



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

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FAQIR Ecosystem

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2025-04-24





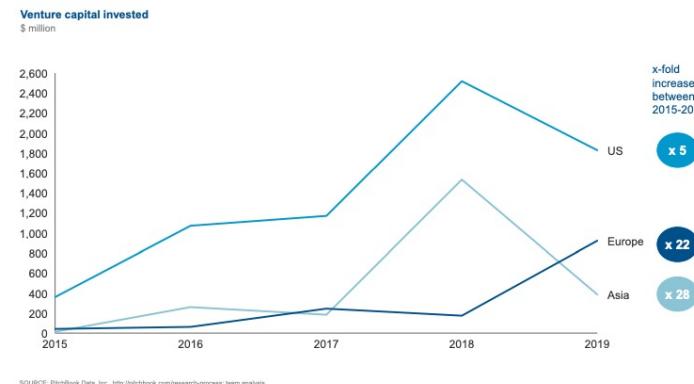
FEBRUARY 3RD-9TH 2018

Doctor You

How data will transform health care

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



Business
Dec 3rd 2020 edition

Health care and technology

The dawn of digital medicine

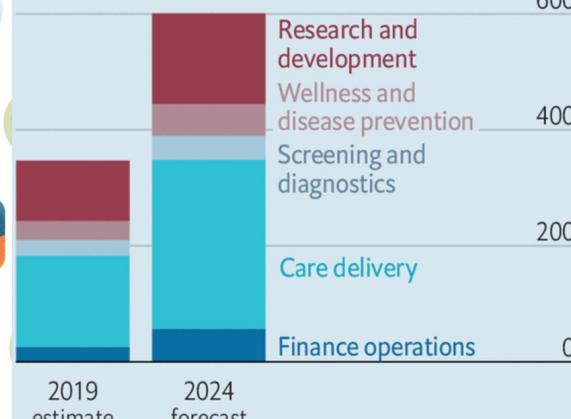
The pandemic is ushering in the next trillion-dollar industry



Adam Maida

Healthy growth

Global digital health, market size, \$bn

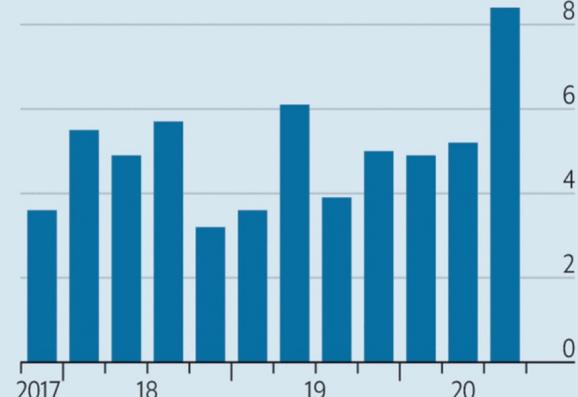


1

2

Hypertension

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



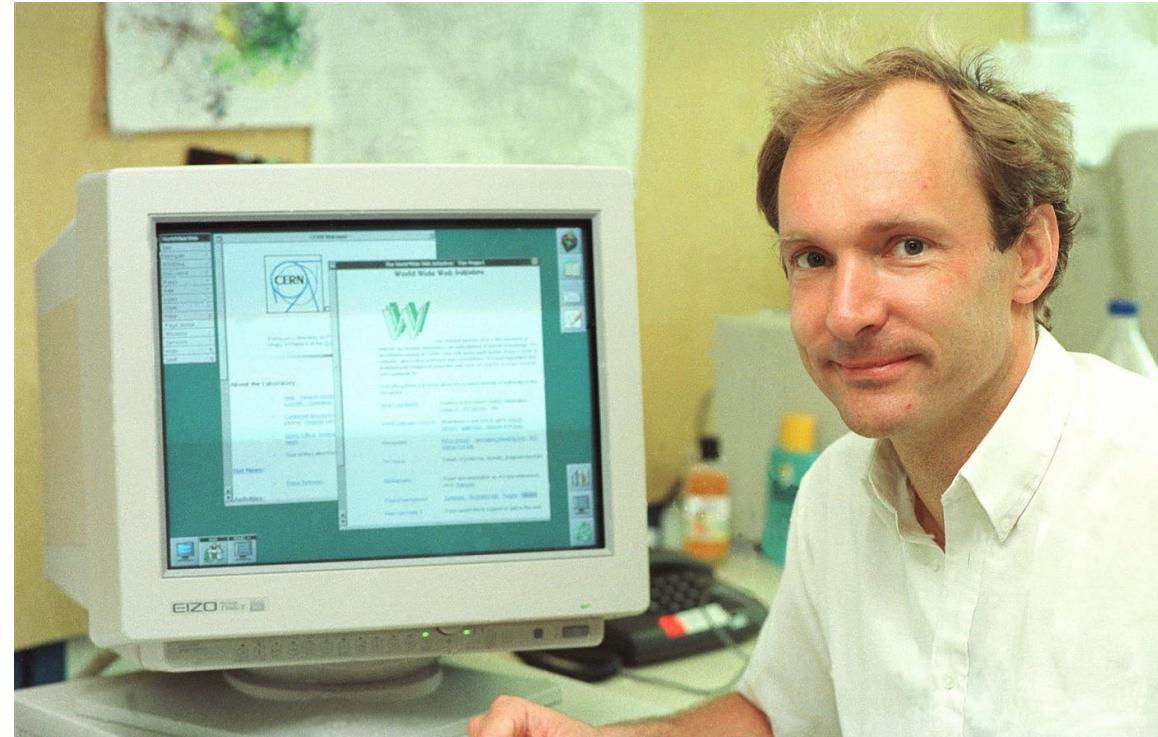
The Economist



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 Search Engine

This is a demo of the Google Search Engine. Note, it is research in progress so expect some downtime and malfunctions. You can find the older [Backrub web page here](#).

Google is being developed by [Larry Page](#) and [Sergey Brin](#) with very talented implementation help by [Scott Henson](#) and [Alan Sternberg](#).

Search Stanford
10 results clustering on Search

Search The Web
10 results clustering on Search

Google earliest alpha stage (1997)

Google!

Search the web using Google!

10 results (Google Search) I'm feeling lucky
Index contains ~25 million pages (soon to be much bigger)

About Google!
Stanford Search Linux Search
Get Google! updates monthly!
your e-mail Subscribe Archive
Copyright ©1997-8 Stanford University

Google Beta homepage (1998)

Google!
BETA

Search the web using Google!
Google Search I'm feeling lucky

Special Searches
Stanford Search
Linux Search

Help
About Google
Company Info
Google Labs

Get Google! updates monthly!
your e-mail Subscribe Archive

Copyright ©1998 Google Inc.

Google Beta homepage (1998)

Google

Advanced Search Preferences Search Tips
drake hotel, chicago Google Search
I'm Feeling Lucky

Searched the web for drake hotel, chicago Results 1 - 10 of about 13,800 Search took 0.08 seconds

CHICAGO HOTELS - Book Your Room Online - LOWEST RATES Guaranteed! Sponsored
www.hoteldiscounts.com Save Up to 65% and Reserve Your Room Instantly! Link

Category: Regional > North America > > Chicago > Travel and Tourism > Lodging > Hotels

The Drake Hotel
Category
Regional > North America > > Chicago > Travel and Tourism > Lodging > Hotels

Drake Hotel, Chicago, United States from HotelBook Your ...
... Drake Hotel Address: 140 East Walton Place Chicago Illinois 60611 United States
Phone: (1 312) 7872200 Fax: (1 312) 7871431 ...
condorist.hotelbook.com/static/welcome_02994.html - 9k - Cached - Similar pages

Sponsored Links
The Wheeler Mansion
Makoko Bed & Breakfast Hotel & Spa - makoko.com
Makoko Bed & Breakfast Hotel & Spa - makoko.com
www.wheelermansion.com
Interest: See your message here ...

First Google search ads (2000)

Google Web Images News Maps New! Prod
posh spice
Search: the web pages from the UK

Web
Image results for posh spice
image results at top of page

News results next

News results for posh spice
Spice Girls: Back and naughtier than ever - 16 Nov 2007
There are seven Spice Kids between them including Victoria boys. "This is our opportunity to say, 'Look! ...
MSNBC - 42 related articles »
Ottawa Citizen

Victoria Beckham - Wikipedia, the free encyclopedia
During her rise to fame with 1990s pop sensation the Spice Girls, she was Spice. Since the Spice Girls followed separate careers, Beckham has ...
en.wikipedia.org/wiki/Victoria_Beckham - 93k - Cached - Similar pages

Video results
YouTube - Ali-G Interviews Posh Spice and David Beckham
Ali-G Interviews Posh Spice and David Beckham for a fun 11 min - ★★★★
www.youtube.com/watch?v=P842Tmi6lrc

Results, images, news, videos (2007)



3: Knowledge Graph in 2012

Google search results for "matt groening":

Search results for "matt groening" show approximately 4,670,000 results in 0.34 seconds.

The main search results include:

- 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
[View images](#)
- Matt Groening - IMDb**
www.imdb.com/name/nm004981/
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/matt-groening-9303117
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_.../jQA37LAT_blog.htm.../](http://www.washingtonpost.com/.../matt-groening_.../jQA37LAT_blog.htm...)
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, Homer Groening
Siblings: Lisa Groening
Awards: Reuben Award for Cartoonist of the Year

Books

The Lisa Book (2004), Bart Simpson's Guide to Life (1993), The Simpsons A Complete Guide to Springfield (1997), The Simpsons Uncensored! (1991), The Simpsons Forever... (1991)

People also search for

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



4: Conversations with Data in 2024



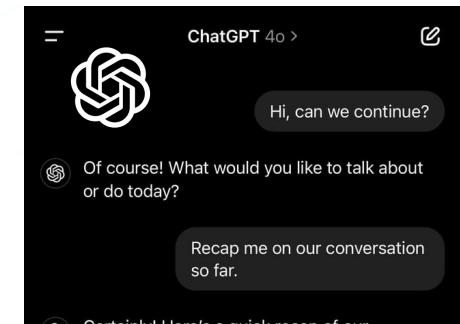
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Intelligent crawling
Indexing



