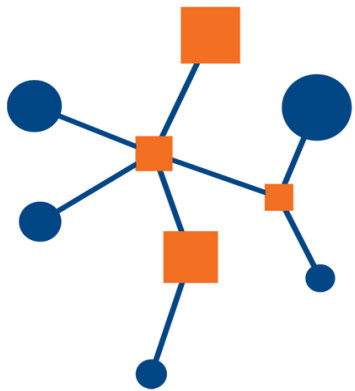


# Strategic Panel 1: Research Infrastructures

# Jens Habermann

BBMRI-ERIC and European Life Science Research Infrastructures

# An Introduction to BBMRI-ERIC & LS RI Cluster



## **BBMRI-ERIC<sup>®</sup>**

The European research infrastructure  
for biobanking and biomolecular  
resources in health and life sciences

EDITH-CSA Meeting  
15/16 July 2024

Prof. Jens K. Habermann  
Director General BBMRI-ERIC

# LIFE SCIENCE CLUSTER

## WHO ARE WE?

- **14 European LS-RIs** providing access to world-class facilities, experts, biological samples, instruments, services & data
- **Mission:** support cutting-edge science by offering access to resources and services to academia and industry
- **Capacity building:** offering training, education, consultation, standardization, harmonization
- **Largest cluster** within currently 28 ERICs that work together in ERIC Forum 2 project



# ERIC FORUM 2 PROJECT

ERIC Forum Project 2.0 addresses **key topics for ERIC implementation and operation**, such as:

- ERIC Regulation implementation
- ERICs and European Science Policy & Research Strategy
- Internationalisation and engagement with 3<sup>rd</sup> countries
- Greening of RIs
- Personnel-related challenges
- Cooperation with ERICs-to-be



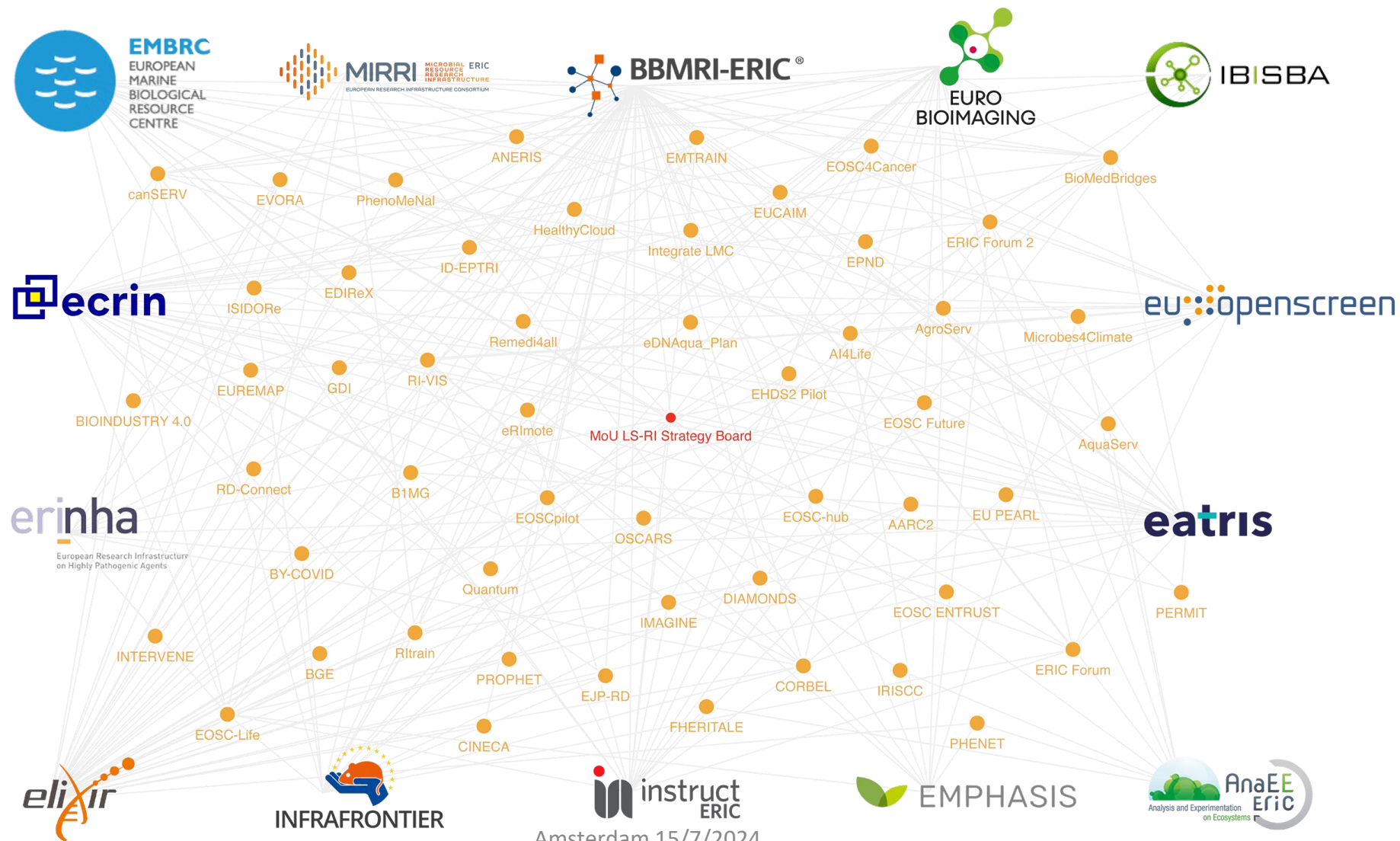
## STRENGTHS OF ERIC MODEL FOR LS RIs INCLUDING BBMRI

- Possibilities for a strong contribution to EU research policy priorities across health and life sciences (and cross-clusters)
- Pooling of European and Member State resources with a pan-European alignment on health research and related topics:
  - HOWEVER: Need for EU policy-makers to encourage new initiatives to cooperate more with existing ERICs/RIs – avoiding defragmentation of RI landscape is a must!
- Collaboration on a range of activities via ERIC Forum 2 project and beyond; LS RIs/ERICs being a strategic asset to structure European Research Area





