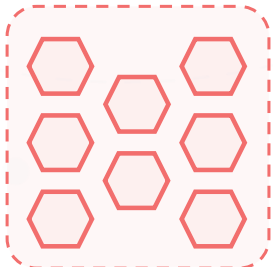




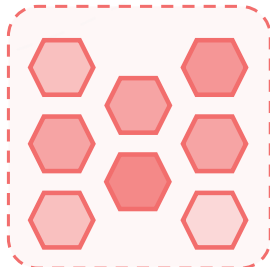
FAQIR Ecosystem



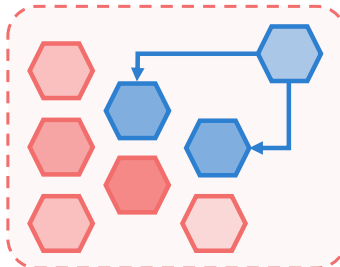
Create personal
data vaults



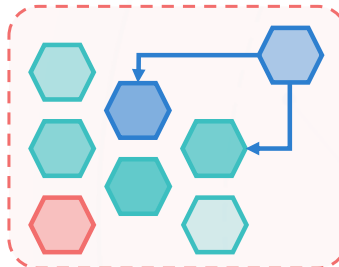
Initialize
test data



Enable for primary use
for care givers



Enable for secondary
use for research

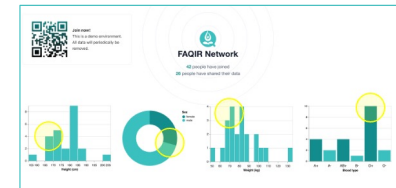
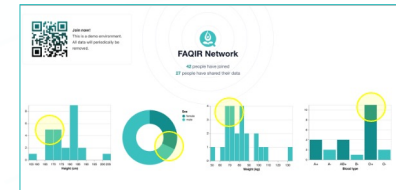




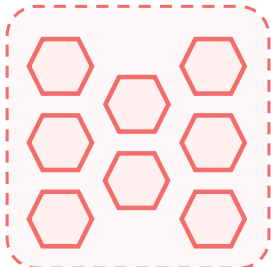
FAQIR Ecosystem



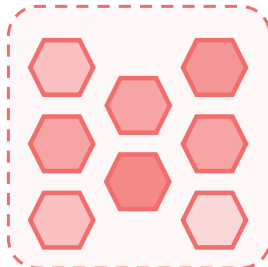
Aggregated dataset & analytics for researchers and policy makers to enable innovation



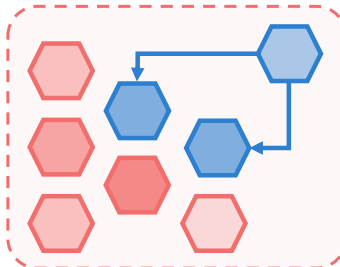
Create personal data vaults



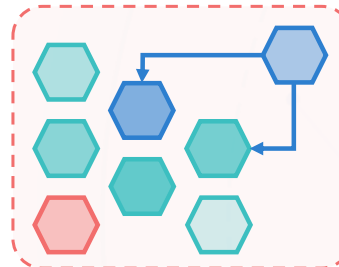
Initialize test data



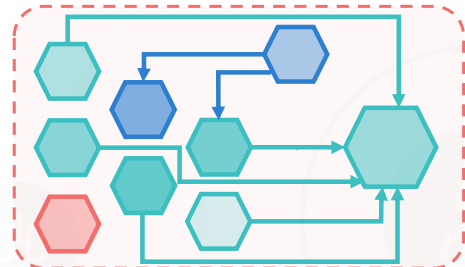
Enable for primary use for care givers



Enable for secondary use for research



Create data aggregator vault & process data request





FAQIR Ecosystem

1

2

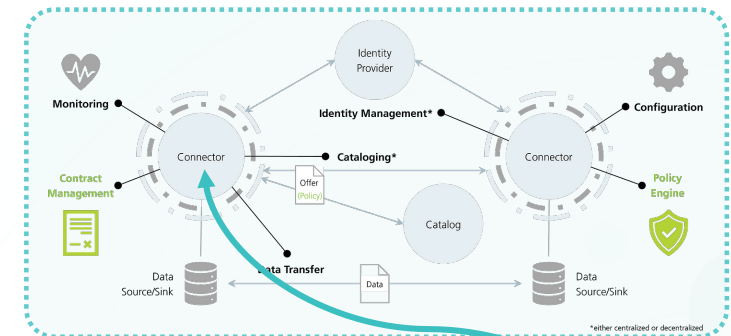
3

4

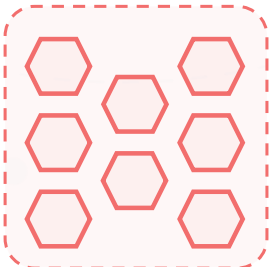
5

6

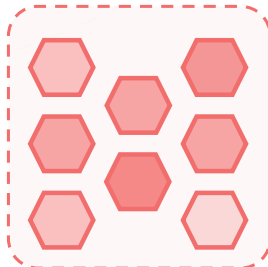
Publish aggregated data, metadata & policies in the HDA Catalog & Flemish Health Data Space



