

Public Private Partnership

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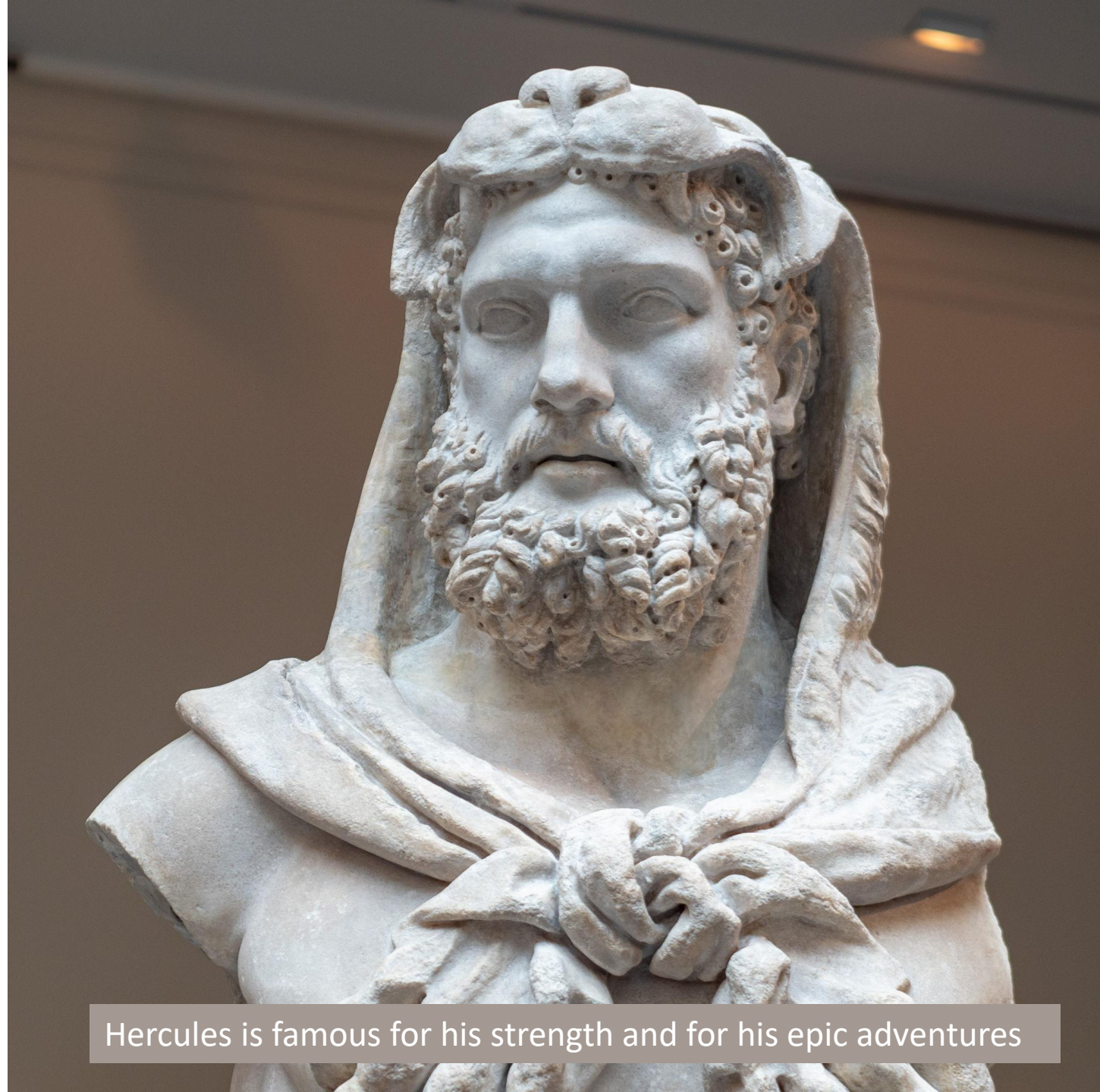
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Market Access NL

Johnson & Johnson Innovative Medicine

HERACLES is a collaboration between IKNL, Stichting Radboud UMC, UMC Groningen, AstraZeneca BV, Janssen-Cilag BV, Roche Nederland BV, Almende BV, Linksight BV, Pharmo Institute NV, SURF BV, CZ Zorgverzekeringen NV, Stichting Olijf and TNO.