# LIFE SCIENCE CLUSTER COLLABORATIONS FOR IMPACT



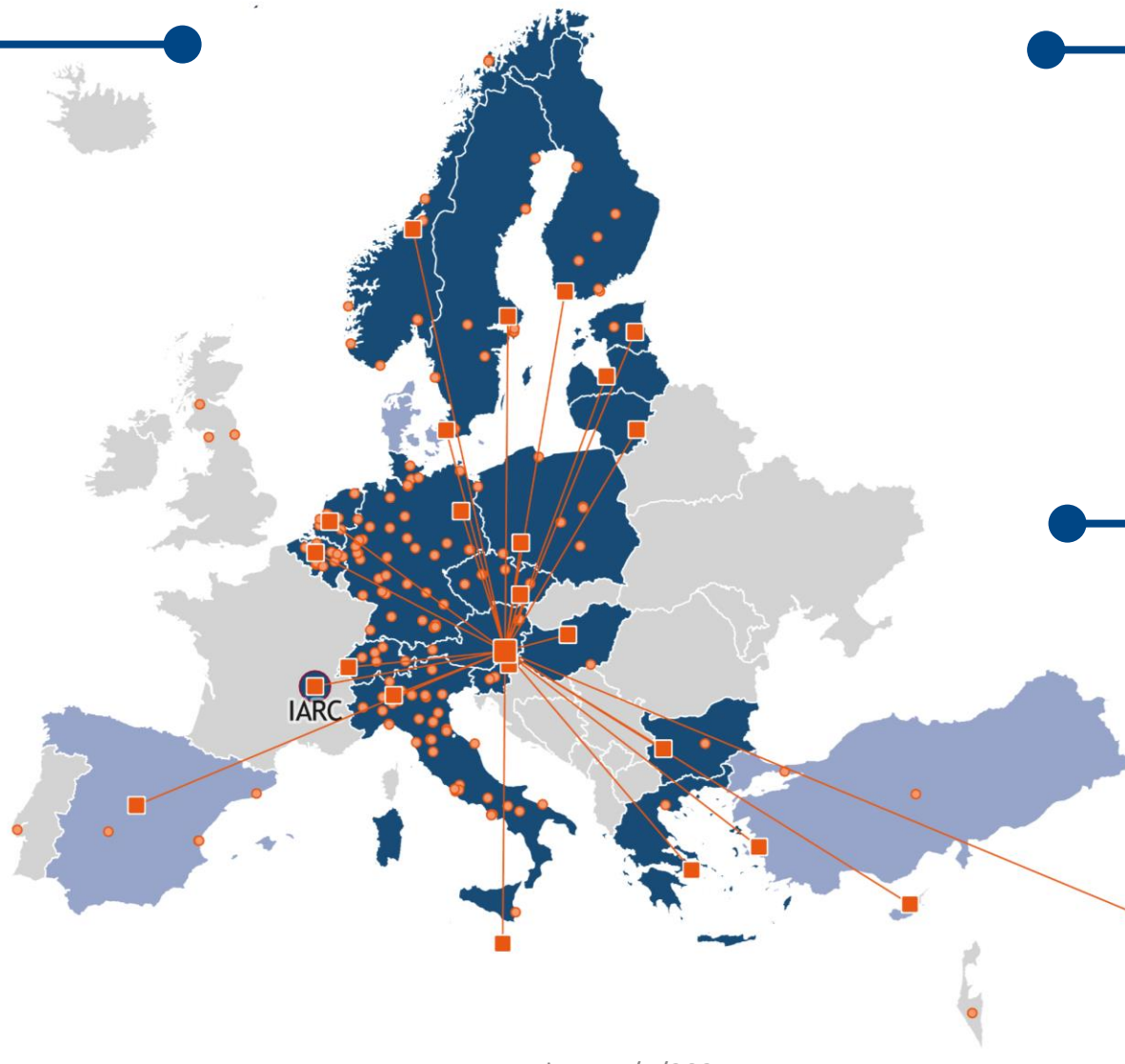
# BBMRI-ERIC

## A DISTRIBUTED LS RI

20

### MEMBER STATES

Austria  
Belgium  
Bulgaria  
Cyprus  
Czech Republic  
Estonia  
Finland  
Germany  
Greece  
Hungary  
Italy  
Latvia  
Lithuania  
Malta  
Netherlands  
Norway  
Poland  
Slovenia  
Sweden  
Switzerland



5

### OBSERVERS

Denmark  
IARC/WHO  
Qatar  
Spain  
Turkey

### COMMUNITY

> 400 biobanks  
+ Affiliated partners  
24 National Nodes +  
IARC/WHO  
1 Headquarter  
3 Biotech Expert Centres  
ELSI, QM, IT Expert Groups



## ONE HEALTH

### DISTINCT BIOBANK TYPES

INTEGRATED  
HEALTHCARE

POPULATION  
BASED

HUMAN  
BIOMONITORING

ENVIRONMENT

PLANT  
DIVERSITY

DOMESTIC AND  
WILDLIFE

Amsterdam 15/7/2024



### VARIOUS REQUIREMENTS

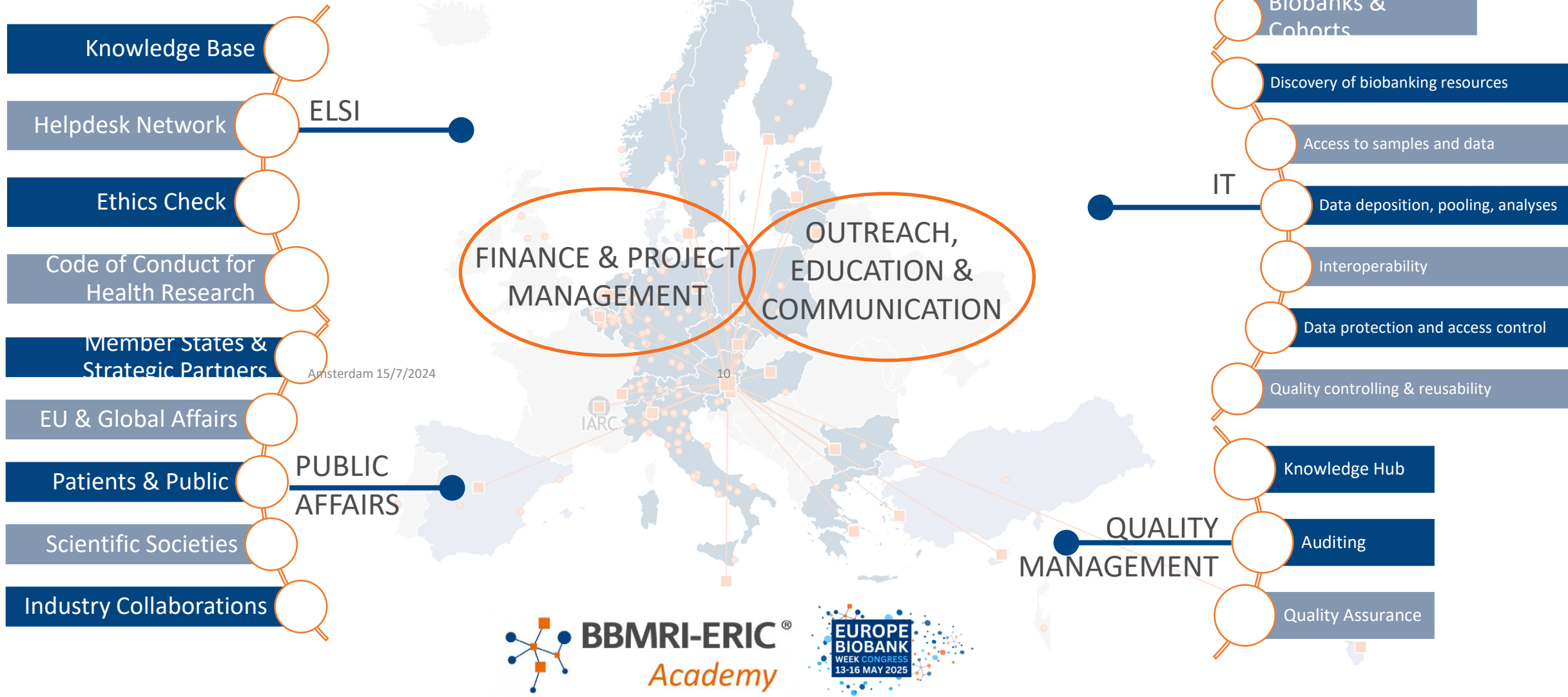
BIOBANKING OPERATIONS  
AND DEVELOPMENT (BBD)

ETHICAL, LEGAL AND SOCIETAL  
ISSUES (ELSI)

QUALITY MANAGEMENT (QM)

INFORMATION TECHNOLOGY  
INFRASTRUCTURE (IT)