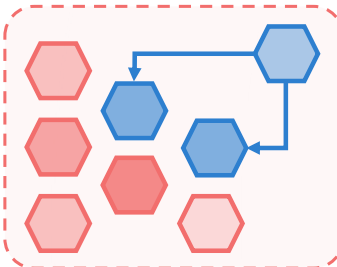
Create personal data vaults



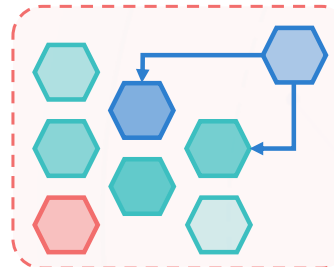
Initialize test data



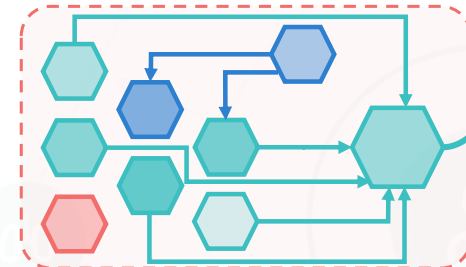
Enable for primary use for care givers



Enable for secondary use for research



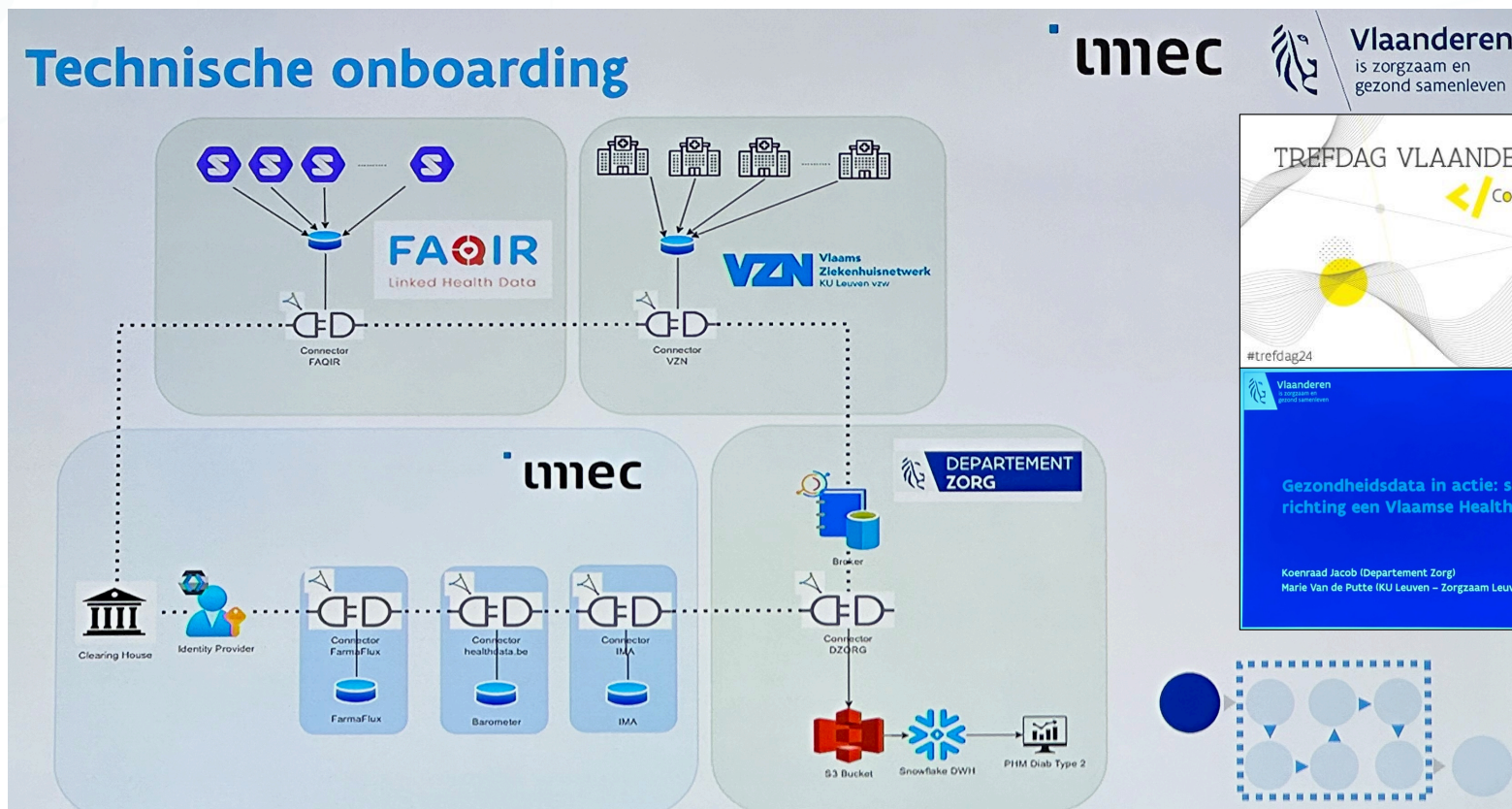
Create data aggregator vault & process data request