Data for Secondary use and AI!

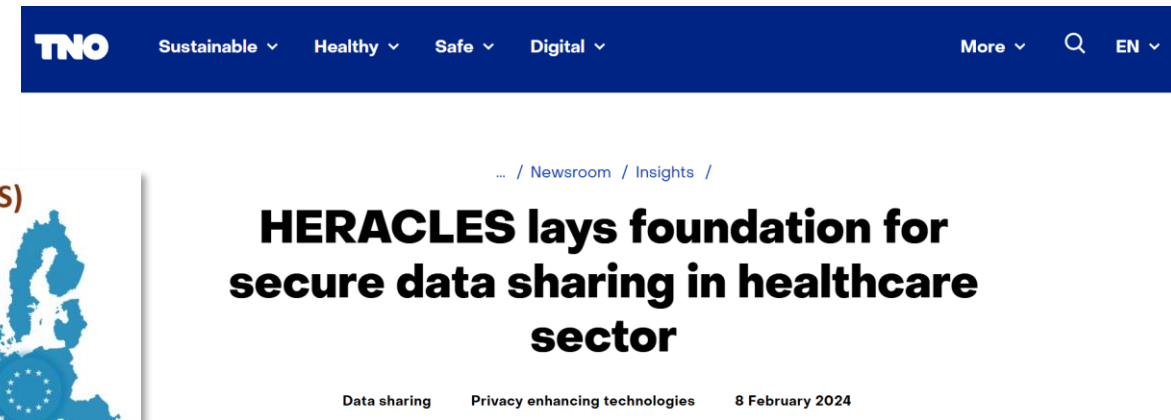
nice but Health Data are not just data.....



Health Data are telling you how healthy you are! These data can be misused easily by researchers, governments and private sector without clear legislation, secure data sharing and Privacy Enhanced Technologies (PET's).