# BBMRI-ERIC: ENABLING HEALTH & LIFE SCIENCES RESEARCH & DEVELOPMENT



# OPERATING IN THE SENSITIVE HEALTH DATA DOMAIN TO ADVANCE PERSONALISED MEDICINE

CANCER

Screening

Prevention

Therapy Monitoring

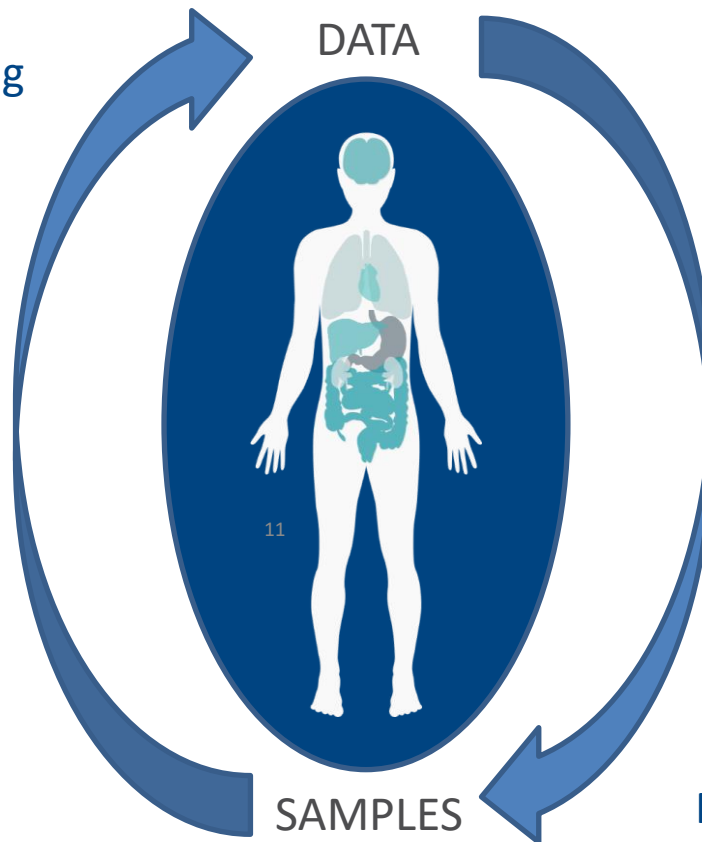
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Surveillance

ANY OTHER DISEASES

Education

DATA



Early detection

(Molecular) Diagnostics

(Minimal invasive) Treatment

Systems Medicine &  
Artificial Intelligence

Therapy  
Prediction

Prognosis

RARE +  
PAEDIATRIC  
DISEASES

COVID-19 +  
INFECTIOUS  
DISEASES



# THE LOCAL BIOBANK ECOSYSTEM

HEALTHCARE INTEGRATED BIOBANKS = DATA INTEGRATION CENTRES

CLINICAL  
CARE



TRANSLATIONAL  
RESEARCH



*In support of*

- Patient Empowerment
- Citizen Engagement
- Clinical Trials
- Molecular Tumour Boards

Patient recruitment &  
**CONSENT**

Sample & Data  
**COLLECTION**

Sample & Data  
**PROCESSING**

Sample & Data  
**STORAGE**

Biobank Information  
Technology (IT) System

Sample & Data **SEARCH,  
REQUESTS, & TRANSFER**

*Enabling access to*

- Sample, clinical, follow-up, and research DATA
- Biomolecular Resources (e.g., OMICs technology)
- Imaging
- Bioinformatics & AI tools

QM-Certified & internationally connected

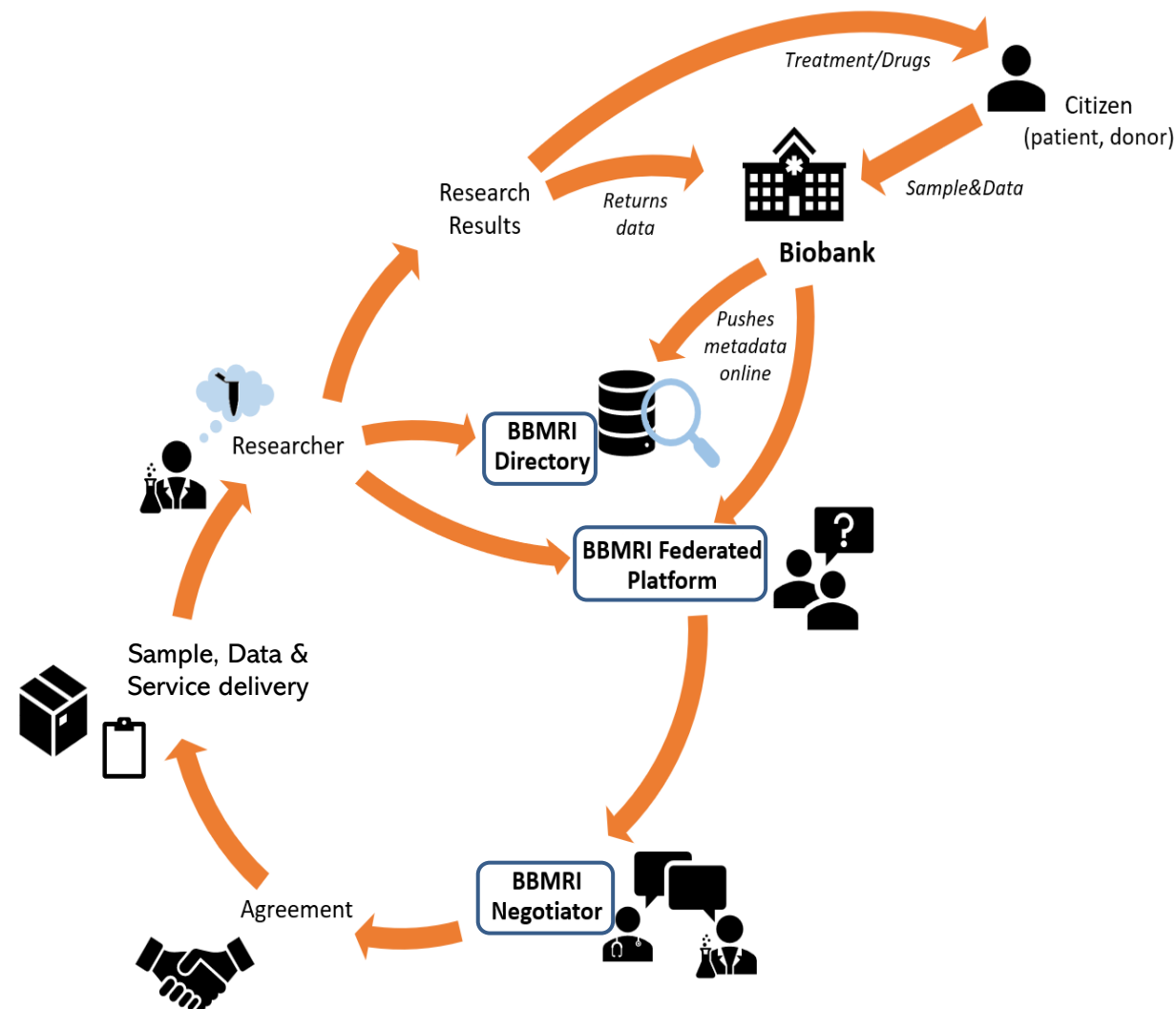
# BBMRI-ERIC ACCESS PIPELINE

- ✓ **BBMRI Directory** largest biobank catalogue worldwide:  
 > 400 biobanks with  
 5.1 Mio. patients  
 across 32 countries and  
 9,000 users in 2023.