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



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



EU Legislation



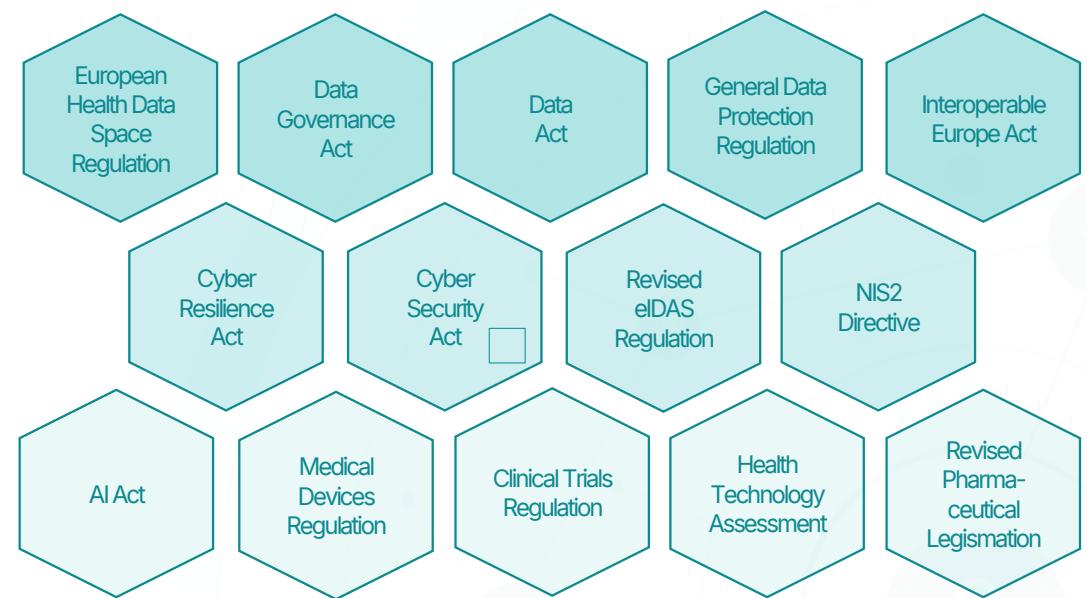
Secure Regulatory Framework



Data Availability
& Sharing

Security
& Trust

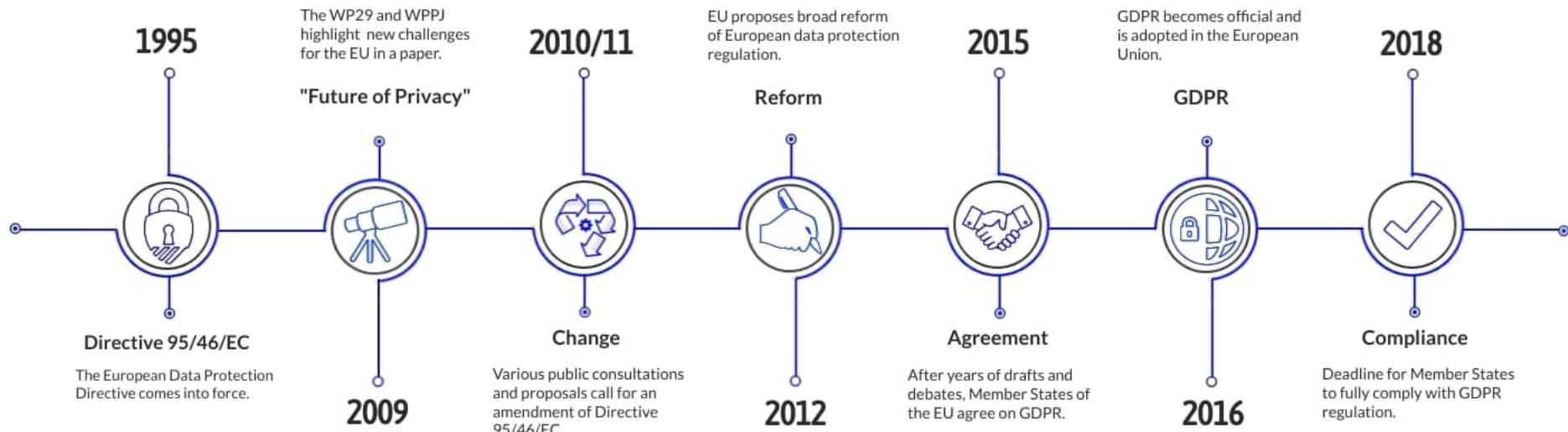
Rubustness
& Safety





A brief history of GDPR

A Brief History of GDPR



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

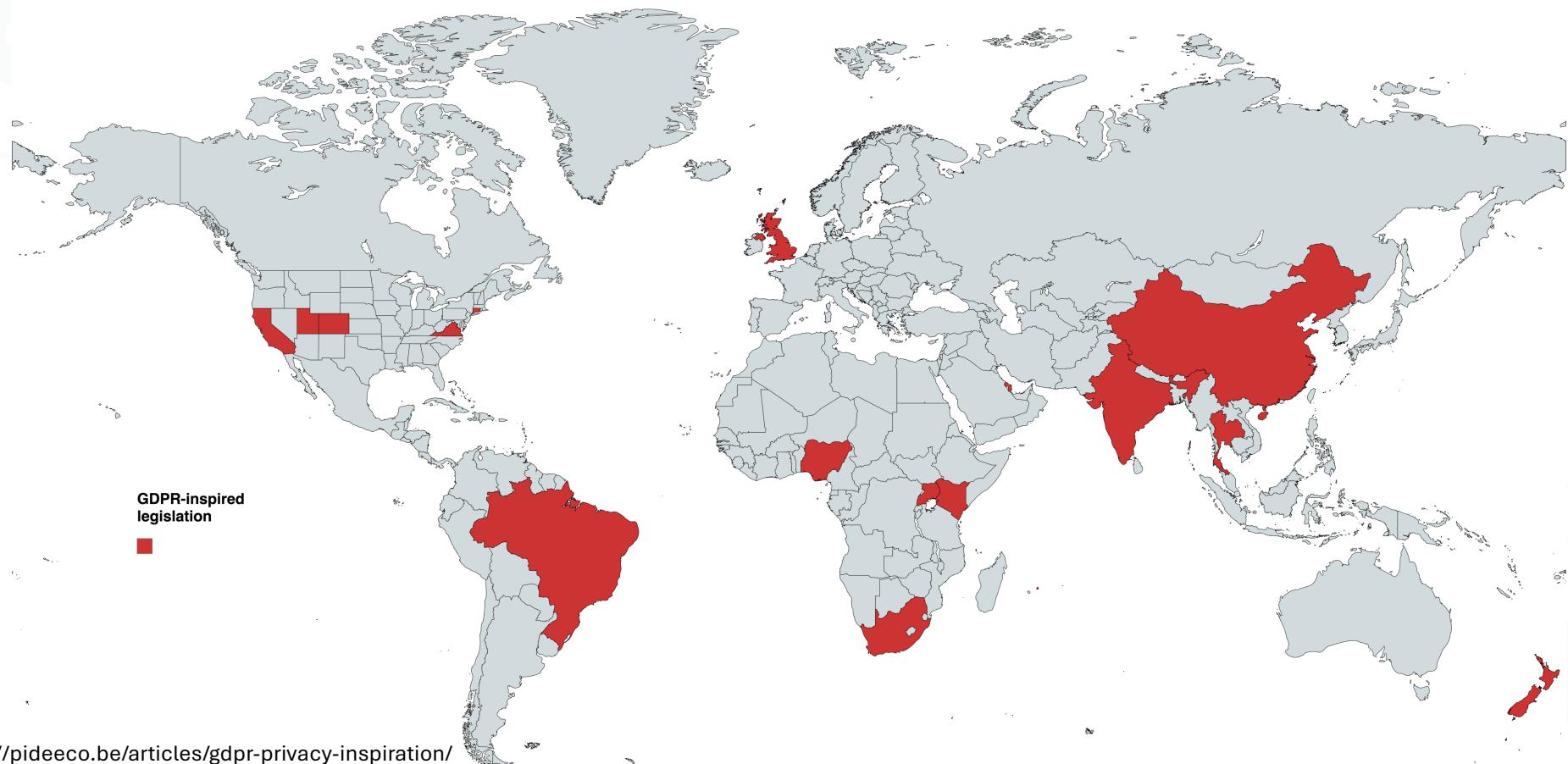
FAQIR Confidential

info@faqir.org

10



GDPR-inspired legislation



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

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Created with mapchart.net faqir.org 11