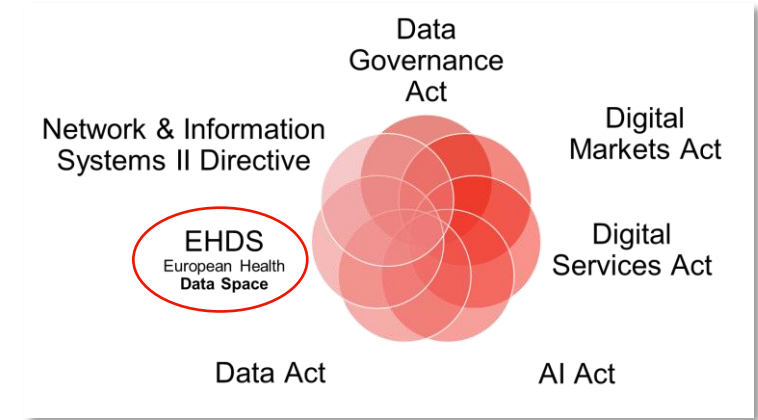
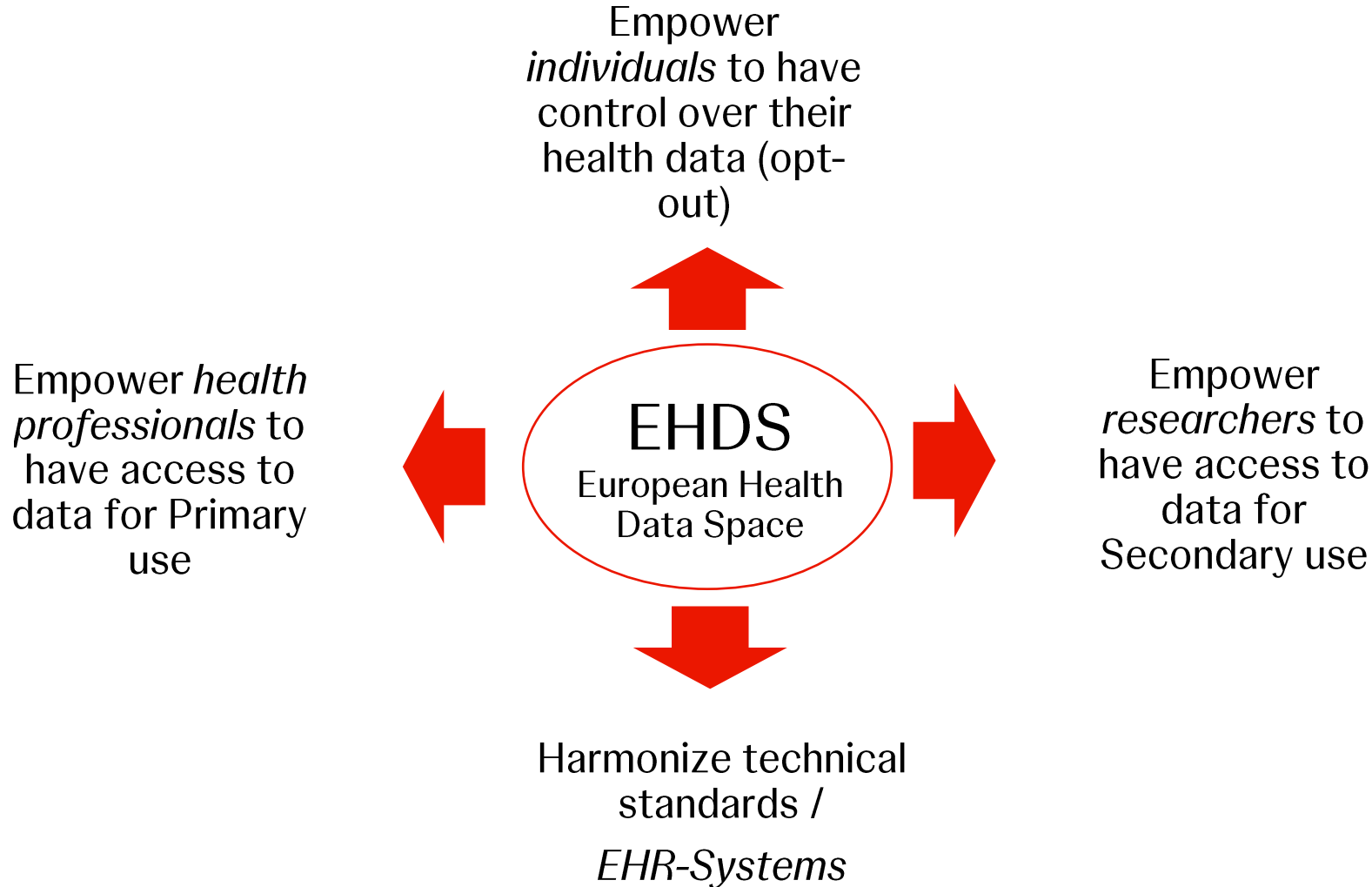
- Researchers could use your health data and publish the results without having your explicit consent!
- Insurance companies and authorities could categorize the population for purposes you never asked for!
- Your Health Data could be used by Big Tech for their business model!

