More value to data: the role of data intermediaries

Health Data Spaces and Ecosystems Workshop

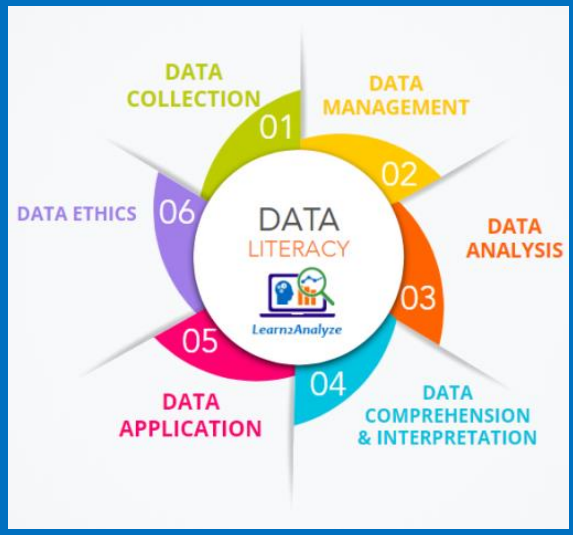
8 November 2021, 15:00 – 16:00 CET

@ehtel_ehealth

Data on the spotlight

Data-rich

Data silos and interoperability



Citizen-centric data sharing

Trust

InteropEHRate
EHR in people's hands across Europe

EHTEL
Collaborating for Digital Health and Care in Europe

OPENDEI

Problem statement

“I want to share and contribute but I am concerned about privacy, security, complexity, usability, illegitimate use…”

Data Governance Act proposal - 3 key areas

(1) access to data held by public sector bodies;

(2) regulation of data sharing services through **"data intermediaries";**

(3) encouraging **"data altruism"**

What are data intermediaries?

Independent report

Unlocking the value of data: Exploring the role of data intermediaries

Published 22 July 2021

Centre for Data Ethics and Innovation

Organisations that facilitate greater access to or sharing of data:

- Cover a range of **different activities and governance models**;
- Can operate within or across **the public, private, and third sector**;
- **Enable responsible data access and sharing,** managing and protecting individual rights and privacy;
- May apply **additional measures to protect** against unethical use of data and ensure it is only used for agreed purposes.

https://www.gov.uk/government/publications/unlocking-the-value-of-data-exploring-the-role-of-data-intermediaries/unlocking-the-value-of-data-exploring-the-role-of-data-intermediaries

What are they here for?

- ✓ **Find** personal & non personal data
- ✓ Provide **technical infrastructure** and support to interoperability negotiating sharing arrangements between parties to share, access or pool data.
- ✓ Manage transfers and **usage rights**
- ✓ Ensure data protection acting as **data custodian** allowing remote analysis through privacy-enhancing technologies or providing **independent analytical services** in a siloed environment.
- ✓ Reduce costs and risks associated with **data processing**
- ✓ Assume the **roles and obligations of a data controller and/or processor**

Why would we need intermediaries?

- Lack of **incentives** to share data > Align incentives to cooperate
- Lack of **knowledge** > Address knowledge gaps
- Lack of **standardization** > Enhance quality, interoperability and data portability
- Commercial, ethical, and reputational **risks** > Limit the purposes for data sharing
- Legal and regulatory **risks** > Apply privacy-enhancing technologies (PET)
- **Costs** of data access/sharing > Create trusted research environments (TRE)
- Missed opportunities to use data in the **public** interest