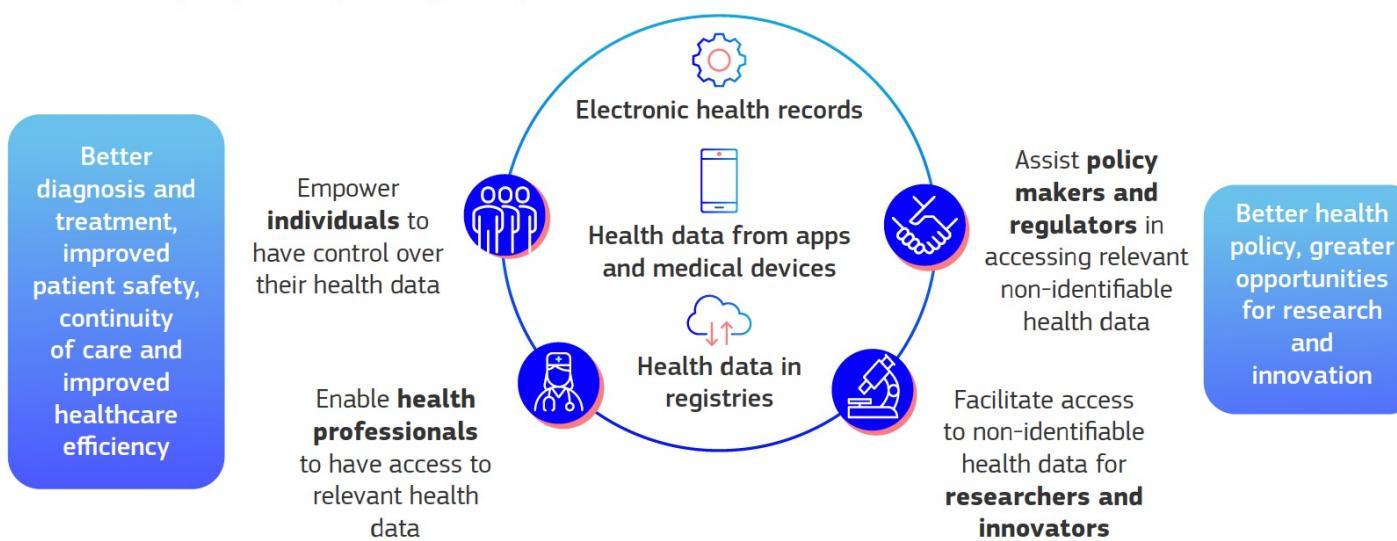


EUROPEAN HEALTH DATA SPACE

#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

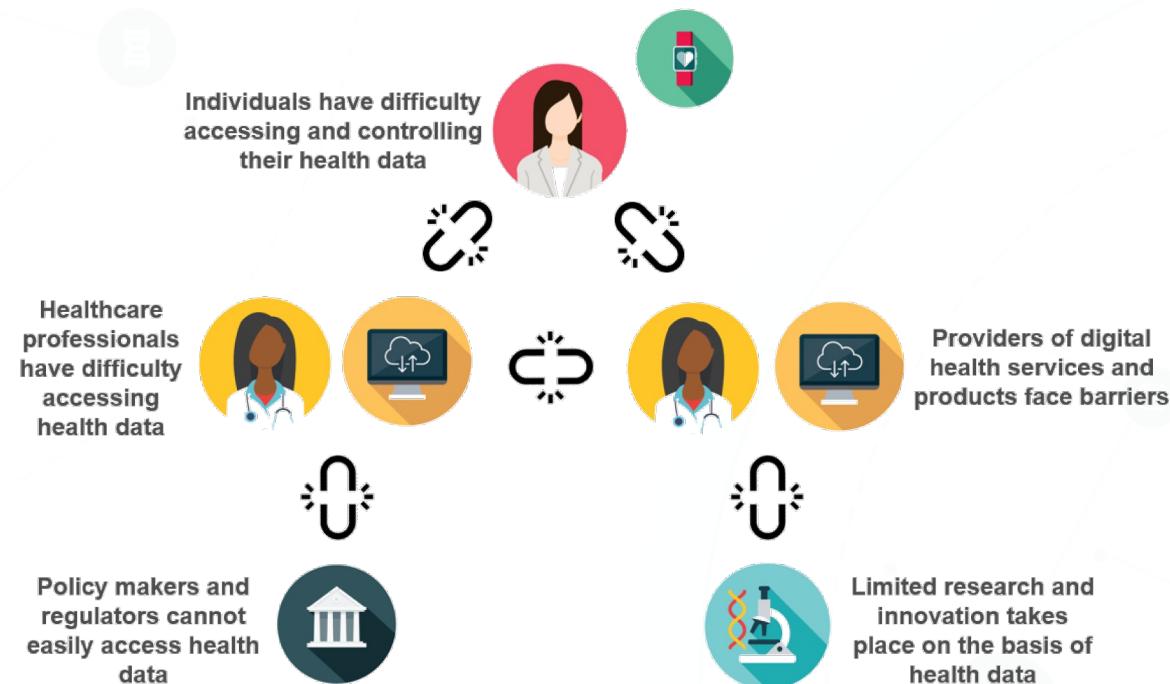


Figure 2 - Problems in controlling, using and sharing health data



EHDS: Benefits

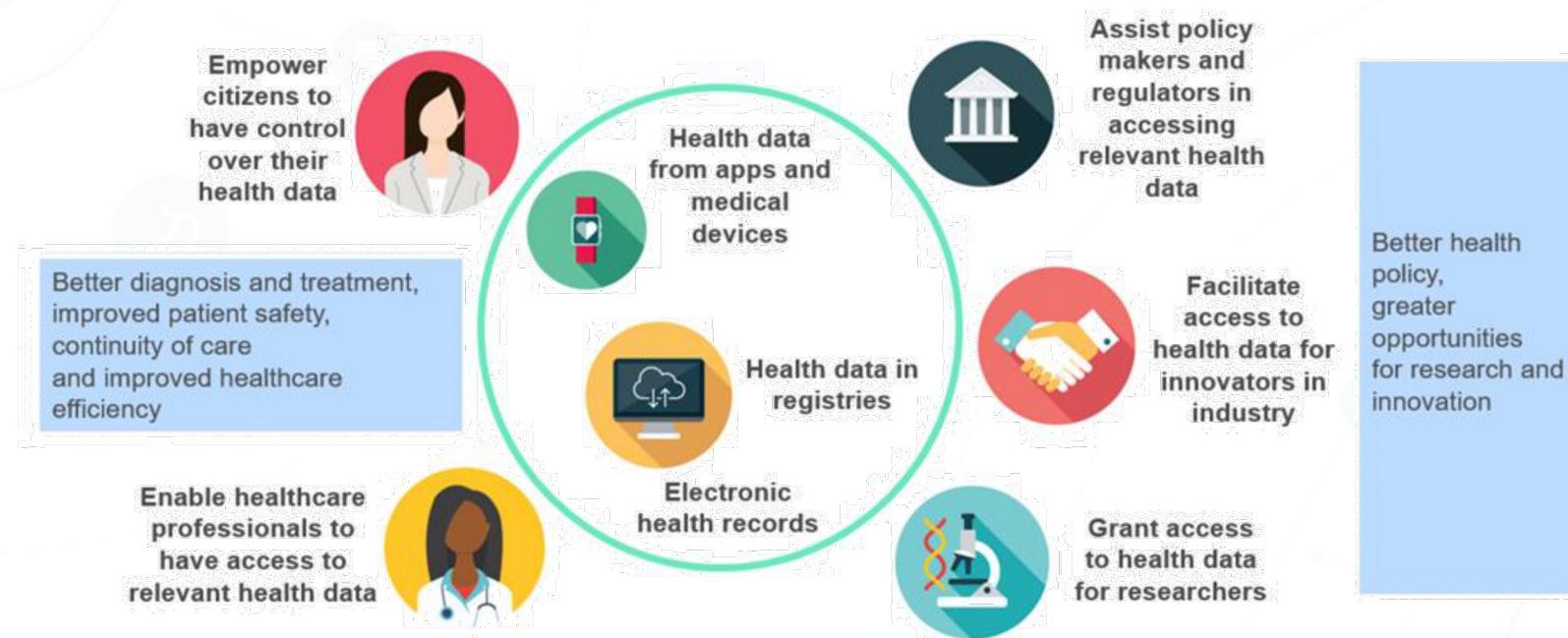


Figure 4. Benefits for users of European Health Data Space



EHDS

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.

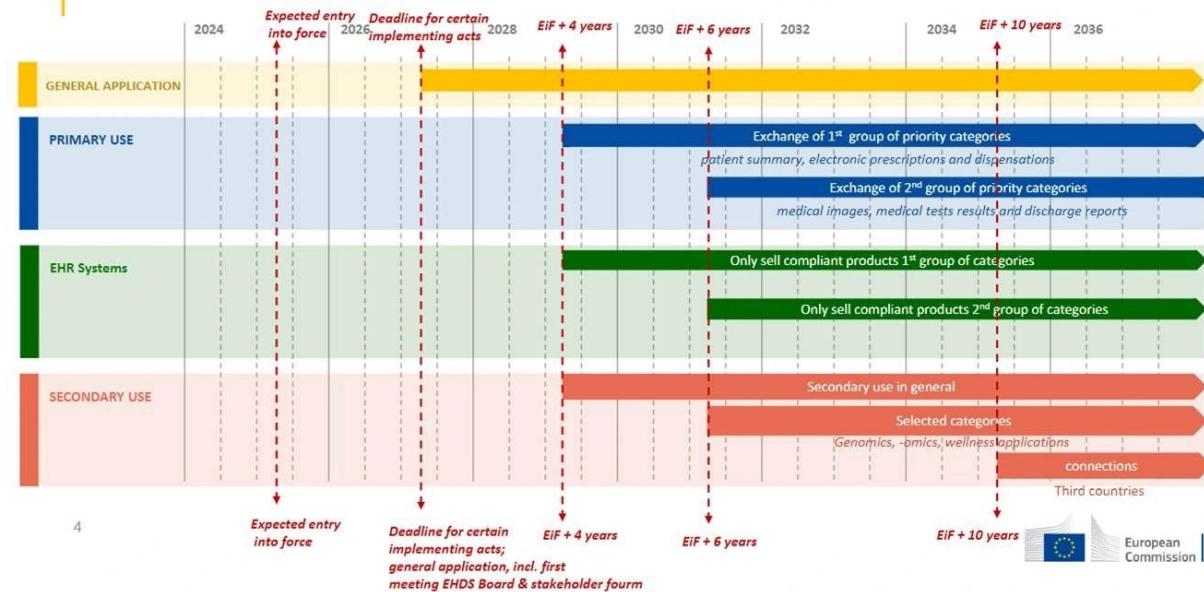


Pierre Cartuyvels and 6 others

5:46 PM · Mar 22, 2024 · 9,154 Views

Formal signing and publication
in Official Journal on 21 February 2025

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



Source: World GeoDemo
(Facebook)

info@faqir.org

17



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

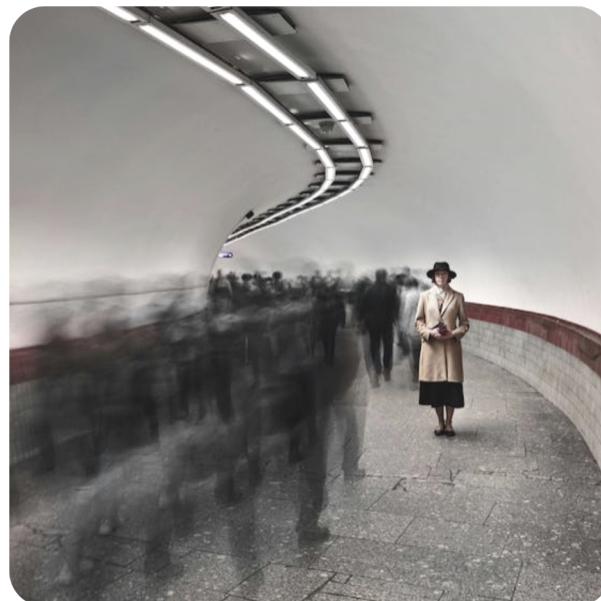


Digital boarding pass

30 sec



An
absurd
situation

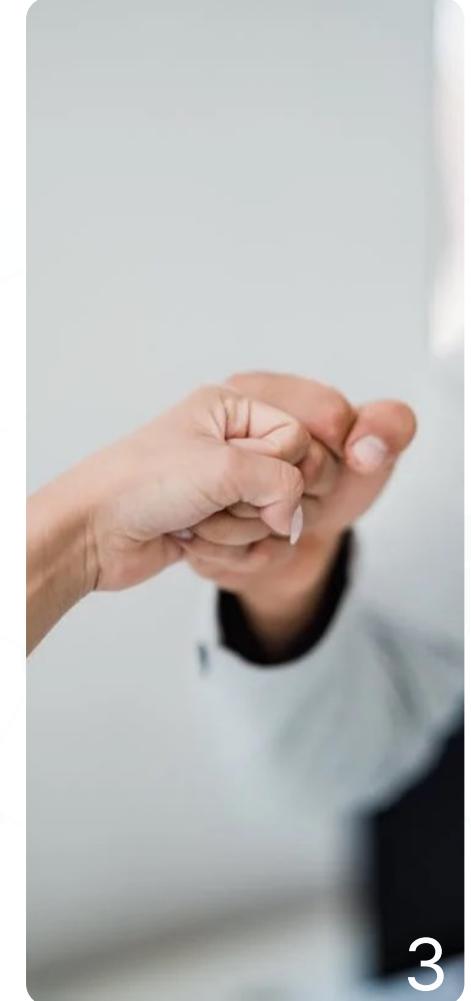
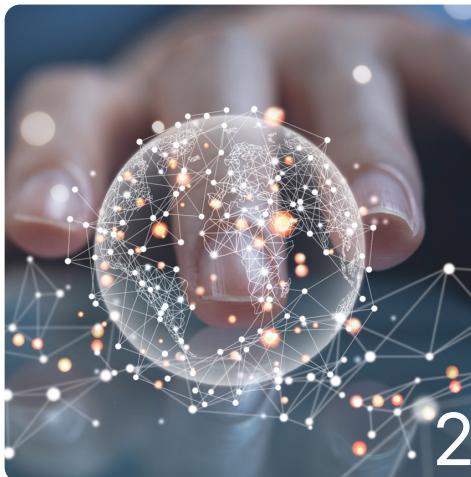


In this age of fast digital progress
the health sector is lagging behind.