Therefor we need guardrails like EHDS
and
Secure Data Sharing



The 4 chapters of the new EU-Legislation should

empower patients, make health care more efficient and strengthen innovation

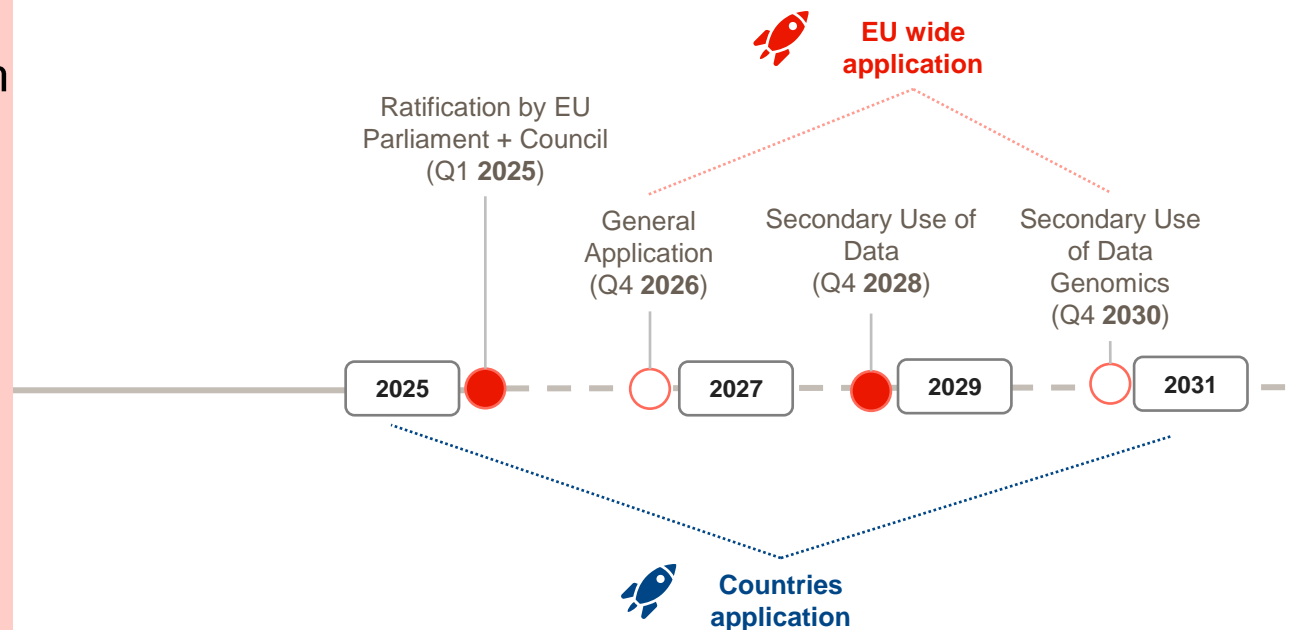


EHDS Timeline

Forthcoming EU application while countries already build their national governance

The EHDS is a game changing moment for health in Europe and for the care our citizens receive. [...] it will unleash the potential of health data for the development of innovative and lifesaving treatments and devices [...] all with strong data protection and security safeguards.