Categories of data intermediaries

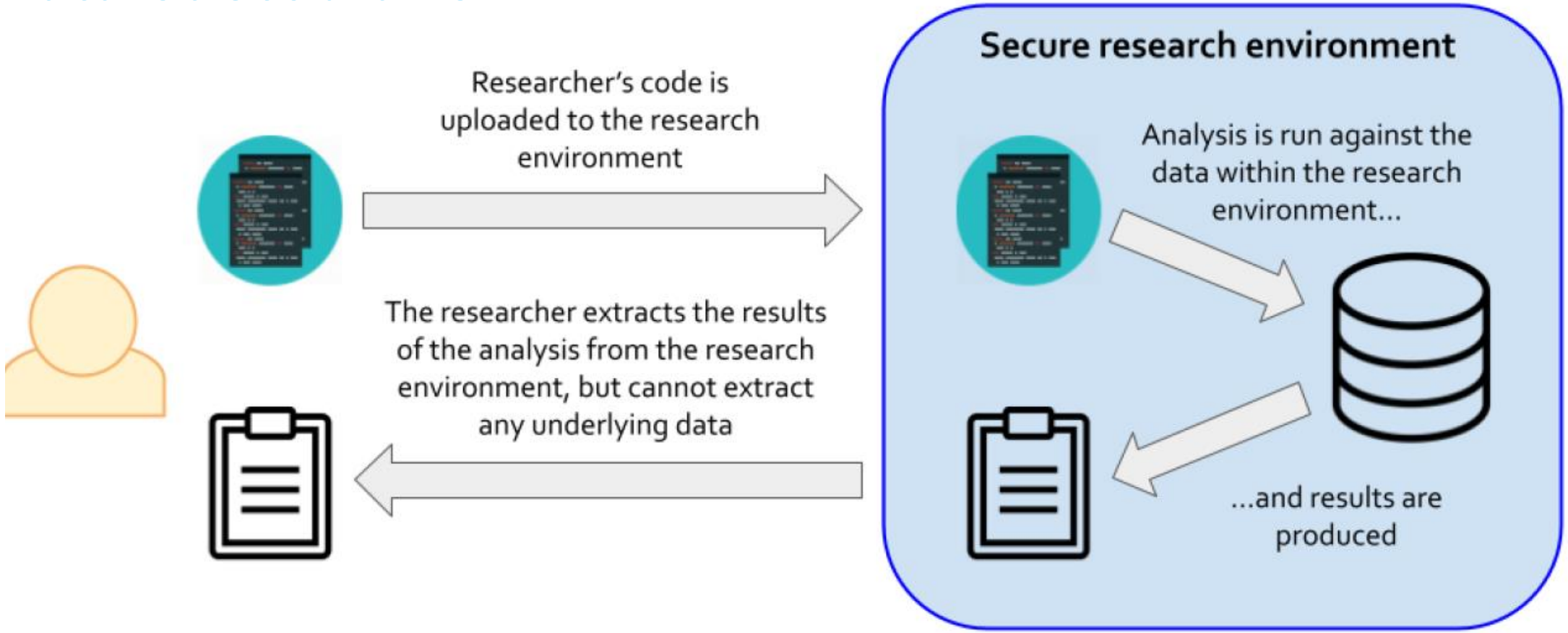
Data Governance Act
B2B: Intermediary between data holders
B2C: Intermediation services between data subjects and potential data users
C2B: Data cooperatives that support individuals or small- and medium-sized enterprises to negotiate terms and conditions for data processing

1. **Data processors**
   - Provide data support services to ensure interoperability of data.

FOCUS

2. **Data custodians**
   - **Data exchanges**: Operate as online data platforms where datasets can be advertised and accessed – commercially or on a not-for-profit basis.
   - **Data custodians**: Enable privacy-protecting analysis or attribute checks of confidential data, for example, via the application of Privacy-Enhancing Technologies (PETs)
   - **Industrial data platforms**: Provide shared infrastructure to facilitate secure data sharing and analysis between companies.
   - **Data trusts**: Provide fiduciary data stewardship on behalf of data subjects
   - **Trusted third parties**: Provide assurance to those looking to access confidential datasets that the data is fit-for-purpose (e.g. in terms of quality or ethical standards).
3. **Personal Information Management System (PIMS)**
   - **PIMS**: Seek to give data subjects more control over their personal data
4. **Data collaboratives**
   - **Data cooperatives**: Enable share data spaces controlled by data subjects

Data custodians



Source: Centre for Data Ethics and Innovation, 2021

Data custodians examples:

Open SAFELY

secure analytics platform for NHS electronic health records.

aws

connects data providers with data subscribers and offers advanced analytics.