Challenges:

1. Finding information
2. Structure
3. Safe sharing





BACK TO THE FUTURE II

PART

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



IT'S A BUMMER MAN

“...but we still use PDFs in healthcare.”

FAQIR

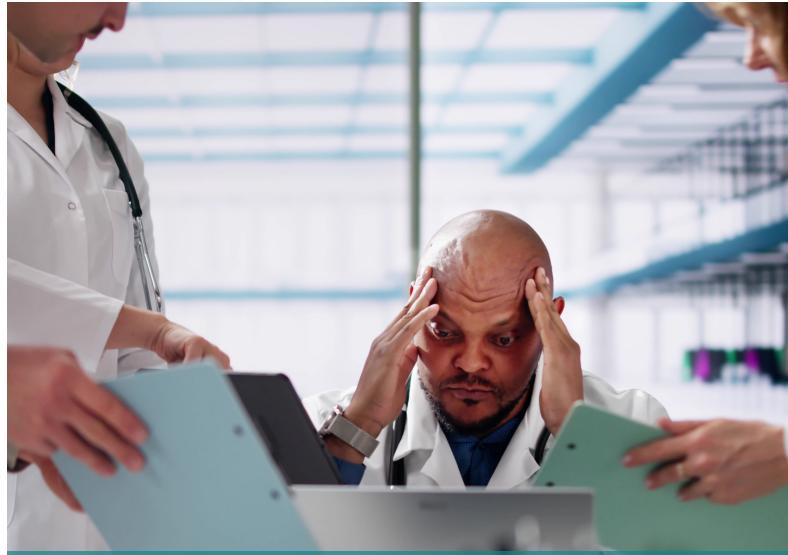


Emergency doctors

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.



Get a glimpse of a patient's health history ...



Download one per one
Unstructured data & PDFs
A lot of manual work
No comprehensive overview

1. A search interface for 'Instelling van auteur' (Author institution) showing a list of hospitals like AZ Diest, AZ Monica Antwerpen, etc.

2. A detailed document viewer showing a complex medical report with multiple sections and tables.

3. A screenshot of a clinical dashboard or timeline showing a sequence of medical events with icons for US, CR, CT, etc.

4. A search interface for 'Resultaten van' (Results of) showing a list of lab test results with columns for date, type, and location.

5. A list of appointment logs with specific entries circled in red, such as 'Anesthesieverbaal' and 'Anesthesieverbaal'.

6. A large, complex timeline or dashboard showing a dense grid of medical events across multiple days.

7. A screenshot of a clinical dashboard showing a timeline of events with various medical specialties listed.

8. A table titled 'Afhaalmedicatie' (Medications to be picked up) listing medications with columns for date, title, and location.



... or a patient population?





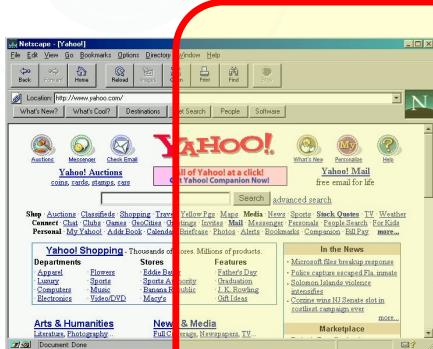
Geneticists & rare disease specialists

- 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?



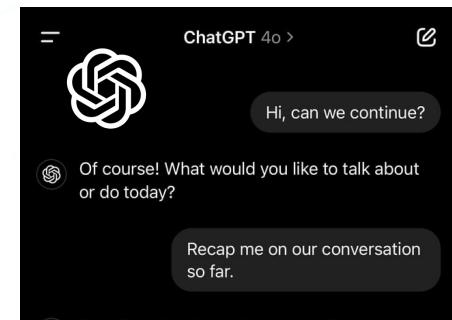
1994: Yahoo Directory Launches
~3,000 Websites
Browse categories
Manually curated



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



2012: Google's Knowledge Graph
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2024: ChatGPT DeepSeek & Grok
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AI-driven Search Conversations

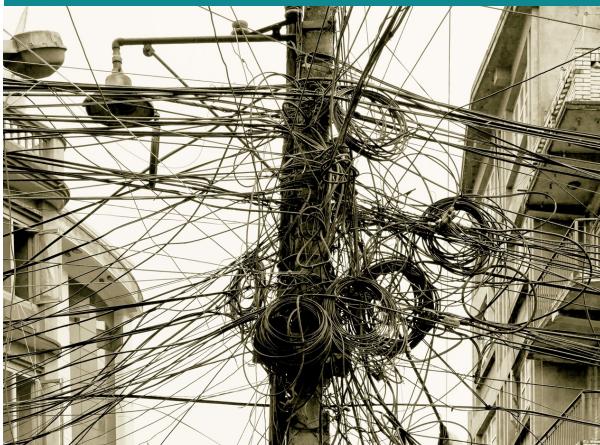


Handling health data is challenging due to **fragmented sources**, **privacy laws**, and **inconsistent standards**, making **integration and secure sharing difficult** for research and policy.



Researchers & Policy Makers

Disconnected
Data



Data
Interoperability



Data
Avalanche





Researchers & Policy Makers

**Small-scale
registries**
**€500K-
€1M**

**18 - 36
months**

**Larger
registries**
€1M- €5M

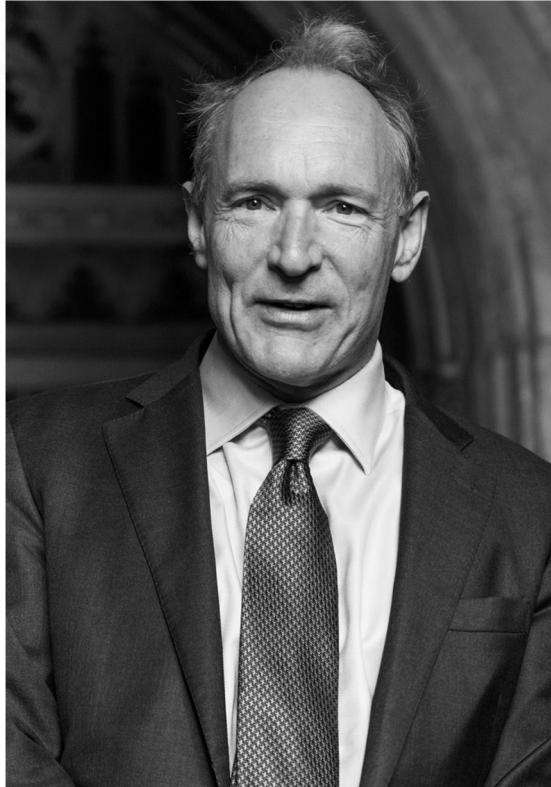
1. Initial Planning & Stakeholder Engagement: 3–6 months
2. Regulatory Approval and Ethical Clearances: 6–12 months
3. Technical Development (Infrastructure & Data Systems): 6–18 months
4. Pilot Testing and Data Collection: 3–12 months

Personal Data Vaults



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

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



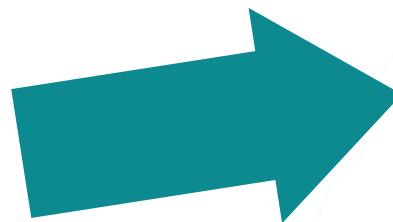
SOLID aims to
restore choice
by separating
data from apps.