Health Commissioner
Kyriakides

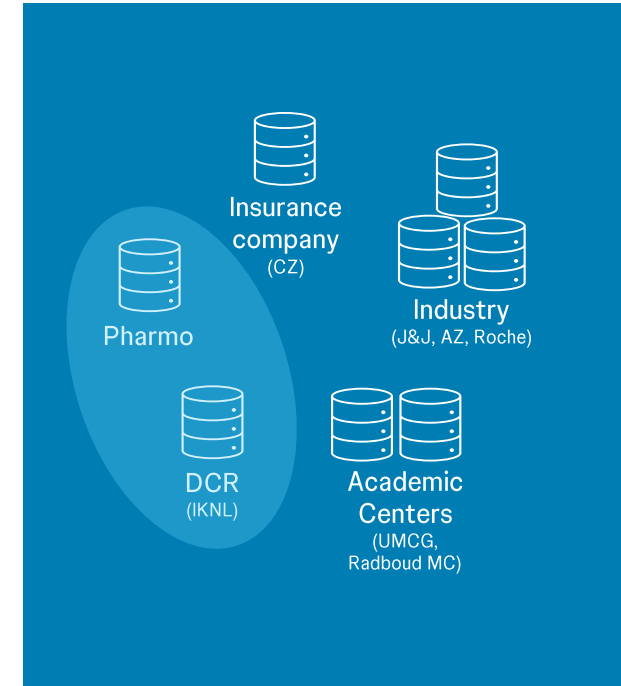


HERACLES

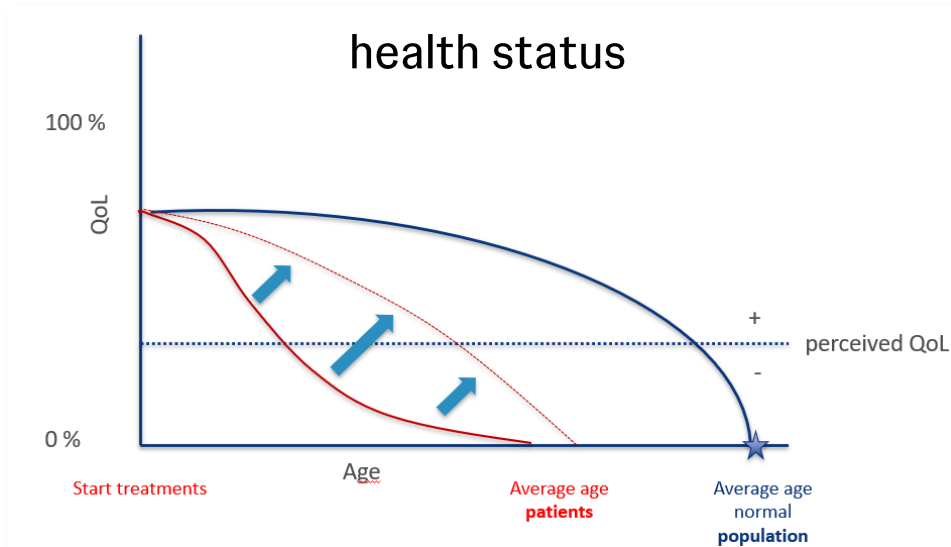
Public Private Partnership

In the HERACLES project, 13 public and private parties are jointly conducting research into two types of cancer. The challenge here is to merge different datasets without putting privacy-sensitive data at risk. Data spaces and privacy-enhancing technologies (PETs) help make this possible. Working with health data continues to require human input, however, as became clear during the first year of the project in which the foundations for secure data sharing were laid.

HERACLES Data Space as network of data holders with health data, data of clinical trials and financial data



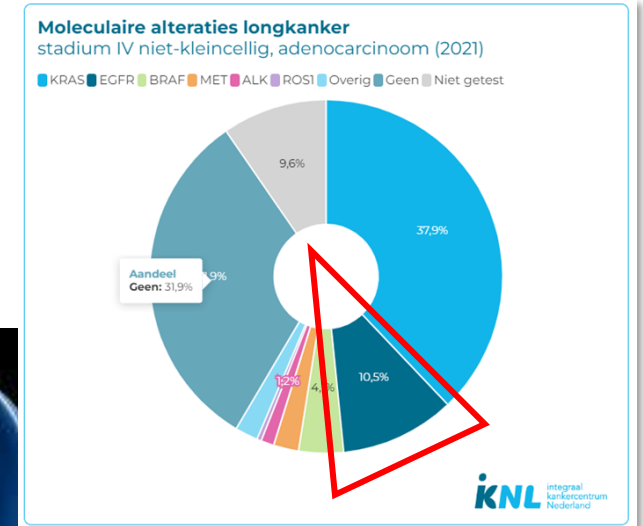
Use-case (why is this so interesting for J&J Innovative Medicine?)



Added value of innovative medicine?

Which indicators and symptoms are correlated with the development of lung cancer and could be decisive to screen the population for early detection?

Lung Cancer



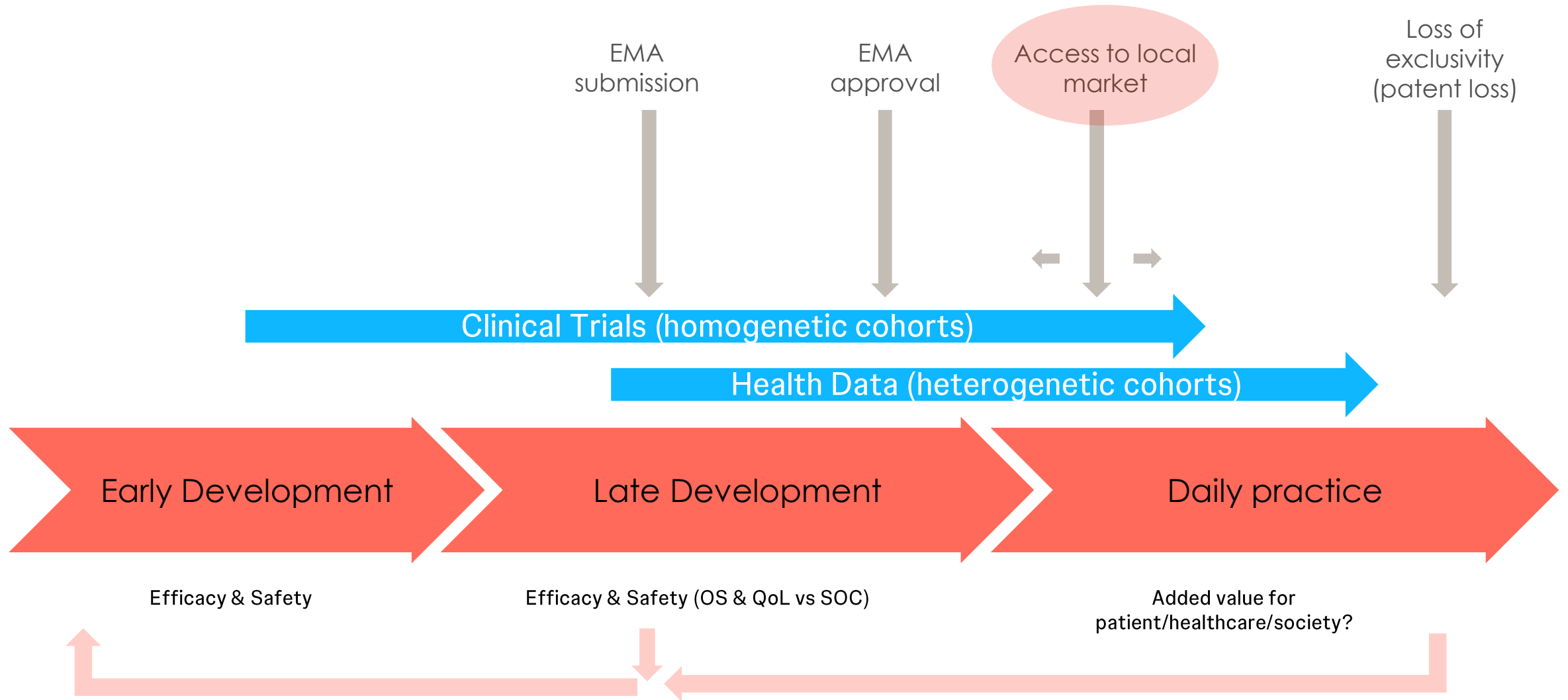
"I expect the work of physicians to change substantially in the coming years. Specialists will then be able to offer people a more tailored treatment plan."