Genomics england

collects sensitive data on the human genome for research purposes

Example 1: **OpenSAFELY**

Data custodian

Research across over 58 million people's health records

> Identified patients most at risk of dying from COVID

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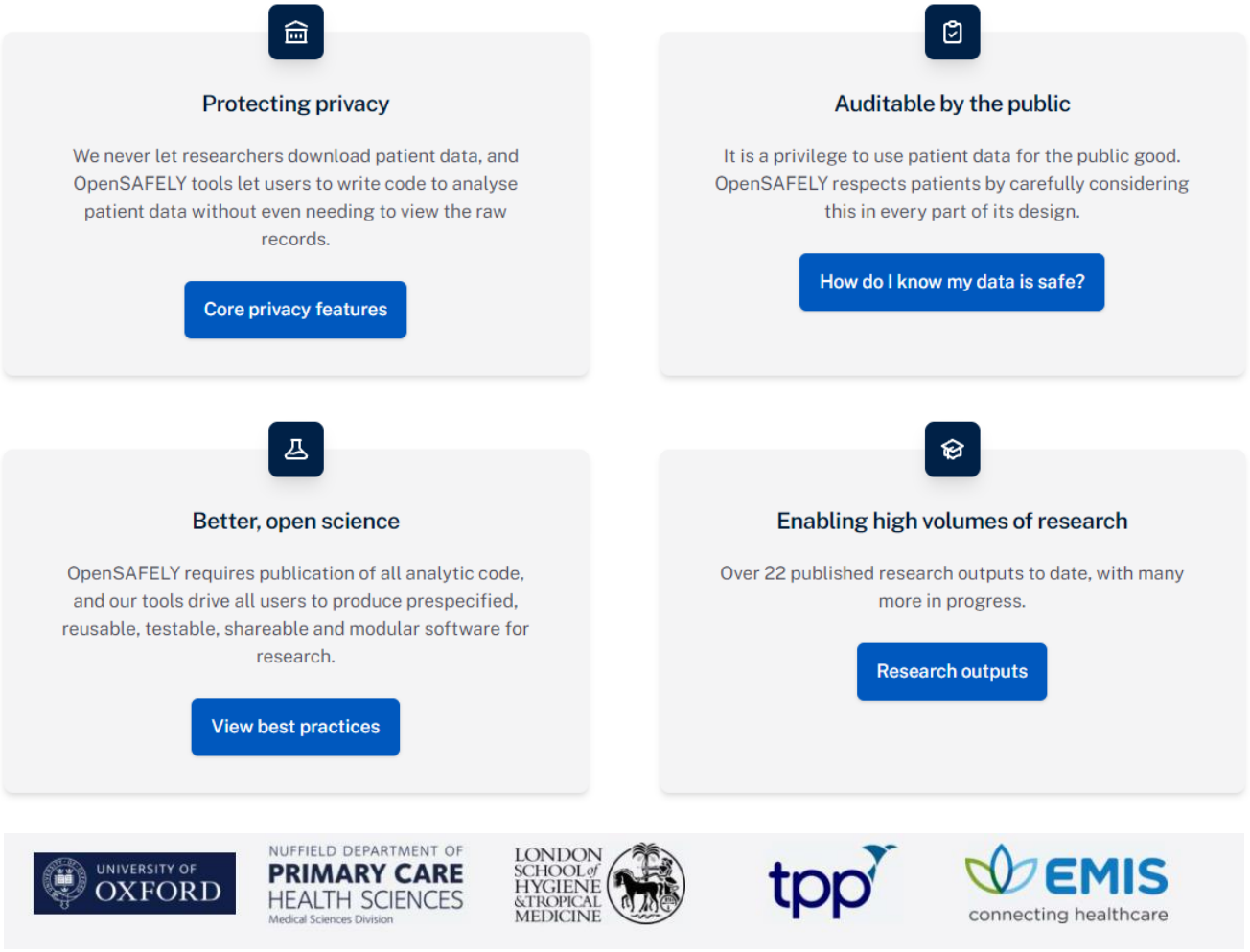

Example 2: **AWS DATA EXCHANGE**

Data custodian

Aggregates and stores **non-personal data** from public and private organisations.

API integrated into **ConvergeHEALTH** (Deloitte) to find, subscribe and use third-party data and analyze it in the cloud.