Sir Tim Berners-Lee



Separating Data from Apps

From unstructured &
fragmented data with
NO CONTROL

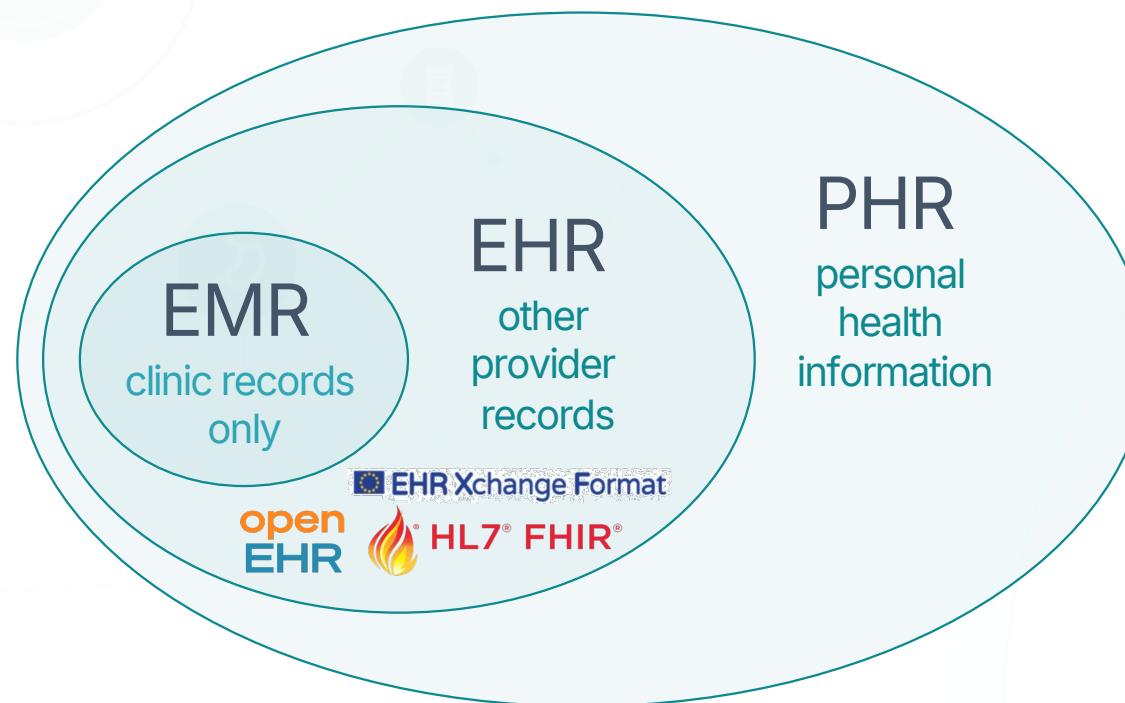


EMPOWERED
towards structured &
hyper-connected data

From Strings to Things



Include Personal Health Data



INTERNATIONAL
STANDARDS
COMMON
DATA MODELS
PERSONAL HEALTH
RECORDS

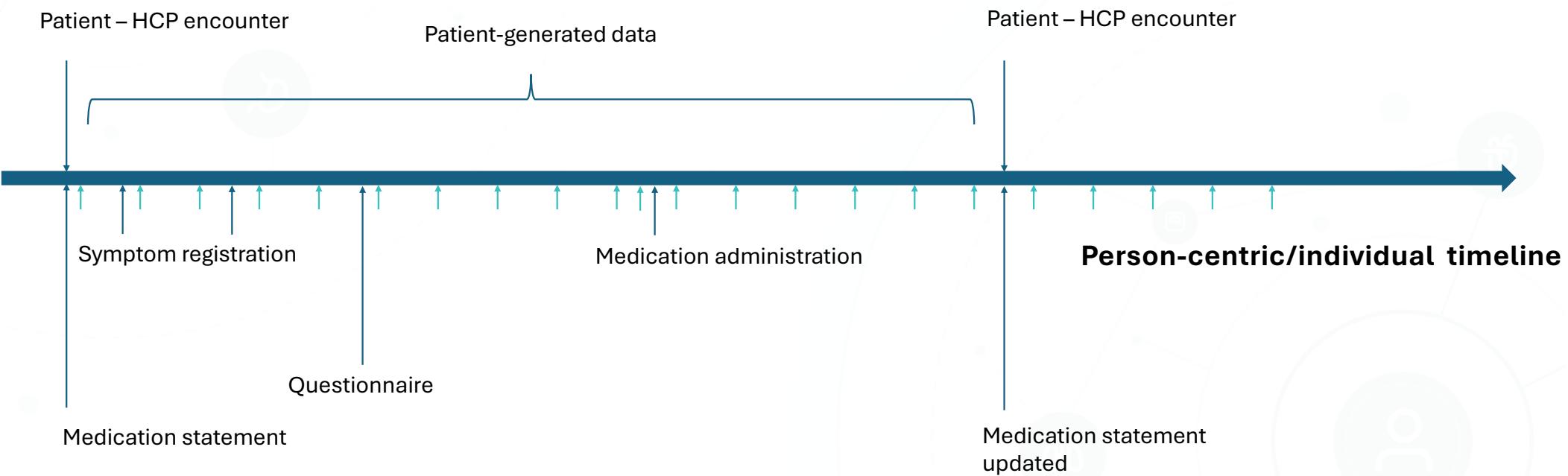


Leading healthcare
terminology, worldwide





Personal Health Record Data Model





PACSOI

PATIENT CENTRIC SOLID

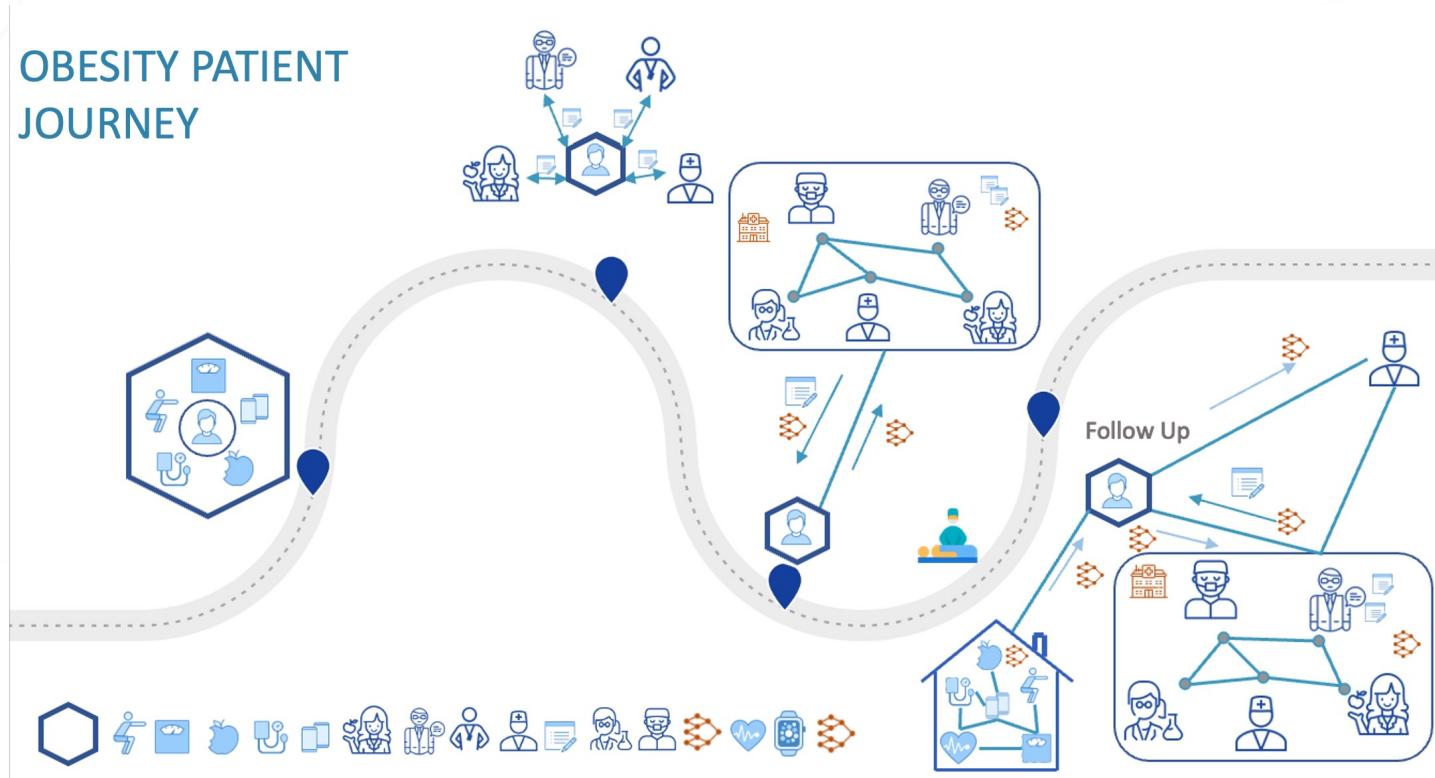


A CONTRARIO





PACSOI: Patient Centric Solid





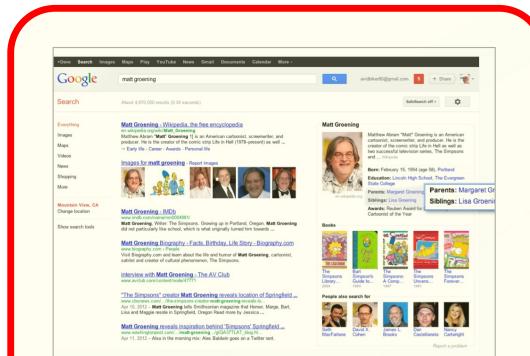
Knowledge Graphs in HealthCare



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Browse categories
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Indexing



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More semantic Knowledge Graph



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~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





FAQIR



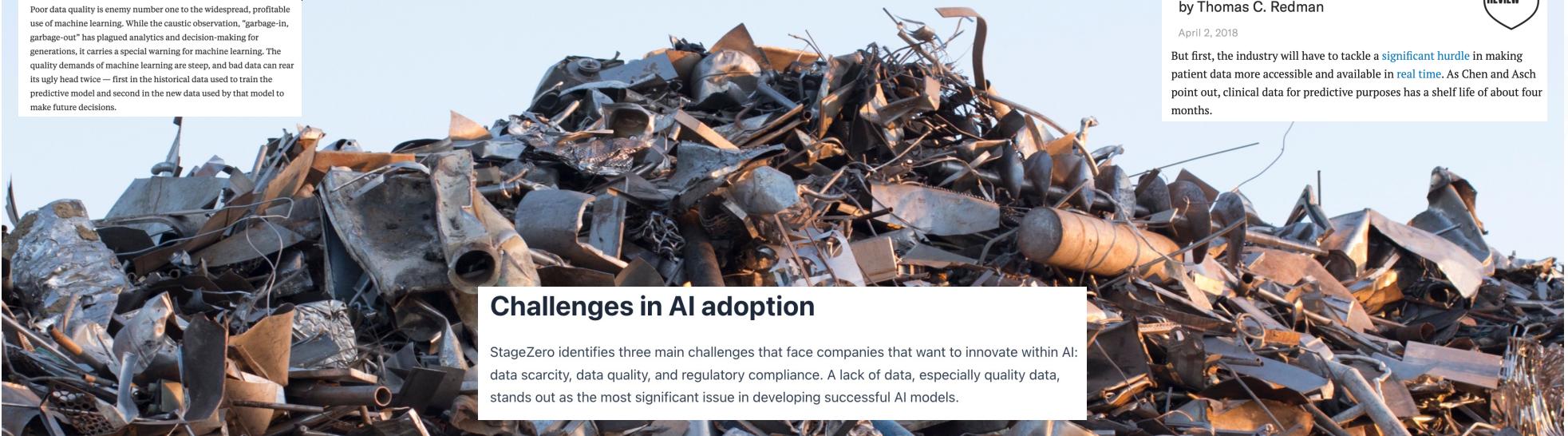
Garbage In - Garbage Out

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.



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.

Analytics And Data Science

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

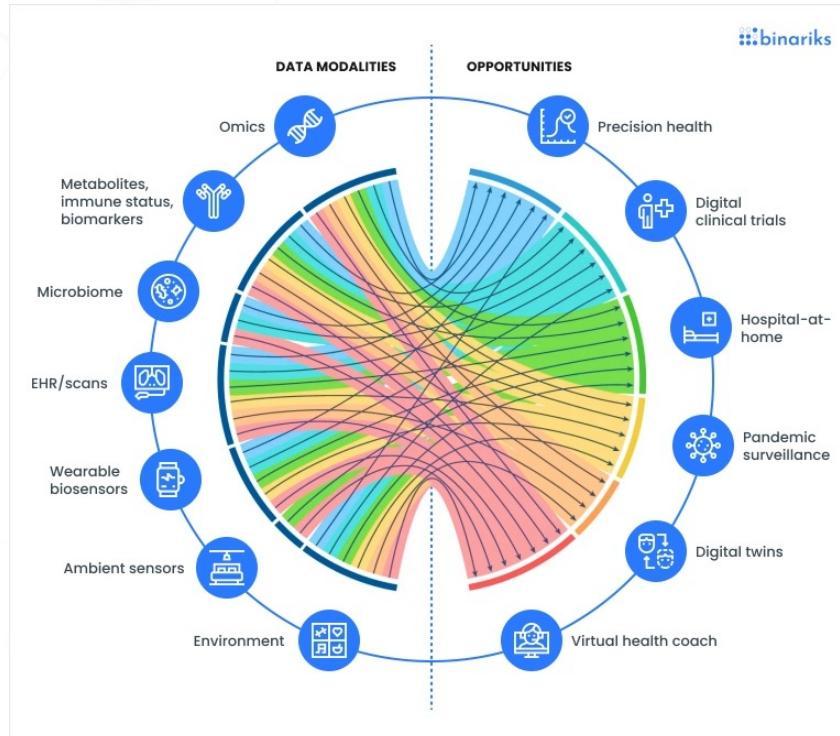
by Thomas C. Redman

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.