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- ✓ **Federated Platform** features 450,000 donors with 200,000 genomes across 10 EU countries today

13





# BBMRI-ERIC ACCESS PIPELINE TO > 400 BIOBANKS/INSTITUTES

## AVAILABLE DATA TYPES

- **7,834 distinct OMOP variables** of clinical phenotype data (incl. biochemical measurements)
- **> 10PB whole slide imaging data** or radiology imaging data
- **OMICs data** (genomics **incl. >200K genomes**, proteomics, metabolomics, etc.)
- possibly other types of data (surveys, genealogy, ...)
- Connection to **national registries** (e.g., survival data, harmonized data on specific diseases)
- **Patient-provided data** (part of patient empowerment)





# BBMRI-ERIC CONNECTING RELEVANT EU INITIATIVES WHILE STRUCTURING ERA

1

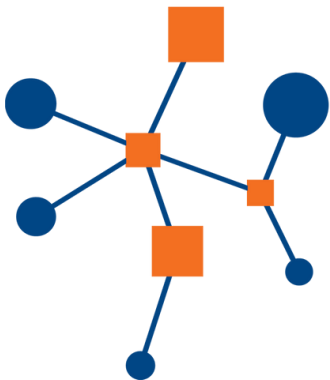
**Cancer Mission & Beating Cancer Plan** (e.g., canSERV, EOSC4Cancer, UNCAN.eu)

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**Pandemic Preparedness**  
(e.g., ISIDORE, BY-COVID, BBMRI-Directory)

2

25 COMPLETED PROJECTS  
23 ACTIVE



**European Health Data Space (EHDS)**

**EOSC Association** e.g., Corbel, EOSC-Life, EOSC Future, BBMRI membership)

**European Partnerships in Horizon Europe** (Personalised Medicine, Rare Diseases)

3



4

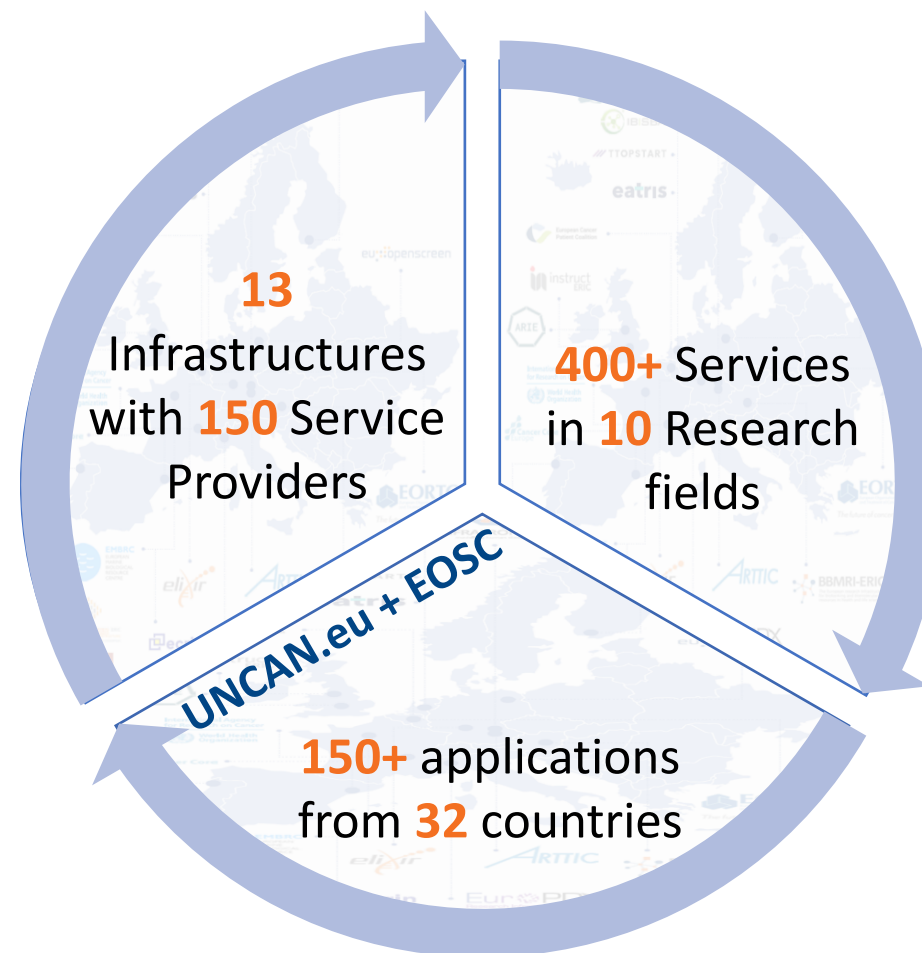




# canSERV

providing cutting edge  
cancer research services  
across europe

- ✓ Defragmenting ERA in cancer research
- ✓ Easy access to cutting-edge expertise, tools and services across Europe
- ✓ One-stop shop for researchers
- ✓ One European Molecular Tumour Board (MTB) Network with MTB Outcome Registry



Funded by  
the European Union

Grant agreement No. 101058620

[www.canSERV.eu](http://www.canSERV.eu)