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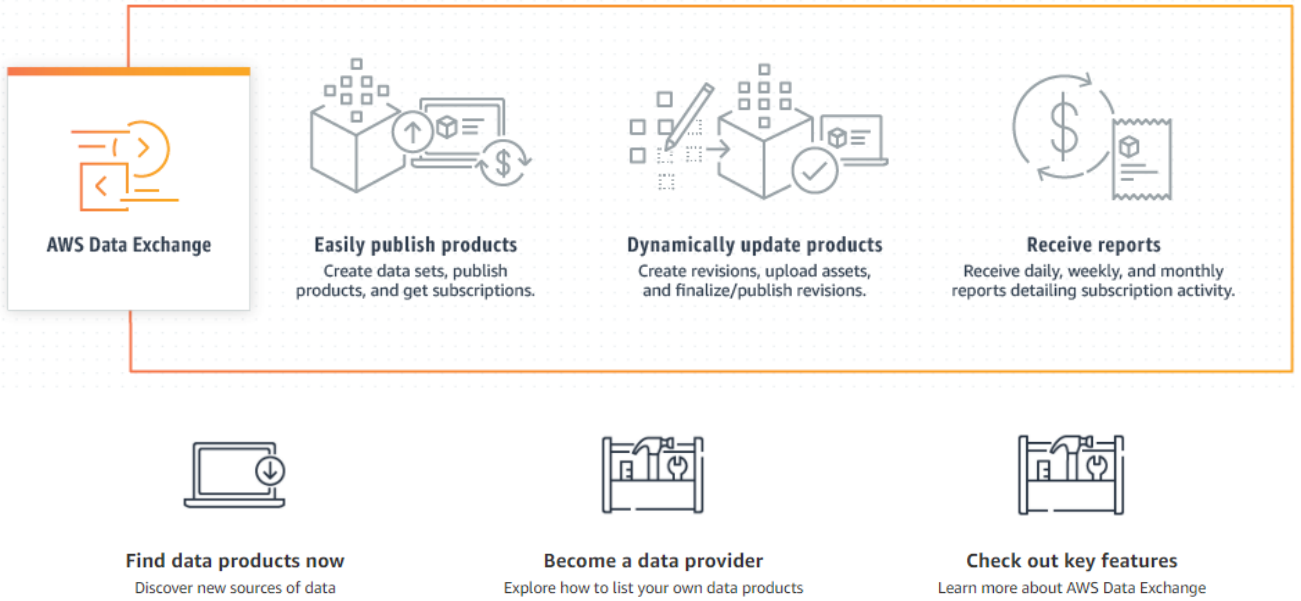

AWS Data Exchange is unlocking a number of data sources that have traditionally been locked in siloes spanning multiple organizations and **gives healthcare stakeholders a scalable and secure service to create new collaborative business models** to reimagine how they approach research, clinical trials, pharmacovigilance, population health, and reimbursement.

Example 3: **Genomics England**

Data custodian

Genomics England operates as a trusted research environment (TRE), granting public and private researchers access to its anonymised data for specific research projects.

- Lack of incentives to share data
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- Commercial, ethical, and reputational risks
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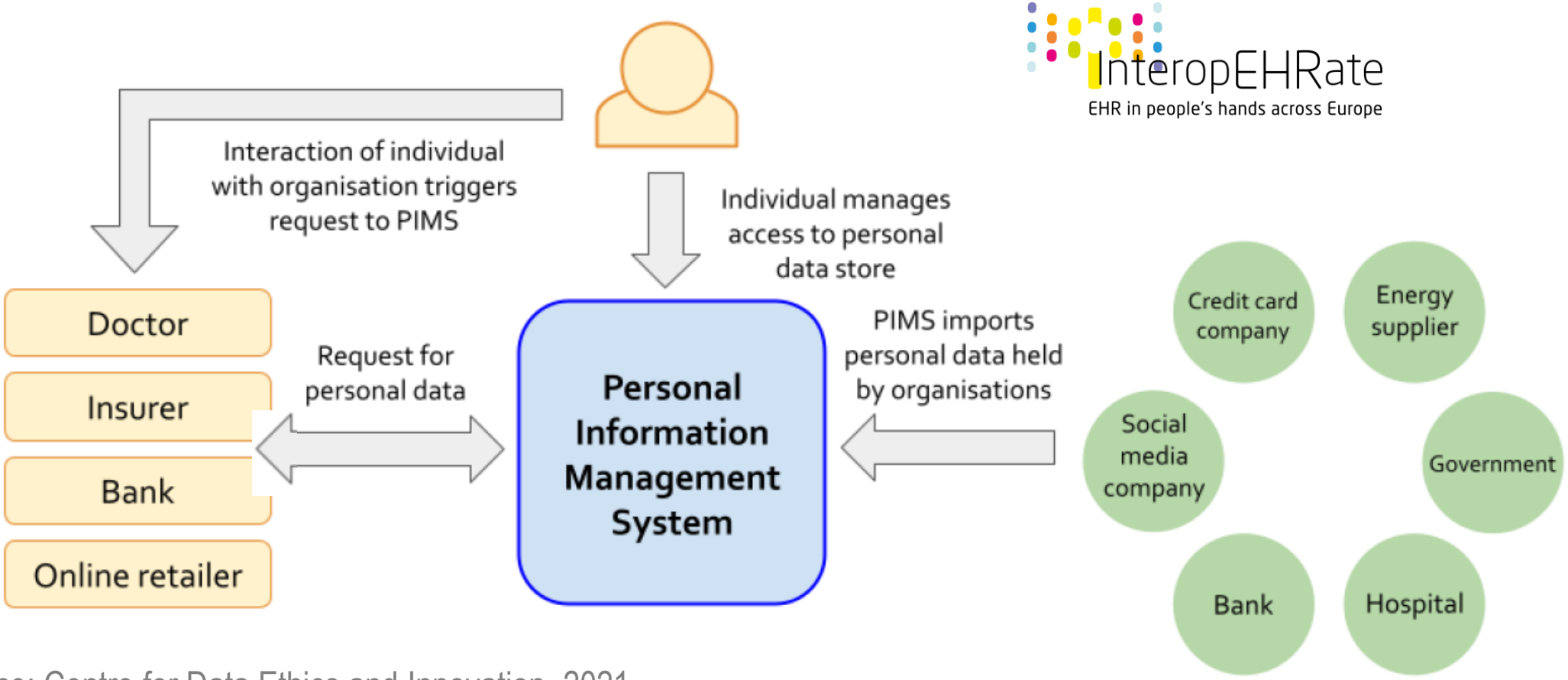
Genomics England never allows the data to be removed from its secure data centre, monitors all activity undertaken by researchers