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.



FAQIR



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 · 542

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

Reuters

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

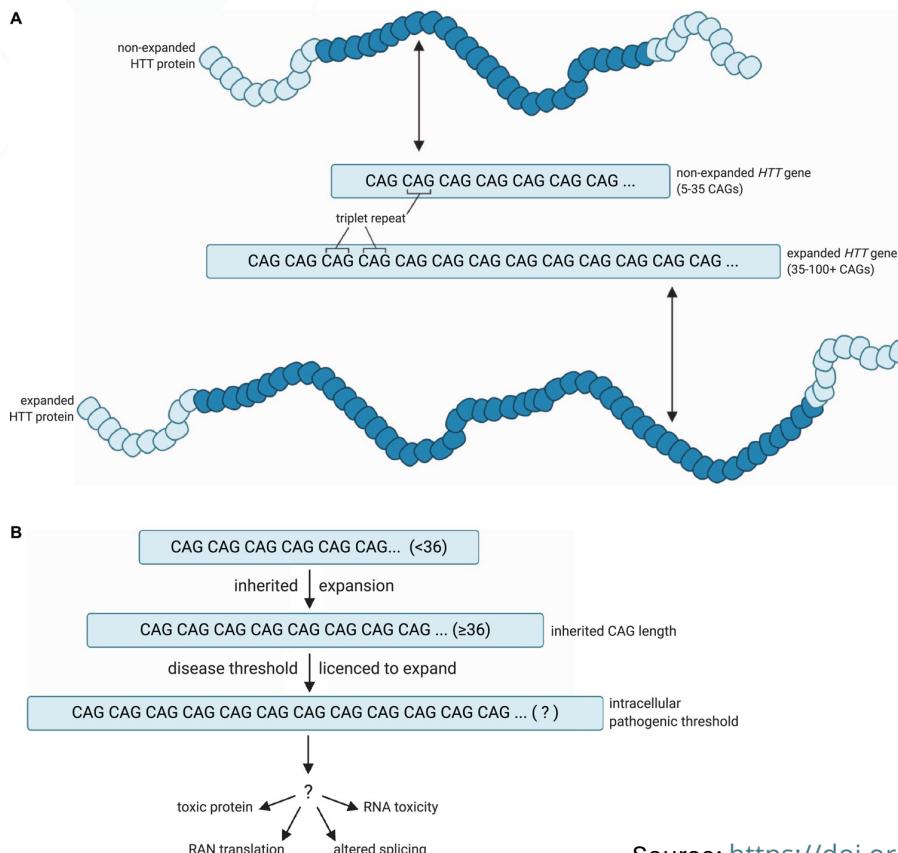
Digital technologies are helping to guide early clinical interventions and assessments of treatment



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



Propagation of impact

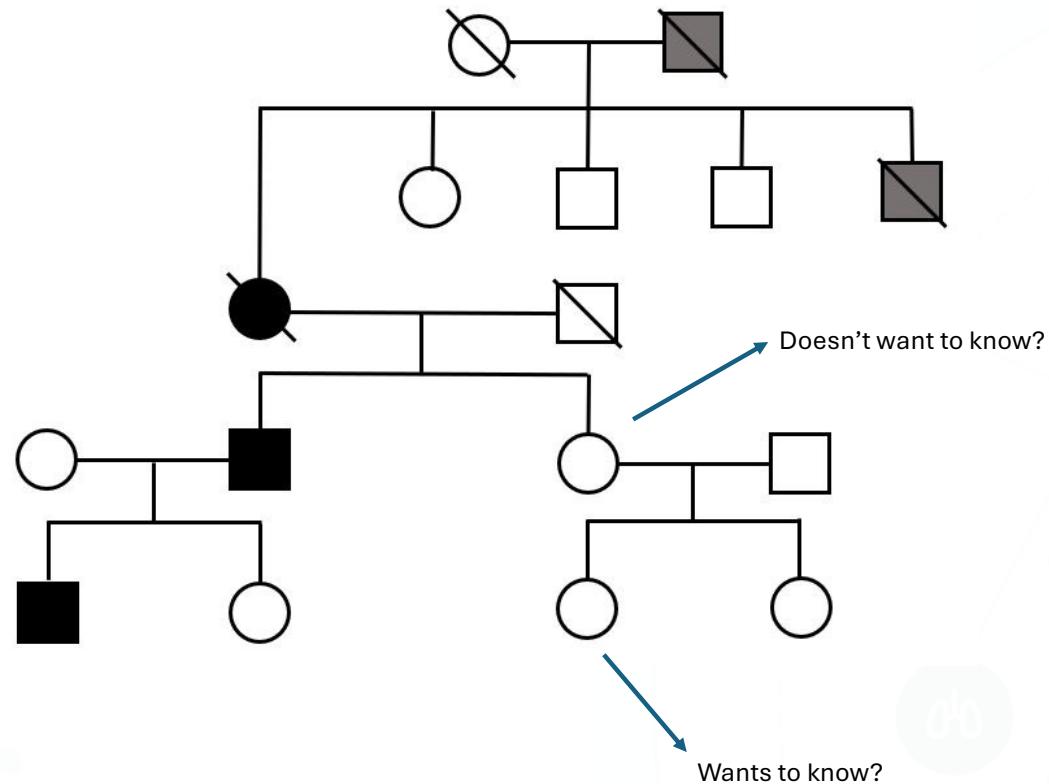


Source: <https://lonestarneurology.net/blog/what-is-huntingtons-disease/>

Source: <https://doi.org/10.3233/IHD-200445>



The right to know or not?





Choose what to share and how long

Alles selecteren		Geen acties van toepassing		
	Aanmaakdatum	Titel	Zorglocatie	
<input type="checkbox"/>	26 mrt 2024 09:13:15	Link naar Cozo	general/practice	
<input type="checkbox"/>	4 jul 2023 10:31:13	pharmaceuticalmedicationscheme	general/practice	
<input type="checkbox"/>	16 dec 2019 13:53:00	1 consult radikale	general/practice	
<input type="checkbox"/>	25 feb 2019 15:25:00	Algemeen-biopsie Pdf	general/practice	
<input type="checkbox"/>	20 feb 2019 16:21:00	turp	general/practice	
<input type="checkbox"/>	20 feb 2019 16:18:00	Anesthesieverslag	general/practice	
<input type="checkbox"/>	15 jan 2018 10:05:00	1 cons gewone prostaat	general/practice	
<input type="checkbox"/>	16 jan 2017 10:14:00	1 cons gewone prostaat	general/practice	
<input type="checkbox"/>	14 sep 2016 16:59:00	Urologie	general/practice	
<input type="checkbox"/>	14 sep 2016 16:13:00	vaporisatie prostaat zonder hormonotherapie	general/practice	
<input type="checkbox"/>	14 sep 2016 16:12:00	Anesthesieverslag	general/practice	

Actie	Verwijderen	Wijzigen
actie	<input type="text"/>	
Additional Text [geen] voedende alegorische tekst als actie	<input type="text"/>	
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2007-12-08	voedende	afname
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	Dossier Gegevens Labo voorstrift: 16/11/23 staalname: 16/11/23 ref.: 819.232.455 ontvogt: 16/11/23 13:19	Dossier Info patient: [REDACTED] uk.ref.: [REDACTED] print: 26/03/24 09:52 status: Volledig
PATIENT  		
HERT13A HERT13B HERT13F		
Analyse	819.232.455 16/11/23	Eenheid Referentie
HEMATOLOGIE		
Betrekking na 1 uur*	2	nm n/a
Erytrocyten	5.13	$\times 10^6/\mu\text{L}$ 9.0-11.5
Hemoglobine	16.3	g/dL 13.4 - 16.5
Hemocrit	45.0	% 39.7 - 49.3
HCV	87.7	fL 85.2 - 96.0



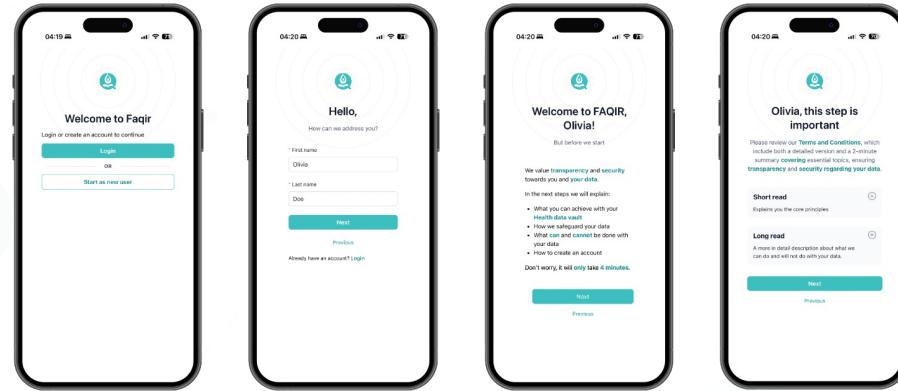
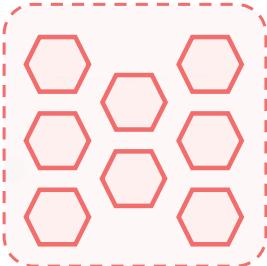
How Does it Work?