BBMRI-ERIC



EURO BIOIMAGING



elixir



ARTIC  
International Agency  
Research on Cancer  
World Health  
Organization



instruct  
ERIC



EORTC  
European Organisation  
for Research and  
Treatment of Cancer



ecrin



TTOPSTART



eatris



IBISBA

eu:openscreen

World Health  
Organization

INFRAFRONTIER  
modelling human diseases

EMBRIC  
EUROPEAN  
MARINE  
BIOLOGICAL  
RESOURCE  
CENTRE

MIRRI

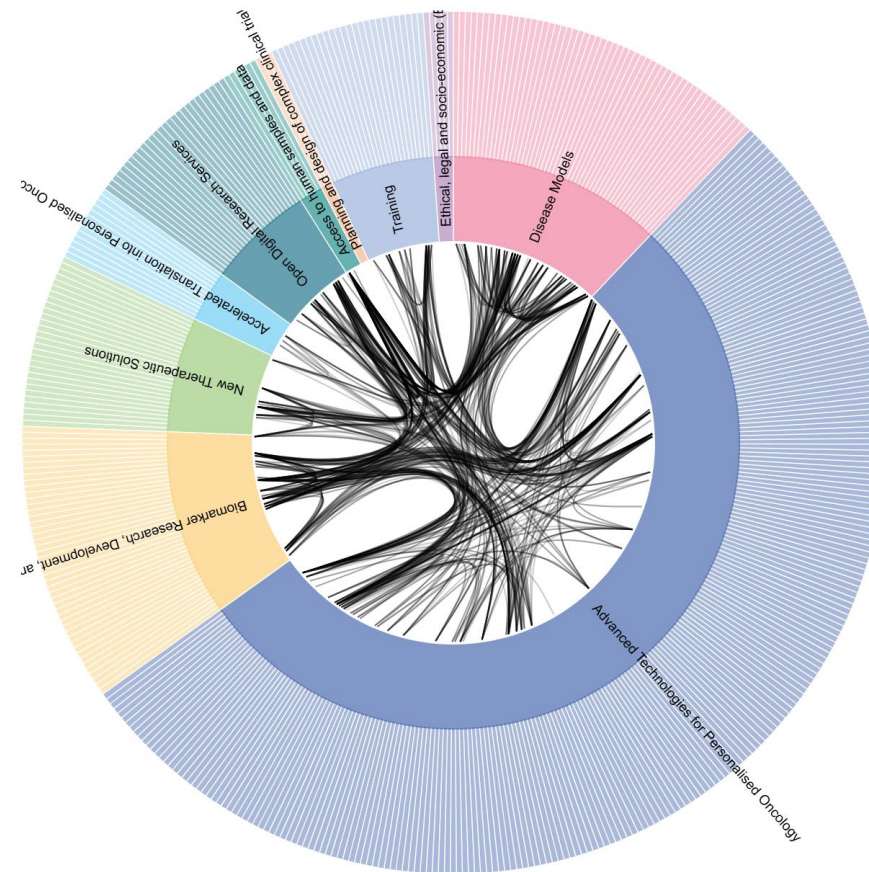
Cancer Core  
Europe

ARIE

# LS RIs

## DEFRAGMENTING

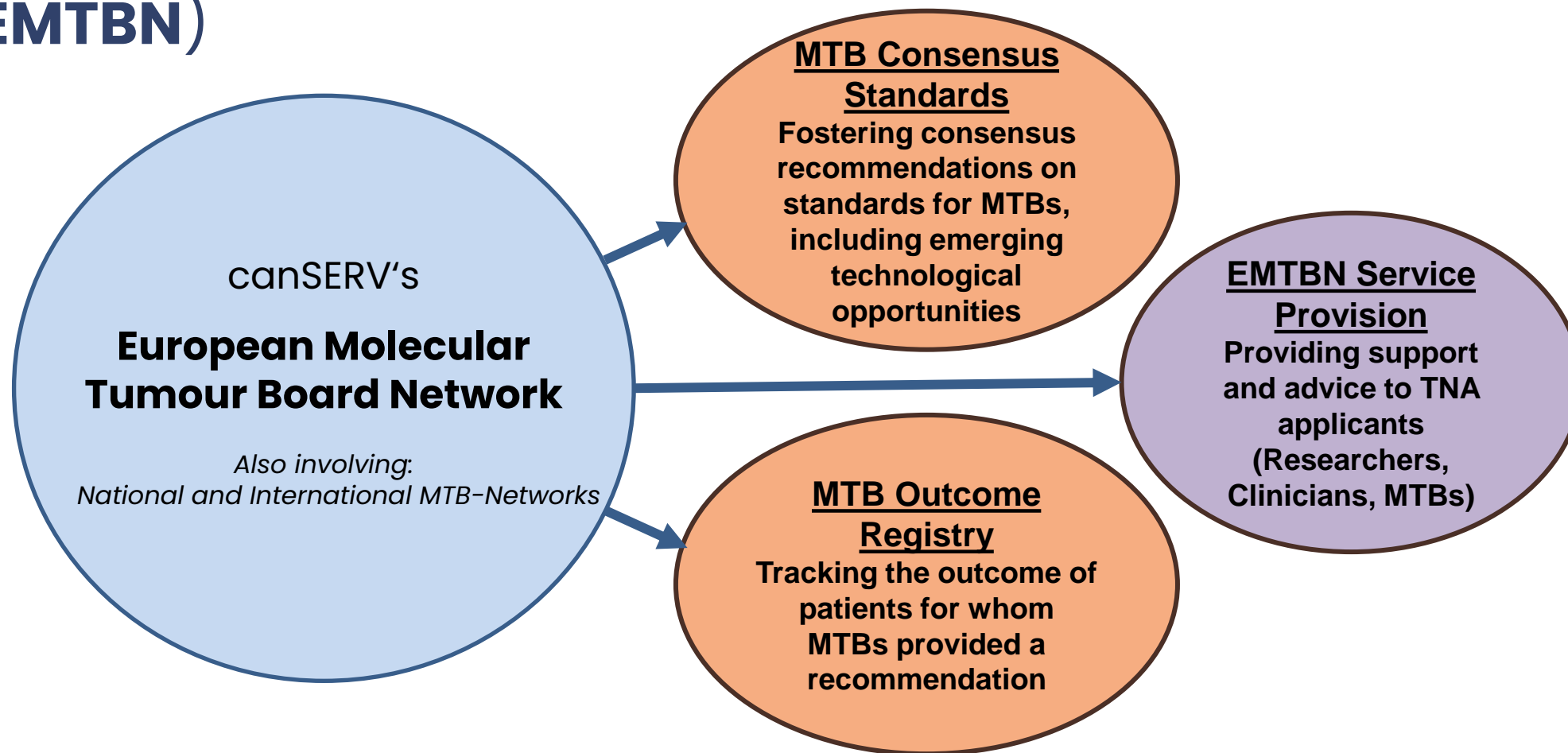
## ERA

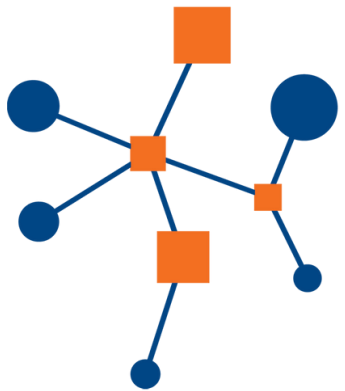


-  Disease Models
-  Advanced Technologies for Personalised Oncology
-  Biomarker Research, Development, and Validation
-  New Therapeutic Solutions
-  Accelerated Translation into Personalised Oncology Clinical Practice
-  Open Digital Research Services
-  Access to human samples and data
-  Planning and design of complex clinical trials
-  Training
-  Ethical, legal and socio-economic (ELSI) dimensions

**\*Service interconnections based on 103 applications**

# European Molecular Tumour Board Network (EMTBN)





# BBMRI-ERIC®

The European research infrastructure  
for biobanking and biomolecular  
resources in health and life sciences

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LEARN MORE  
AND GET IN  
TOUCH

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*LinkedIn: [@bbmri-eric](https://www.linkedin.com/company/bbmri-eric)*

*Twitter/X: [@bbmrieric](https://twitter.com/bbmrieric)*



# Kyriacos Hatzaras

European Commission, DG CNECT





## European Virtual Human Twins Initiative

# EU Healthcare Infrastructures

15 July 2024

CNECT.H3 eHealth, Wellbeing and Ageing





- Federated European Infrastructure for Intensive Care Unit (ICU) Data
  - DIGITAL, WP 2023-2034, 5 MIO EUR co-funding – *GAP phase*
  - Data intensive computational model-based tools for decision support and risk prevention
  - Goal to identify personalised interventions in real-time
  - 6 clinical use cases towards creating the “VHT of the ICU patient”
- Demonstrate ICU dataset integration and use with VHT models in 4+ clinical domains



## ■ Advanced VHT Platform for Models Integration & Validation

Procurement action, DIGITAL EUROPE WP 2023-2024 – *Evaluation phase*

### Key Principles

- ❖ Advanced platform: : distributed, featuring AI & synthetic data use, with OSS specifications
- ❖ Partnerships & collaboration support: 'co-simulation' paradigm with supporting functionalities
- ❖ Security & compliance: Intellectual Property Management policy, anonymous data, SecDevOps process for software development
- ❖ LL requirements definition: opportunity for the ecosystem to engineer the Advanced Platform to its requirements
- ❖ Minimum open source specifications: allow a wide user base to link with, utilise, develop platform resources: APIs for AI, analytics, modelling packages, the VHT Framework
- ❖ Sustainability: catering for EU funded projects' outputs: EDITH, ICU, TOOLS-05-03