Michel van den Heuvel, Pulmonologist and Head of department at UMCU

Early Development



Daily Practice



Health Data for research!

Trials, Registries and Claims Databases

multiple data entry

- Registries (PLCRC/DICA/NKR for colon cancer)
- Product monitoring
- Phase IV trials
- Drug Access Protocol (DAP)
- Drug Rediscovery Protocol (DRUP)

high administrative burden, high cost per RQ, standardized data in centralized data base, not ready for cross border reuse

Innovation by
improved
legislation
(EHDS) and
technology

Secondary Use Health Data

single data entry

- Data Spaces with Federated Learning (FL*), computing is with pseudonymized or anonymized decentralized health data
- Data Spaces with Multi Party Computation (MPC*), computing is with encrypted centralized health data
- Data Spaces with Health Data in secure data environments (HDAB's), computing is with pseudonymized or anonymized centralized health data

low administrative burden, low cost per RQ, standardized data at the source, ready for cross-border reuse

* Privacy Enhanced Technology (PET)

Carwash for Health Data to overcome GIGO

Data cleaning

- Combine the right data-items on patient level
- Leave out the records with too much missing data to analyze
-



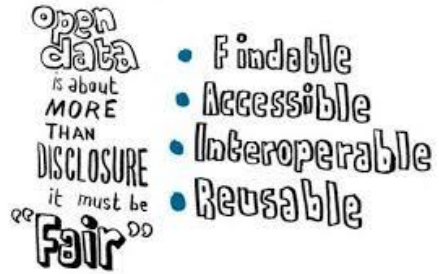
Carwash of Heracles

Data cleaning

- Combine the right data-items on patient level
- Leave out the records with too much missing data to analyze
-



What we need!