SOLID – FAQIR – IMEC – Flanders

Technische onboarding



imec



Vlaanderen
is zorgzaam en
gezond samenleven

TREDFAG VLAANDEREN DIGITAAL

Connecting the dots

24 OKTOBER 2024
FLANDERS EXPO GENT

#trefdag24

Vlaanderen
is zorgzaam en
gezond samenleven

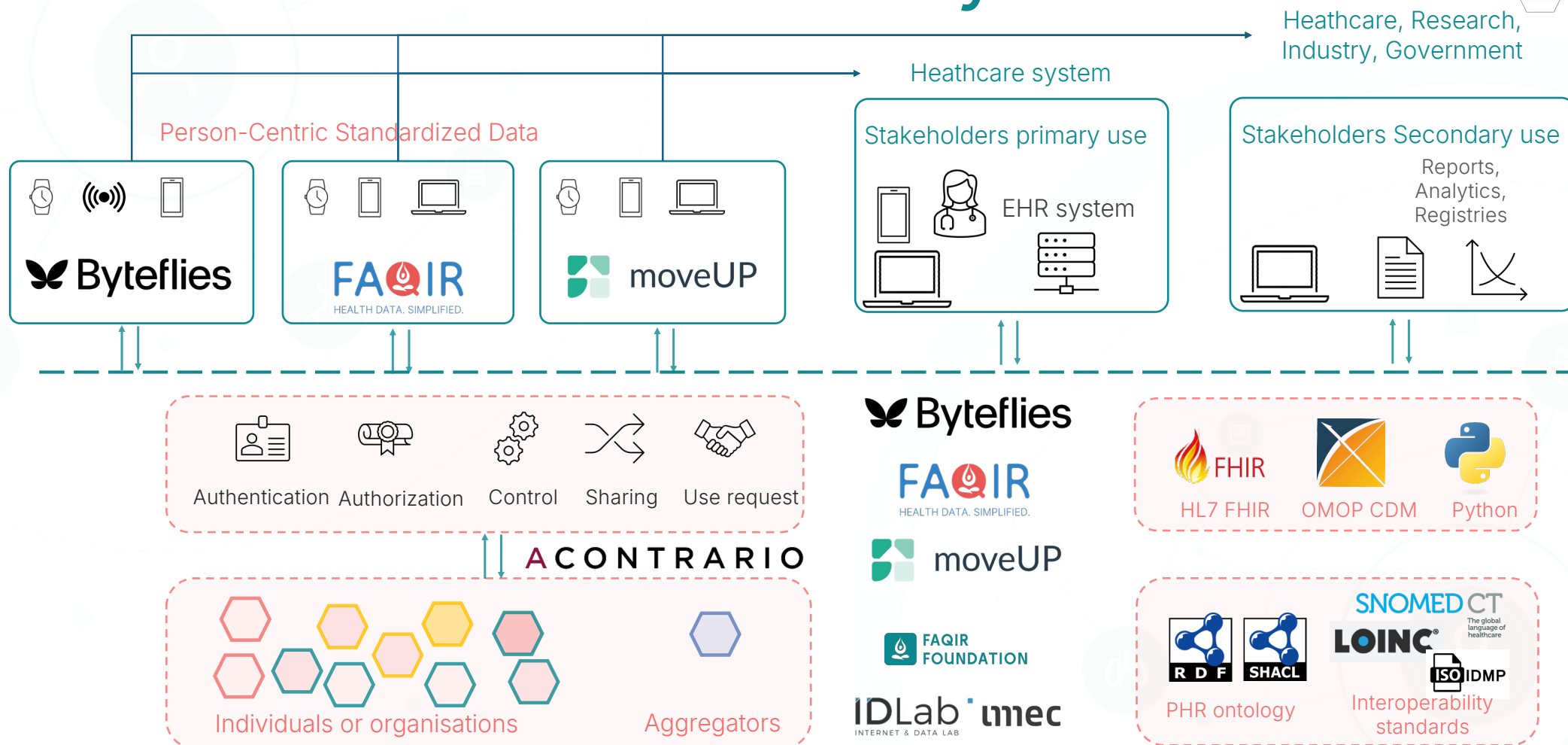
imec

Gezondheidsdata in actie: samen
richting een Vlaamse Health Data Space

Koenraad Jacob (Departement Zorg)
Marie Van de Putte (KU Leuven – Zorgzaam Leuven)



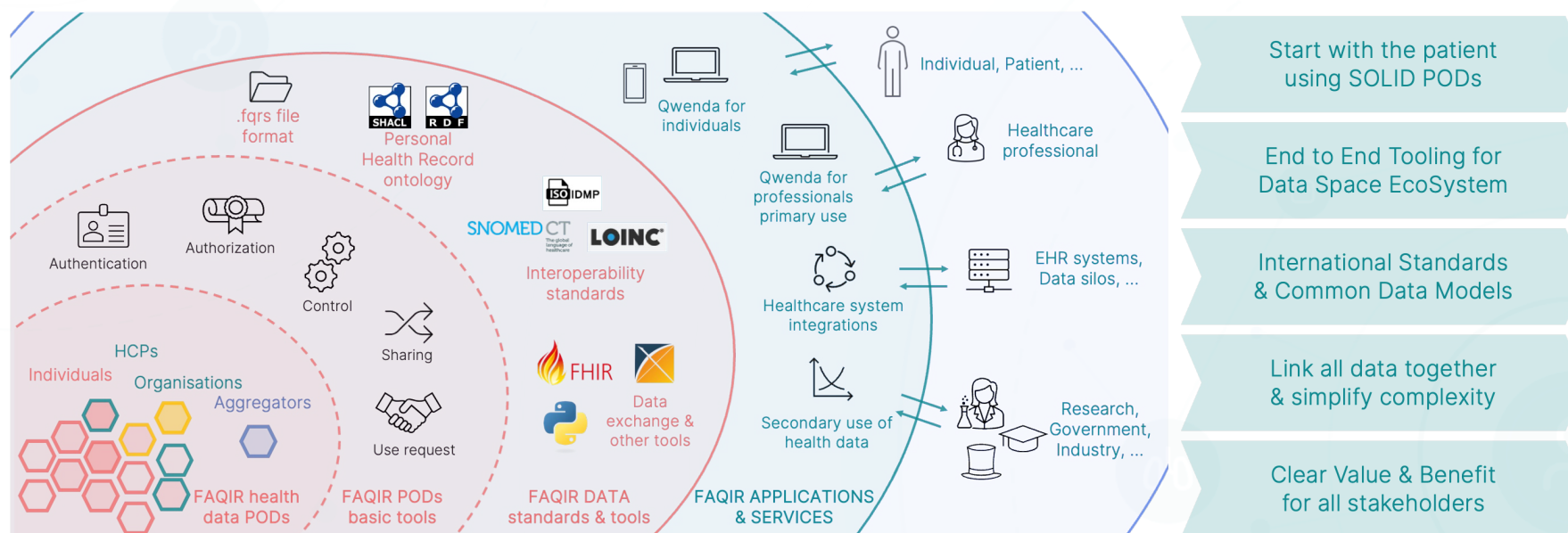
PACSOI Ecosystem





Bringing it all Together

Innovative Tech (SOLID) + New (EHDS) Legislation + Collaborative Expertise = Huge Impact & Value for Many





Keep it **safe**

SOLID enables to bring together & access all your health information in a private, secure & safe environment.

Make it **simple**

Intuitive and easy to manage all health info & events with our applications and dashboards.

You're in **control**

Control what data is shared with who for what purpose to enable transparency & trust.



Patient Stories Podcasts





Ghent University
Fac. Pharmaceutical Sciences
Fac Engineering & Architecture
Filip.pattyn@ugent.be



FAQIR Institute bv
Filip.pattyn@faqir.eu



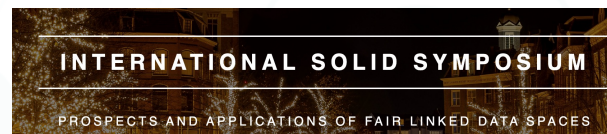
FAQIR Foundation vzw
Filip.pattyn@faqir.org

Questions?

Filip Pattyn

<https://www.linkedin.com/in/filippattyn/>

+32 486 739 129



2025-04-24