FAQIR Ecosystem

1

Create personal
data vaults

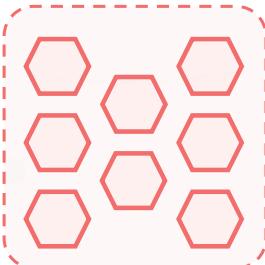




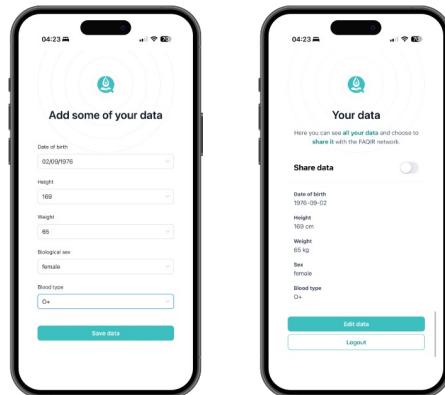
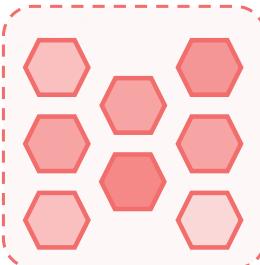
FAQIR Ecosystem



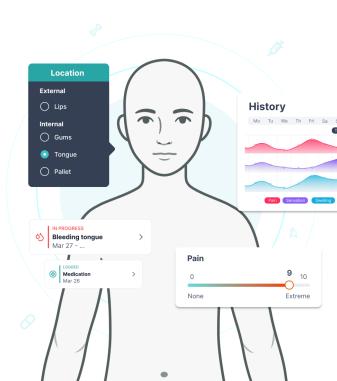
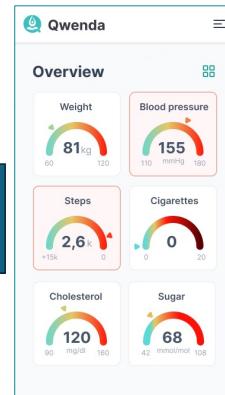
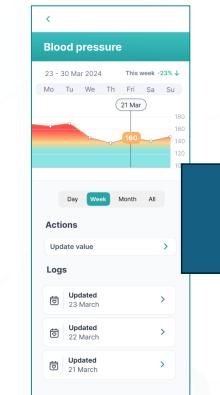
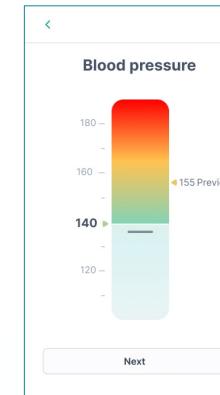
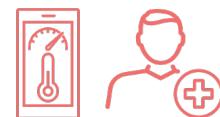
Create personal
data vaults



Initialize
test data



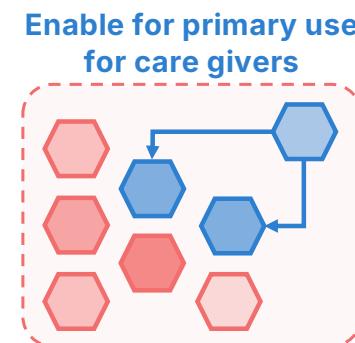
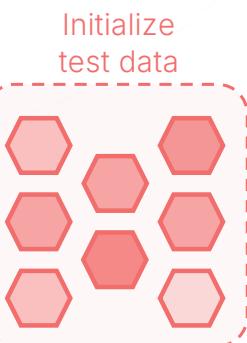
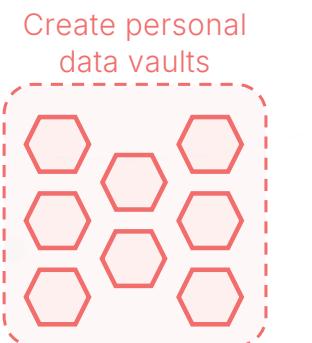
Automatic or manual
entry of health events,
medical encounters,
medications, QOLs ...





FAQIR Ecosystem

1 2 3

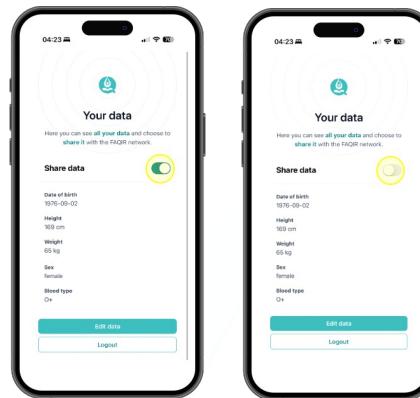
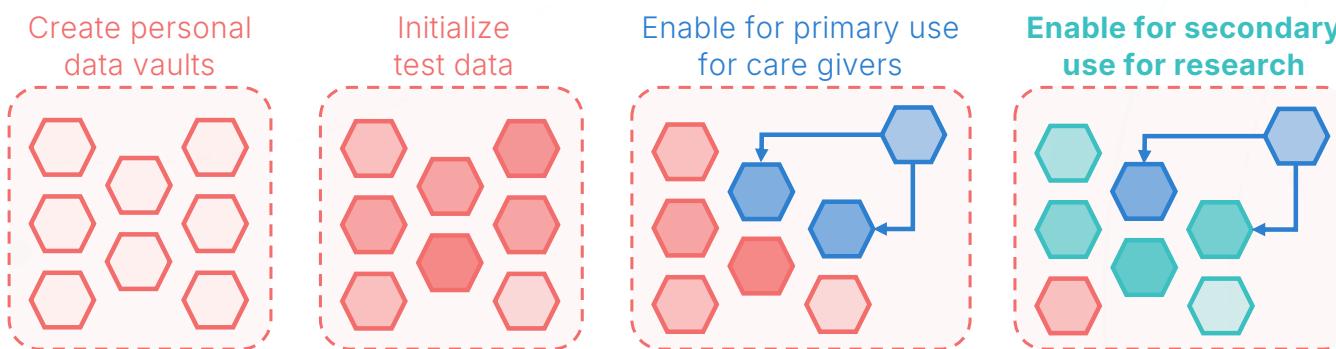


Web application for healthcare professionals for data dashboarding of individuals and groups





FAQIR Ecosystem

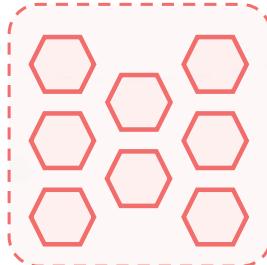




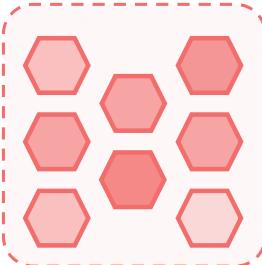
FAQIR Ecosystem



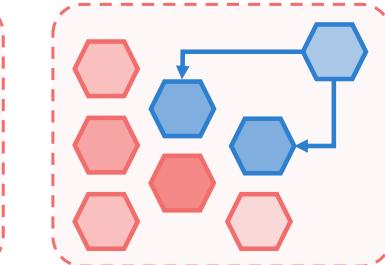
Create personal
data vaults



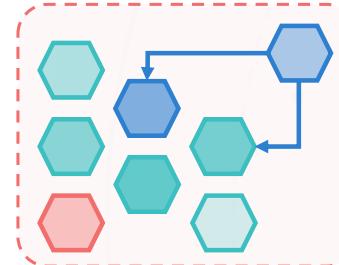
Initialize
test data



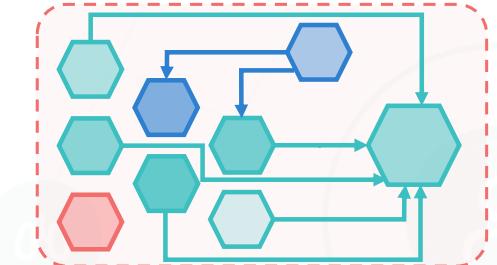
Enable for primary use
for care givers



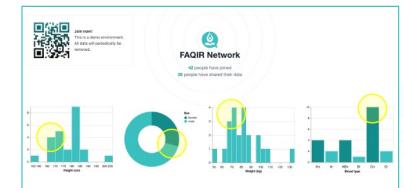
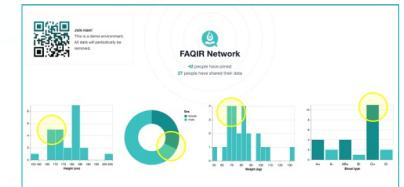
Enable for secondary
use for research



**Create data aggregator vault
& process data request**



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



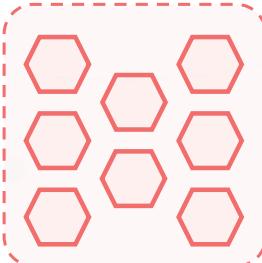


FAQIR Ecosystem

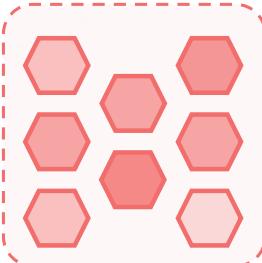
- 1
- 2
- 3
- 4
- 5
- 6

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

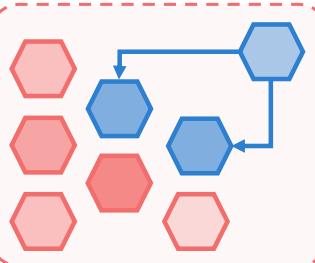
Create personal data vaults



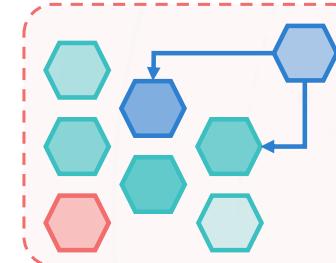
Initialize test data



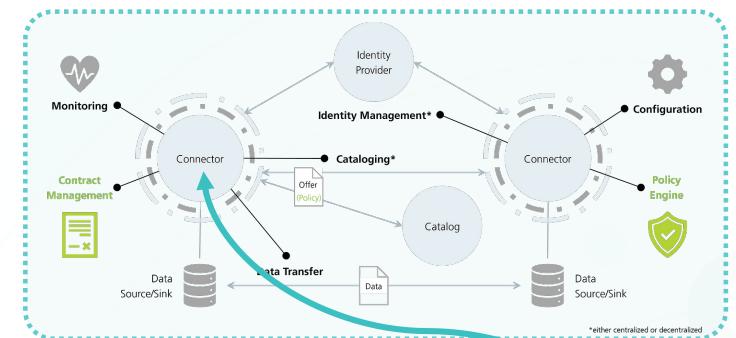
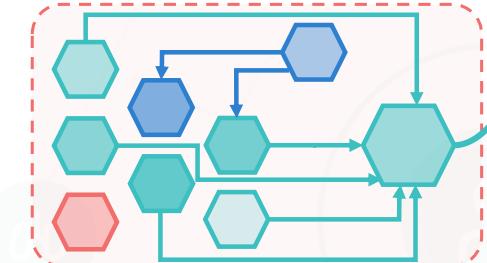
Enable for primary use for care givers