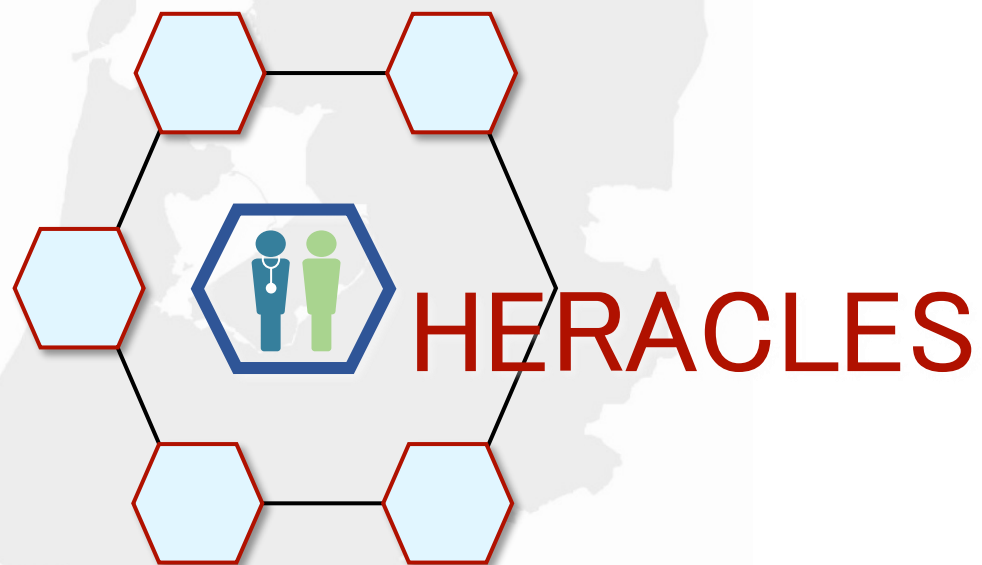


- Standardized Health Data at the source (data entry)
- Identifier for subjects
- Data Solidarity





**BENNETT
INSTITUTE**
FOR APPLIED
DATA SCIENCE



‘Data is like nuclear
material, not oil’