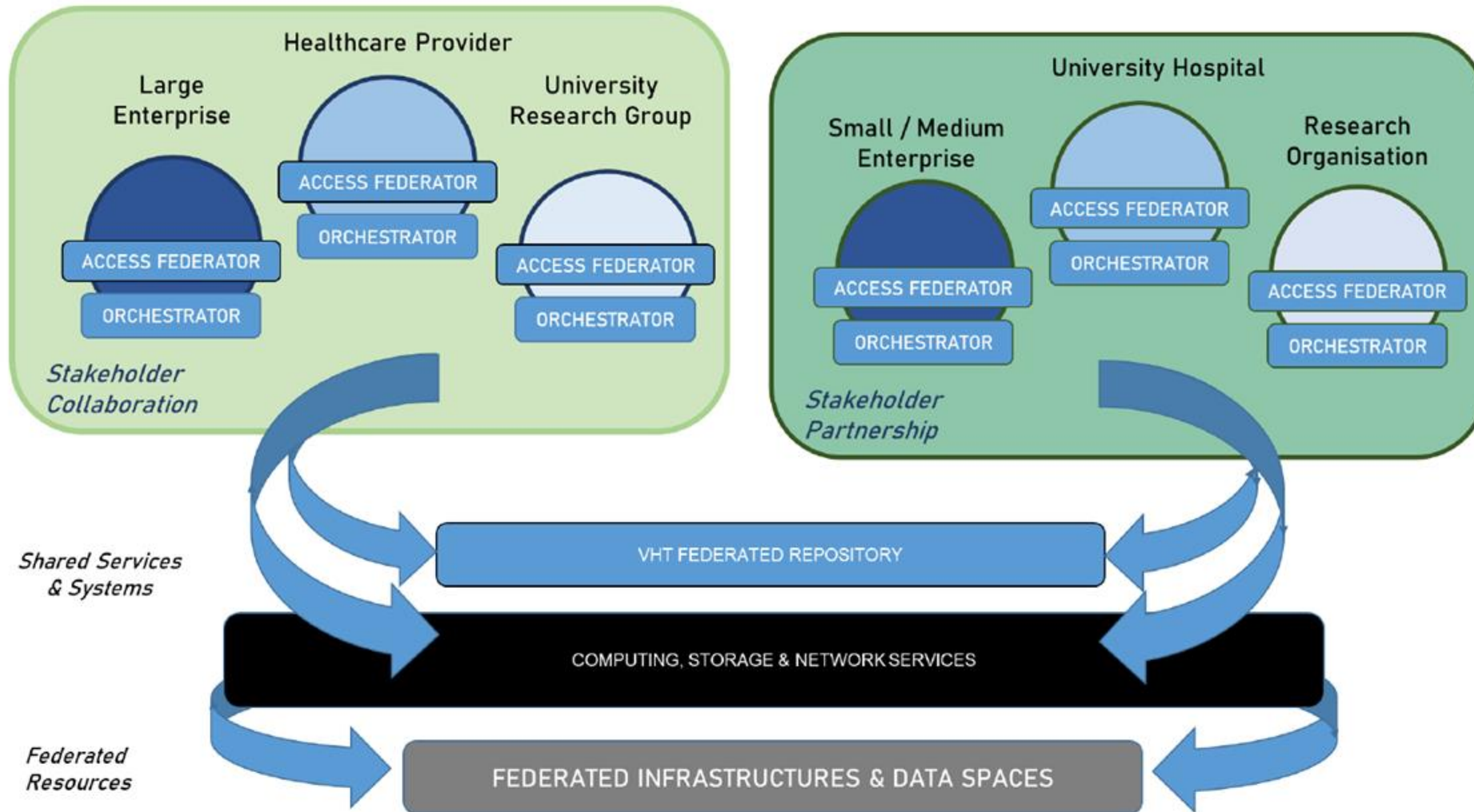




# European Virtual Human Twins



## Medium to long term view





# Strengthening synergies with other EU initiatives



## Cancer Imaging Initiative

- Links resources and databases to establish an open infrastructure of cancer images
  - Fosters innovation and deployment of digital technologies for improved clinical decision-making, diagnostics, treatment and prediction



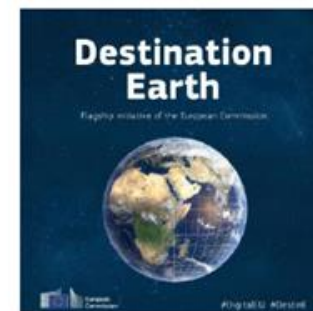
## 1+ Million Genomes

- Enables secure access to genomic data and the corresponding clinical data
- Facilitates research, personalised healthcare and public health



## Destination Earth

- Ecosystem and platform for computational models of organs and organ systems
- Supports prevention, diagnosis and treatment





# Strengthening synergies with other EU initiatives



European Health Data Space  
Regulation (**EHDS**)

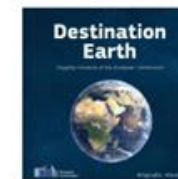
Cancer Imaging Initiative  
**Cancer** Image Europe Platform



1+ Million Genomes Initiative  
**Genomic** Data Infrastructure



**DestinE** Platform



## *European Virtual Human Twins Initiative*

Commission Communication on boosting **startups**  
and **innovation** towards **trustworthy AI**

Commission Communication on **Virtual** Worlds





# Many thanks

CNECT.H3



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# Jeroen Belien

Amsterdam UMC & Health-RI

# Jeroen Belien



Amsterdam UMC, department of pathology, associate professor (medical informatics)

&

Health-RI: ecosystem/infrastructure for secondary use of health data for research, policy and innovation; lead architect

Relevant EU initiatives/projects: 1+MG/GDI & HDAB-NL

# National nodes of European (ESFRI) infrastructures

Health-RI bundles national nodes of

- **BBMRI:** Biobanks & Cohorts
- **ELIXIR:** Life science data infrastructure
- **EATRIS:** Translational Medicine

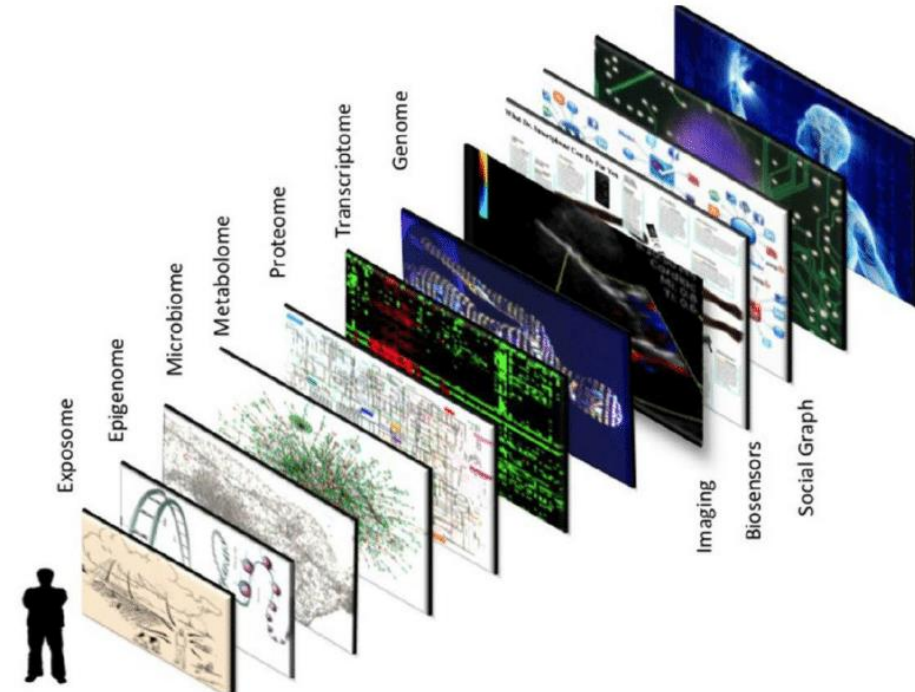
Each with specialised (inter-)national networks and (inter-)national sources of data, biomaterials, facilities and related services

-> **shared services portal**



# Possible links to (future) VHT

working towards a data-driven  
holistic life course approach for  
precision prevention, health &  
medicine



<https://doi.org/10.1186/s12918-017-0521-2>



# Claire Biot

Dassault Systèmes



# Invitation to join upcoming Virtual Human twin symposium

## 10TH INTERNATIONAL VIRTUAL HUMAN TWIN EXPERIENCE SYMPOSIUM

GENERATIVE SCIENCES FOR SOCIETY

**30 - 31 October, 2024**

Institut Pasteur, 209-211 Rue De Vaugirard, 75015 Paris

For the second part of our Science Week, the 10th Annual Virtual Human Twin Experience Symposium opens the door to a new way of understanding, representing and simulating entire human bodies. Its aim is to unleash the identification of therapies and treatments. The virtual human twin is a real metamorphosis for collective practices.