The PIMS model: focus on citizens and patients

Enabling individuals to control how data about them is used and for what purposes

- Difficulty to have a full overview of and control over the data they share
- Demand for mechanisms to **"rebalance the current power imbalance between individuals and corporations"**
- **Return control to users by enabling all information related to them to be stored in a single location and managed through a single interface**
- Provide fine-grained control over who has access to data about them, and are empowered to withdraw that access at any time
- facilitate an individual's right to erasure under existing data protection legislation by automating the process of requesting data deletion from an organization
- **Enable** automatic opt-outs on data sharing for uses that may be considered undesirable
- **Could provide fine grained identity management features**

The PIMS model



InteropEHRate
EHR in people's hands across Europe

Source: Centre for Data Ethics and Innovation, 2021

Example 4: **NESTA DECODE**

Not-for-profit PIMS

A toolkit to provide useful **guidance and resources** for private and public organisations to prepare for and design data-sharing initiatives, helping them identify **the right combination of options** for the specific and unique context for the given circumstances.

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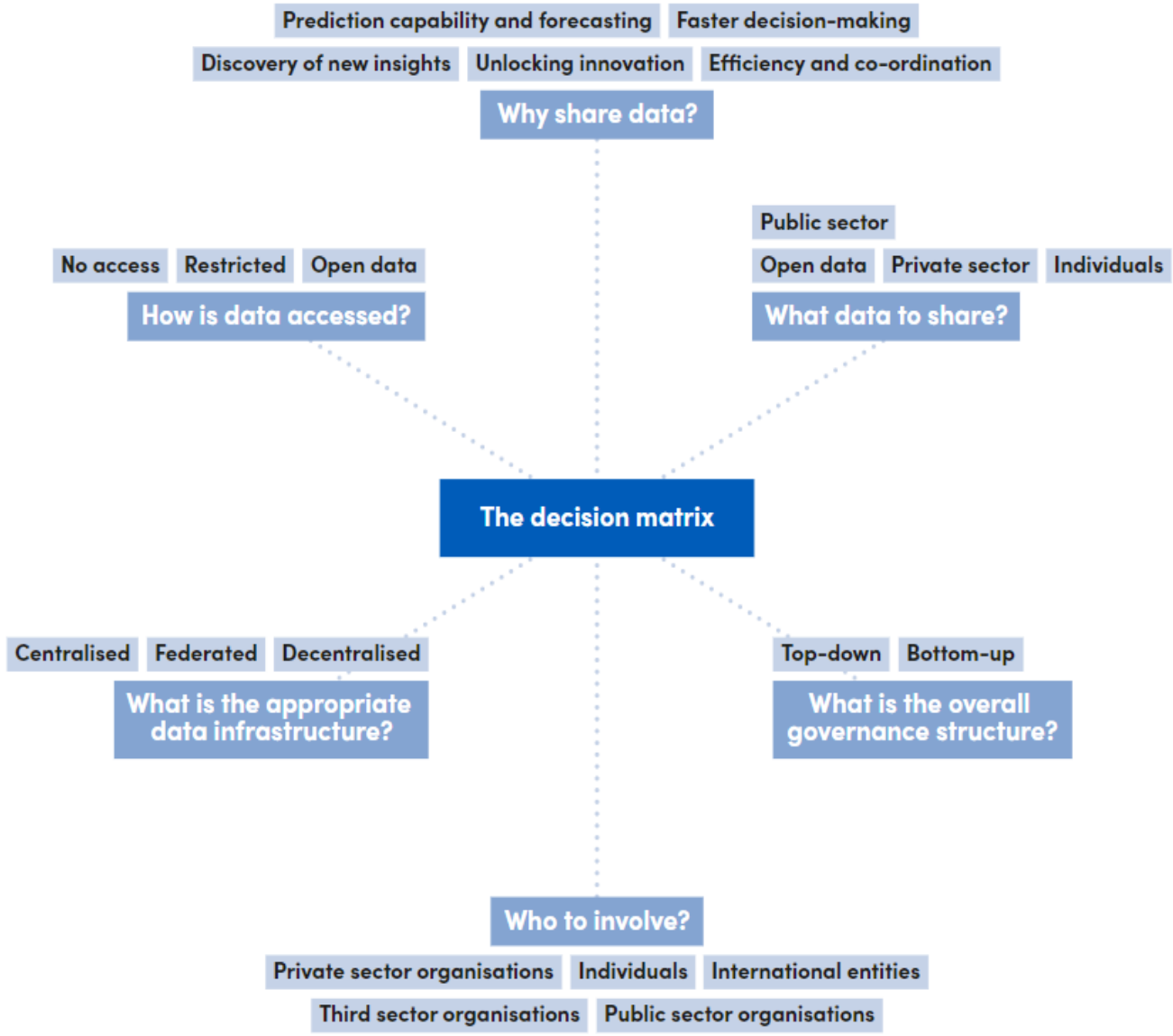


DECODE provides decentralized, privacy-enhancing, rights preserving tools to give back data sovereignty to people and enable citizens' digital right

1 **Modular and interoperable.**

DECODE tools can be combined and used as part of any platform or app.

2 **Free and open source.**

All work produced by the project is published as free and open source.

3 **Decentralised & blockchain-enabled.**

In DECODE operations are processed, validated and updated on the Sawtooth ledger platform.

4 **Privacy enhancing.**

Personal data on DECODE is defined in terms of 'Attribute-Based Credentials' collected and stored in a secure digital wallet.

5 **Based on cutting edge research.**

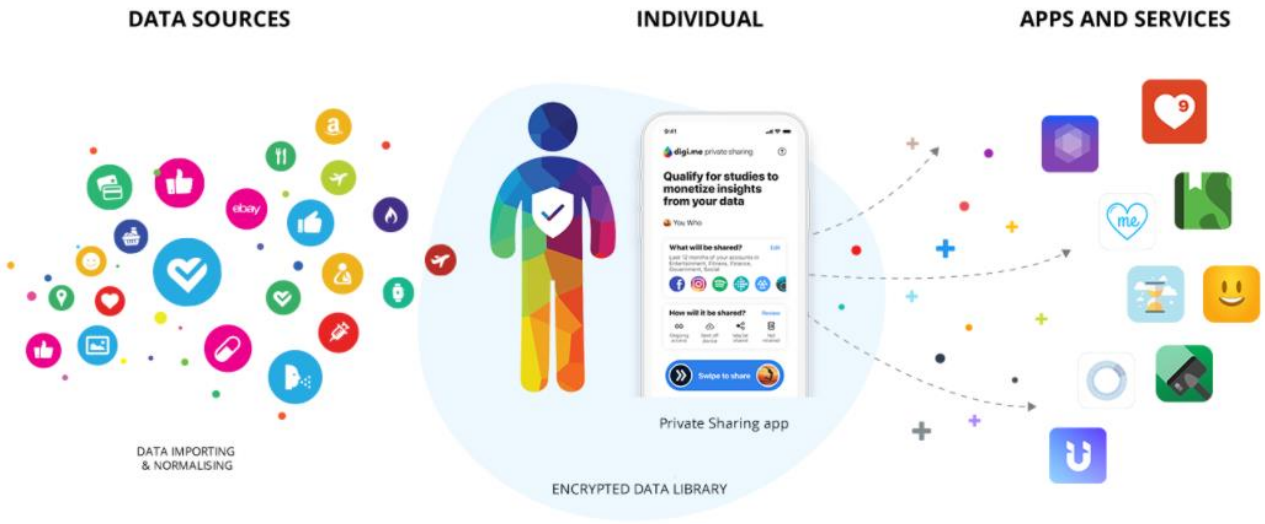
Based on the selective disclosure credential scheme 'Coconut', providing full blockchain integration.