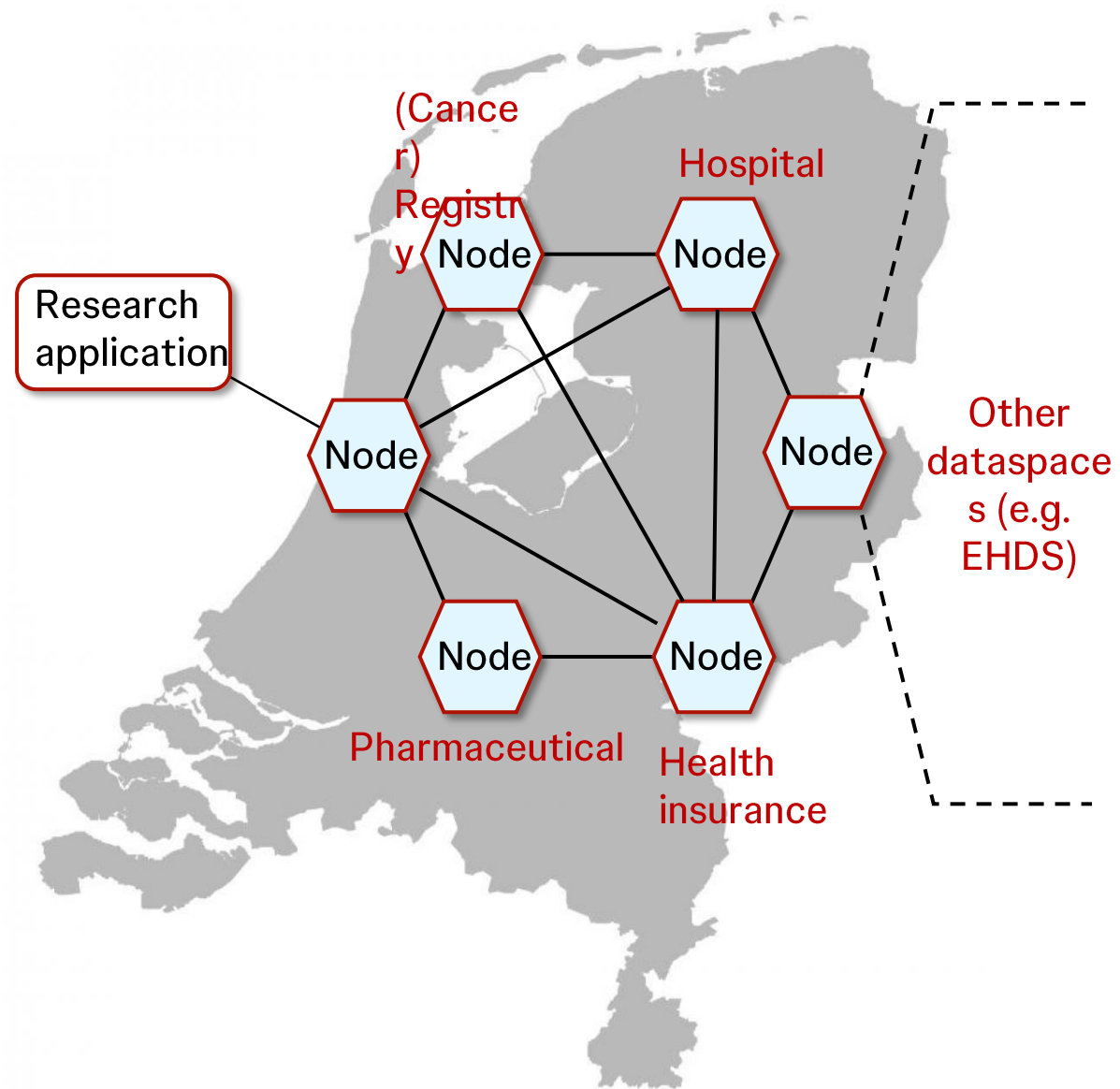
Common failure modes

- Single monolithic projects where all components of the job are given to one huge team, so that sight of non-delivery in any individual component is obstructed.
- Monolithic projects becoming politically powerful and too big to fail.
- Lack of accountability and oversight, leading to bad incentives.
- Lack of technical skills and knowledge in senior leadership.
- Giving the task to teams with technical skills but in adjacent domains, like statistics or research, rather than platform delivery.
- Giving the task to large unfocused public sector organisations with multiple other tasks, who are then: distracted by other tasks; able to divert attention on failing platforms by delivering on other tasks; tempted to divert funds to other work in their organisation; prioritise their own requirements in the new platform over other users' needs.
- Wishing away the core problem of “data management”, the preparation of raw data into analysis-ready datasets.

How to act?

- Don't build one single huge database
- Do build a network of connected data centres
- Don't give all the tasks to one huge monolithic delivery organization
- Do build a network of standalone services, stitched together into a platform





High level infrastructure process flow

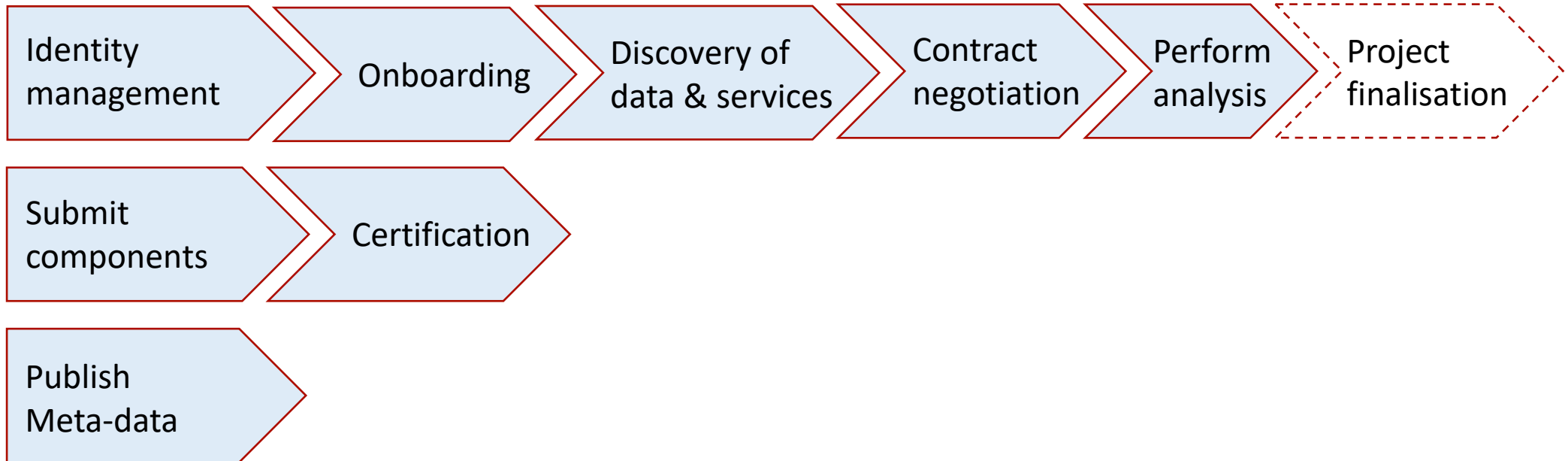
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EHDS



EHDS: "Data discovery" "Data permit" "Data use"

HERACLES



Learnings

- Data standardization is essential, also for the application of MPC and FDN
- Data linkage is essential for a learning health care system → data space
- Data quality is often lacking, no focus on patient journeys
- High costs at start and therefore the added value should be shown fast
- Data spaces should fit the (inter)national context (HDAB)
- Acceptance by all stakeholders is key (citizens, data controllers)

The TNO logo is displayed in a bold, black, sans-serif font.The J&J logo is displayed in a bold, red, sans-serif font.

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