[REGISTER](#)

[2023 REPLAYS](#)



Ecosystem  
for Digital Twins  
in Healthcare

Amsterdam 15/7/2024

# Christopher Esterhuyse

UvA

University of Amsterdam  
on the AMdEX Project  
at EDITH-CSA Ecosystem  
by Christopher Esterhuyse



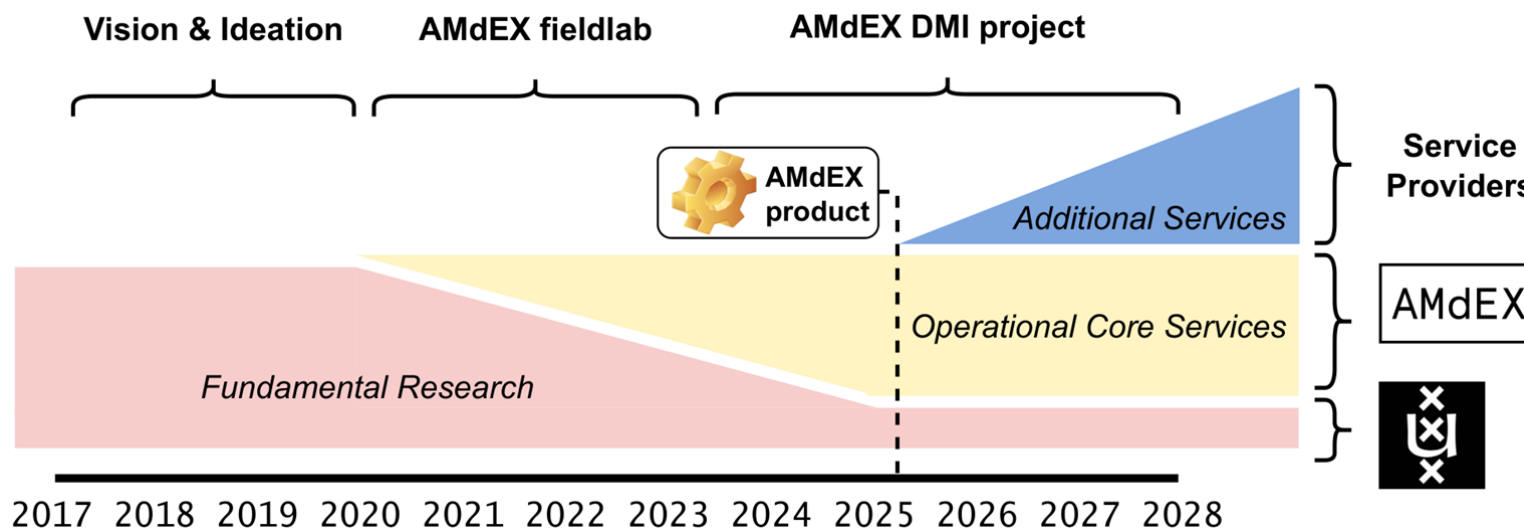
# The AMsterdam data EXchange

**AMdEX develops tools** for safe inter-organisational data exchange. The project has private and public partners, and involves **academic research** in conjunction with **industrial developments**.

## Websites:

AMdEX project: <https://amdex.eu/>

DMI-ecosystem: <https://dmi-ecosysteem.nl>



## Contact:

Principal Investigator  
Prof. Dr. Sander Klous  
[S.Klous@uva.nl](mailto:S.Klous@uva.nl)

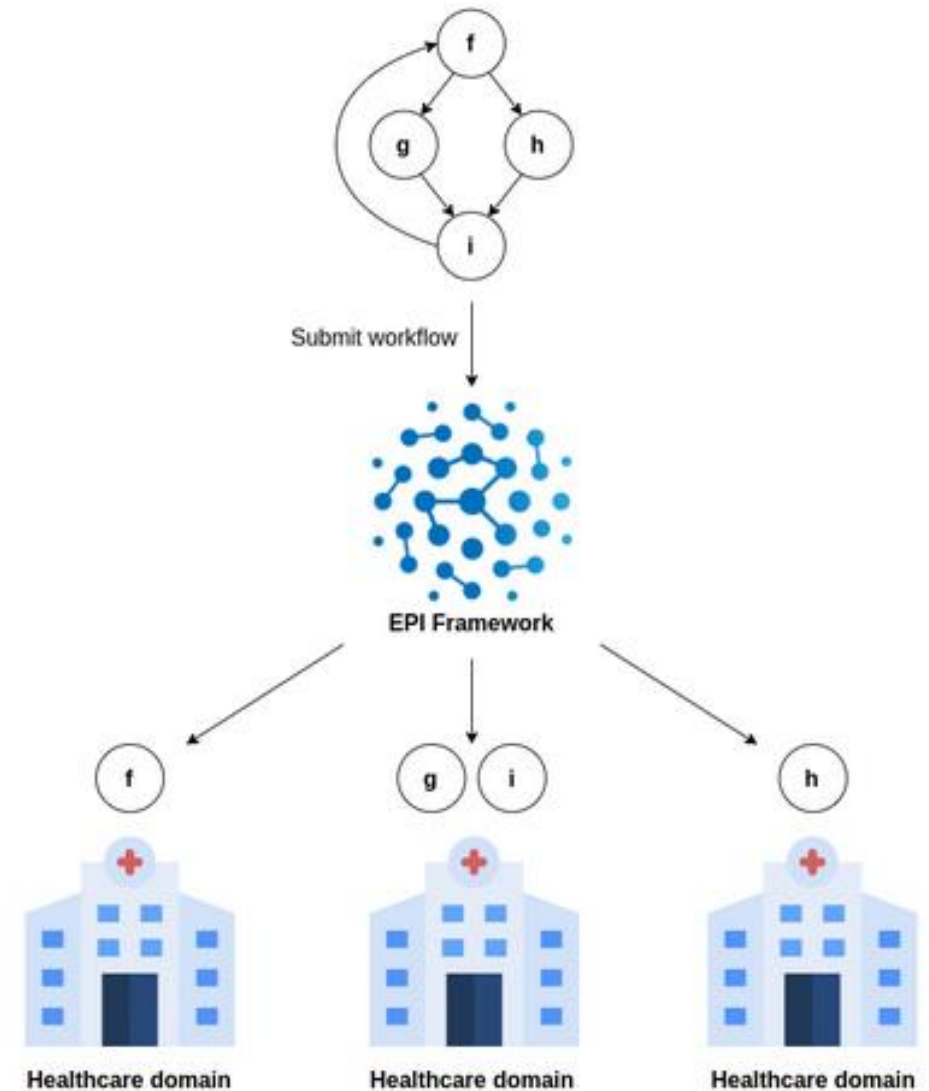


# Example Use Case

Federated Medical AI Data Processing:

- A federated system of hospitals processes data ...
- ... while preserving hospital-local policies.  
E.g. “Bob’s records must never leave the EU”

This case comes from the Enabling Personalised Interventions (EPI) project, and remains relevant.