Pilots

- Digital Democracy and Data Commons (DDDC)
- Citizens' IoT Data Governance
- Anonymous Proof of ID
- Ethical Social Network

Example 5: **DIGIME**

For-profit PIMS

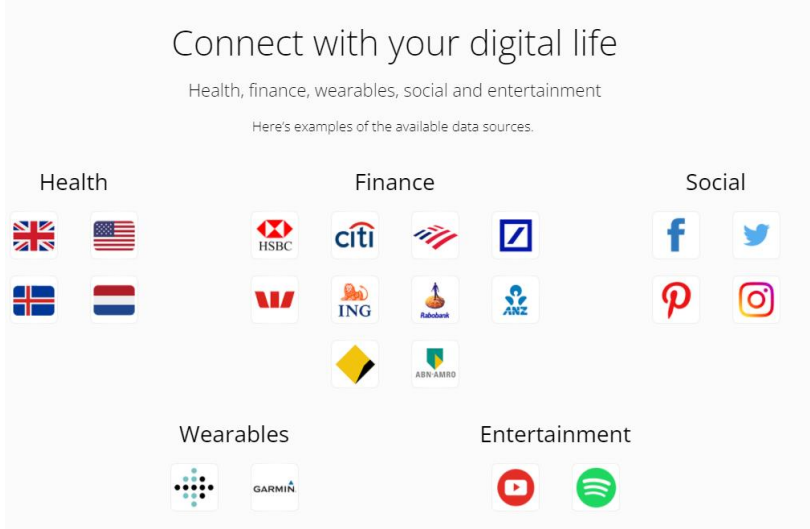


England - NHS GPSoC
Status: Reviewed and approved

USA - Epic / Cerner
Status: Reviewed and approved

Netherlands - Medmij
Status: Audited and certified

Iceland
Status: Audited and approved



Chosen in ICELAND for PHR storage (and sharing)

Example 6: **SOLID Project**

PIMS in Pilot

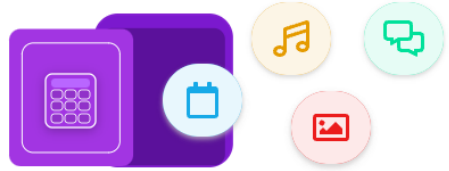
Solid is a specification that lets people store their data securely in decentralized data stores called **Pods**.

Pods are like secure personal web servers for data. When data is stored in someone's Pod, they control which people and applications can access it.

Piloted in Manchester (UK) and Flanders (Belgium)

Get a Pod

Pods are where you store your data. Any kind of data can be stored in a Solid Pod. Once stored in a Pod, you control who can access your data.



You can get a Pod from a Pod Provider, or you may choose to self-host your Pod.

Key messages

- Data intermediaries can play a vital role in accelerating data-driven **innovation** and overcoming **standards** adoption bottlenecks.
- **Transparency** of data intermediaries operations are fundamental to gain **trust** and credibility in data markets.
- They can become **health data ecosystem** creators or facilitators, enabling a **citizen-centric health data sharing** approach.

Q&A session and panel discussion

Isabelle de Zegher
b!loba
Belgium

Nikolas Molyndris
Decentriq
Switzerland

Gabor Bella
University of Trento
Italy

Angelo Marguglio
Engineering SpA
Italy

What's next?

#Imagining2029

Session 2.
Enabling citizens to be in better control of their own health data.
30 November 14:30

We will learn more about:
- Data cooperatives
- Dynamic consent

https://www.ehtel.eu/events/11-events/127-2021-thought-leader-ehtel-symposium.html