Enable for secondary use for research

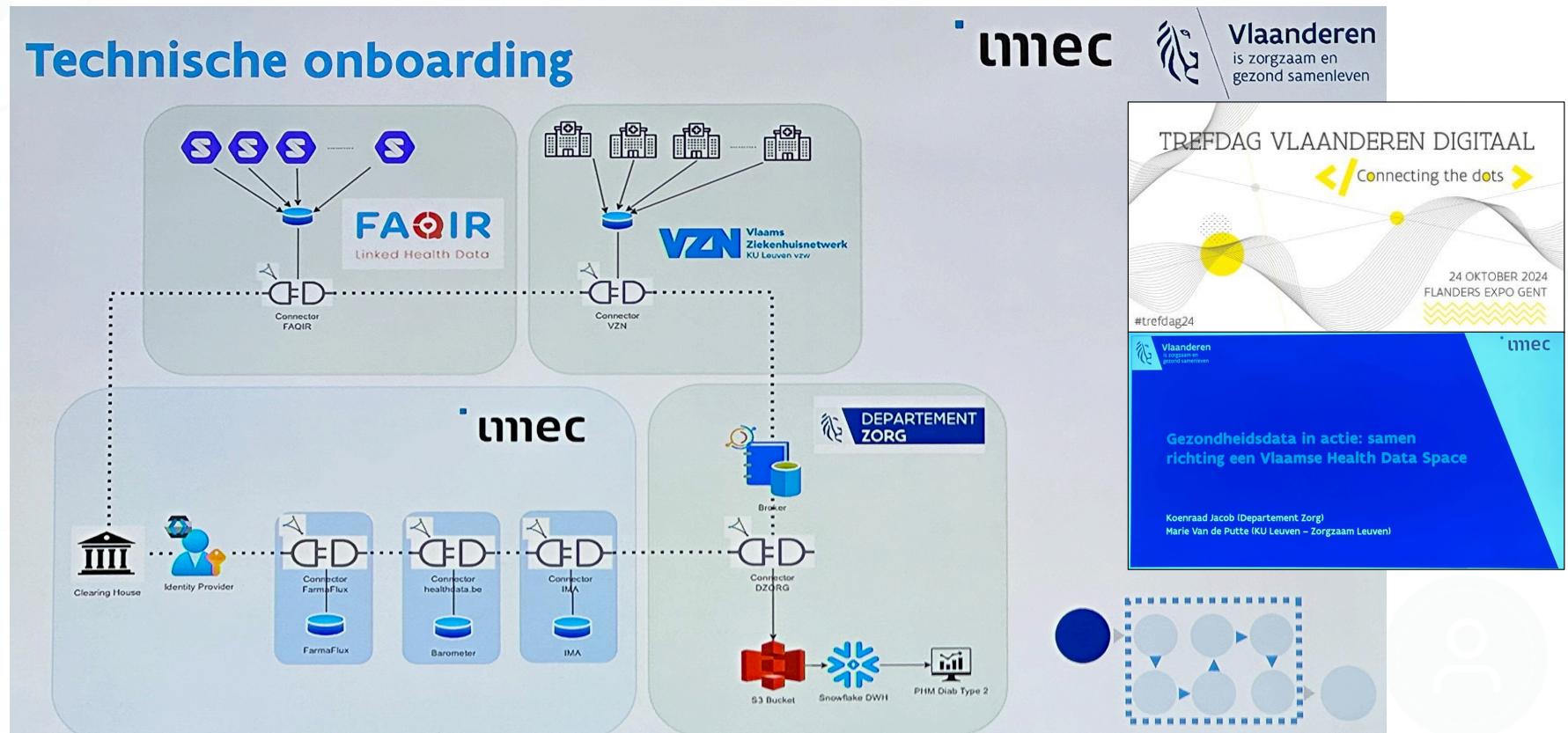


Create data aggregator vault & process data request





SOLID – FAQIR – IMEC – Flanders

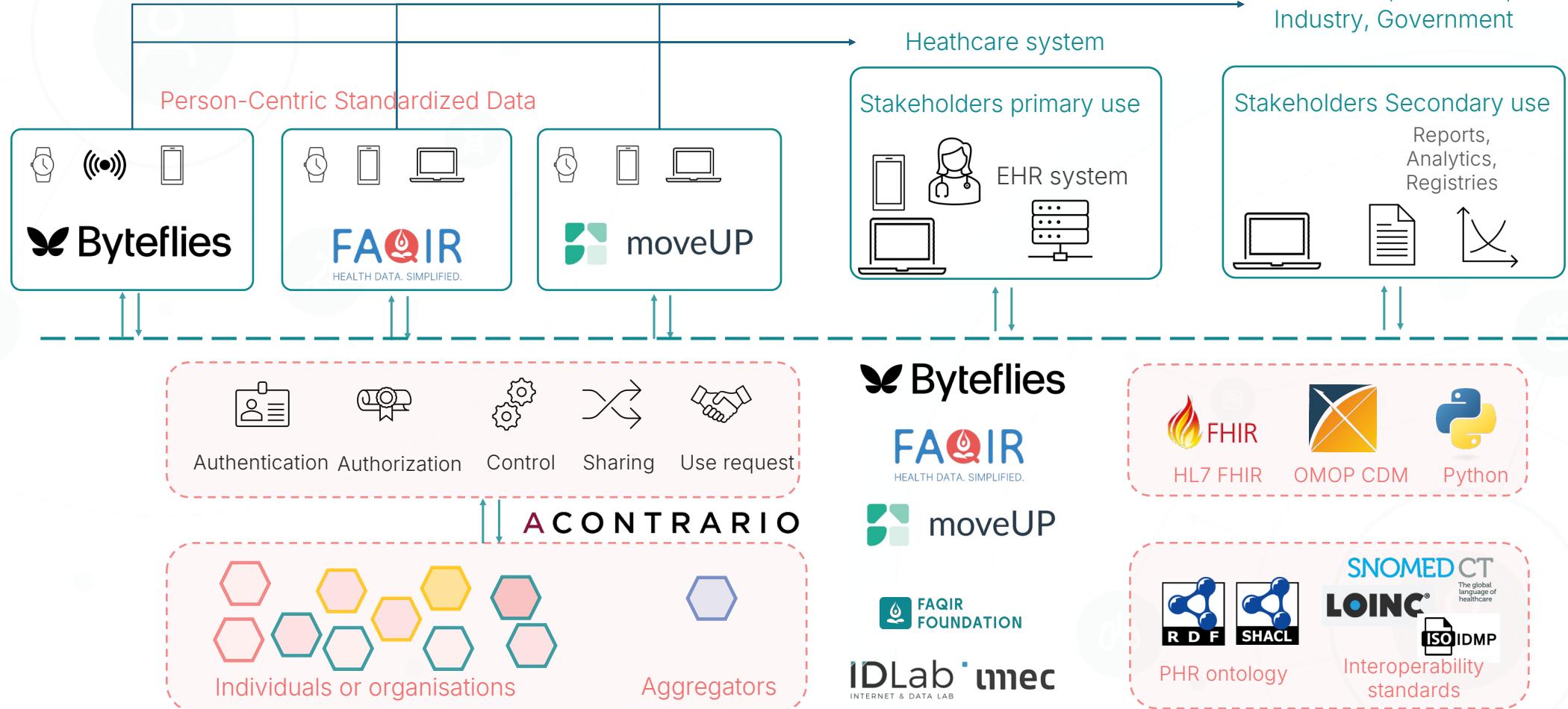




PACSOI Ecosystem

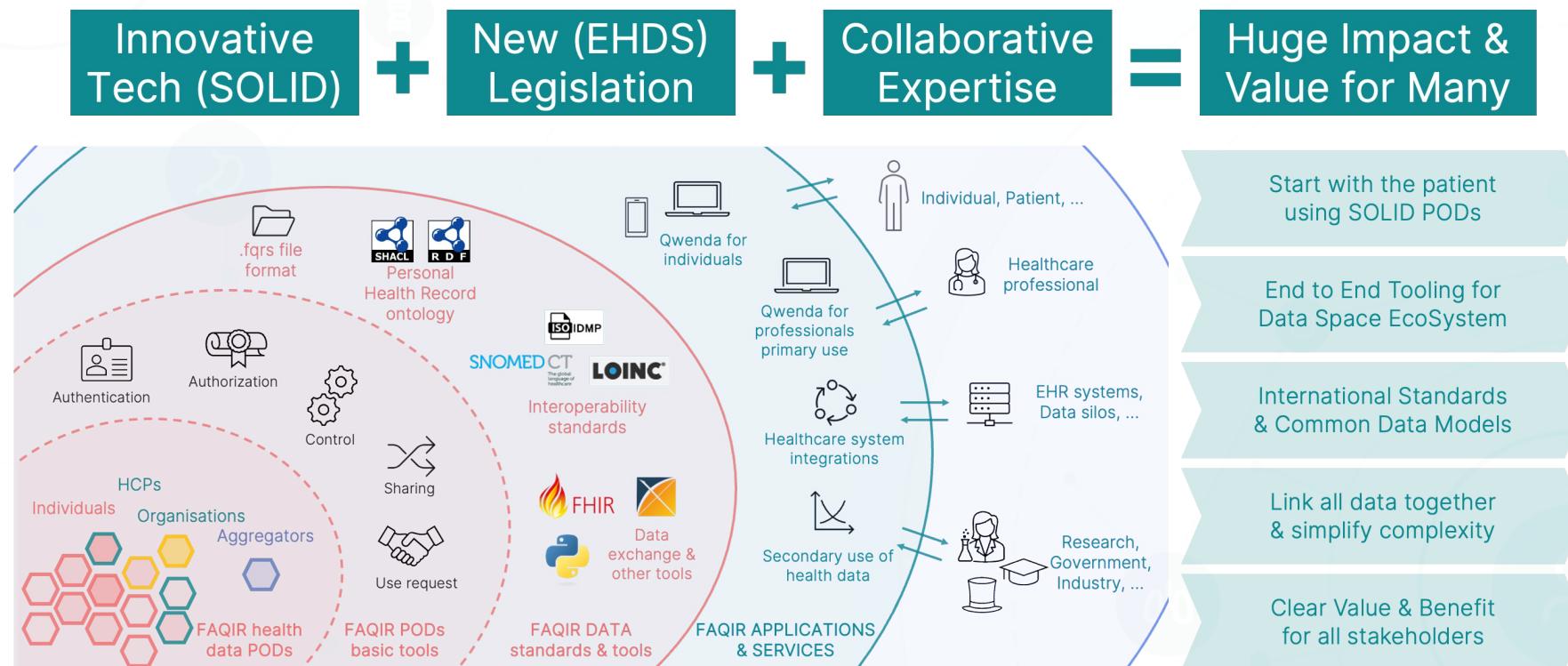


Healthcare, Research,
Industry, Government





Bringing it all Together





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





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HEALTH DATA ... SIMPLIFIED

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Fac Engineering & Architecture
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A CONTRARIO

 GHENT
UNIVERSITY

 Byteflies

 IDLab
INTERNET & DATA LAB

 moveUP

Questions?

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+32 486 739 129



2025-04-24