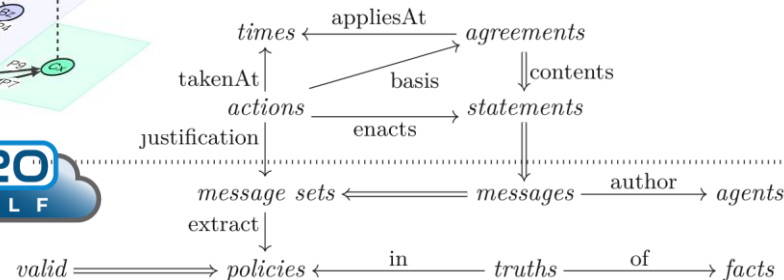
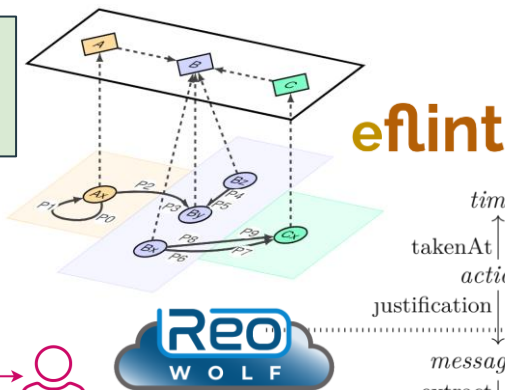
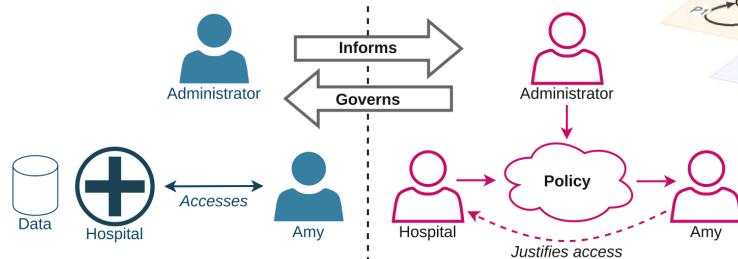
# Research @ University of Amsterdam



**My research focus** is on the analysis and control of federated systems via formal specifications.

**We develop** languages, formalise agreements, and prove and enforce properties in software systems.

```
% Statement 's6' authored by 'administrator'
ctl-authorises(administrator, bob, x-rays)
:- ctl-authorises(h1, bob, x-rays),
   ctl-authorises(h2, bob, x-rays).
```



Other work at the university includes:

- Hardware & Network Security
- Software Languages & Verification
- Concurrent & Distributed Systems
- Network & Legal Policies
- ... etc.

**Contact:**

PhD Student  
Christopher Esterhuyse  
[c.a.esterhuyse@uva.nl](mailto:c.a.esterhuyse@uva.nl)

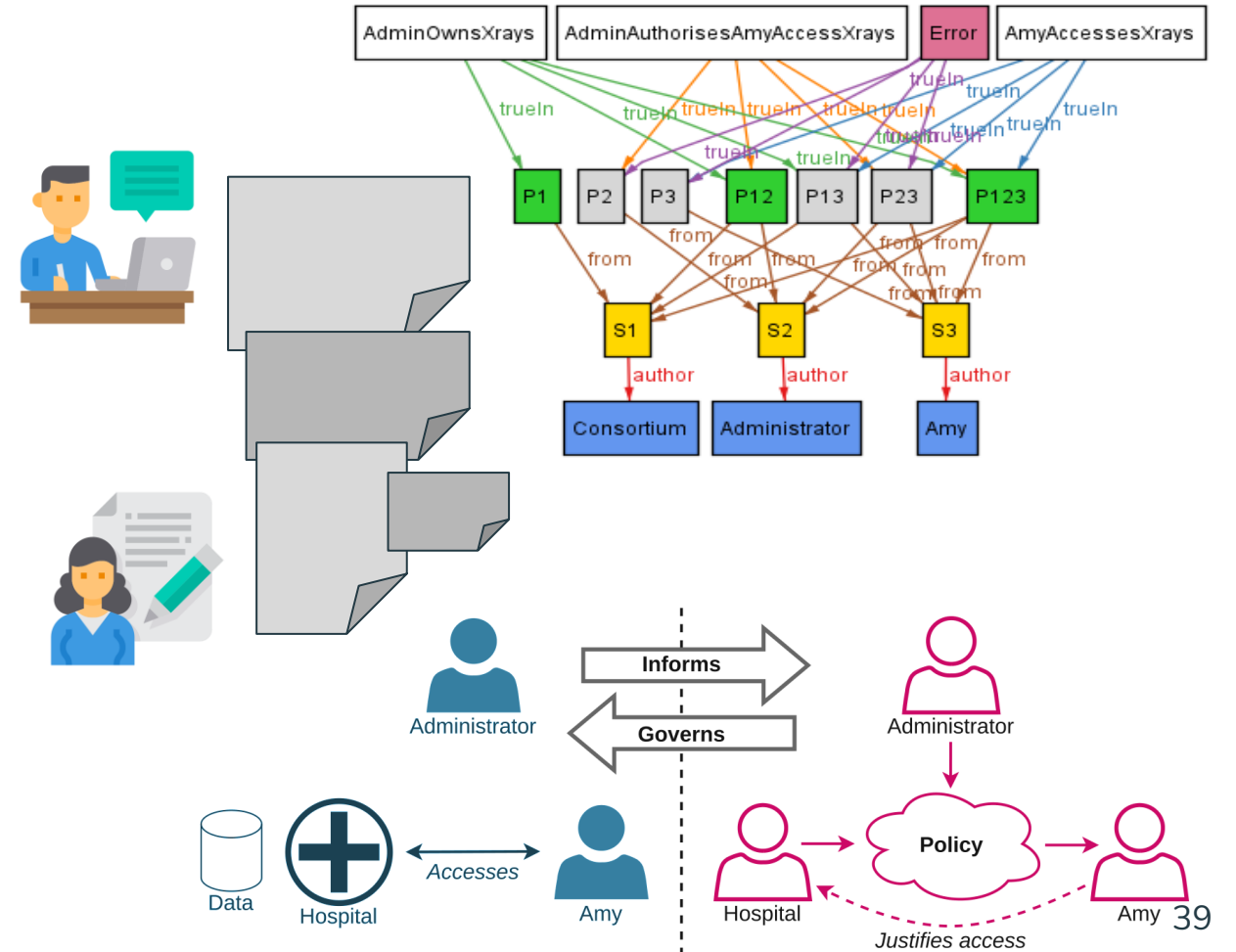




# Example Solution

Using the JustAct framework:

- Amy processes Dan's data ...
- ... while Bob amends the agreement ...
- ... and both use automated reasoning to check that these acts are permitted.





# Link to EDITH-CSA

The big ideas behind AMdEX:

- Inter-organisational collaboration **requires** precisely agreed and controlled data sharing.
- **The key points** of our approach:
  - Precise, flexible, transparent agreements.
  - Reliable, semi-automated enforcement.
  - Fundamental sovereignty of data control.

Looking back:

- Our approach is validated by prior works with medical, commercial, public, ..., partners.

Looking forward:

- Interested? Reach out and get involved!  
(contact [S.Klous@uva.nl](mailto:S.Klous@uva.nl))