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Flexible and responsible manner: Is it necessary to mobilize data?

Laura Portell-Silva (BSC) · Eva Garcia-Alvarez (BBMRI-ERIC)

HealthyCloud project has received funding from the European Union's Horizon 2020 research and innovation programme under the grant agreement N° 965345.

Sharing is caring, and it is the right thing to do

Motivations

- Accelerating research
- Increased visibility and discovery of your research data
- Increased (re)use of your research data
- Compliance with funders, publishers and other policies

Challenges

- Understanding data protection
- Use of **(meta)data standards**
- No data **repository**
- Missing skills or resources

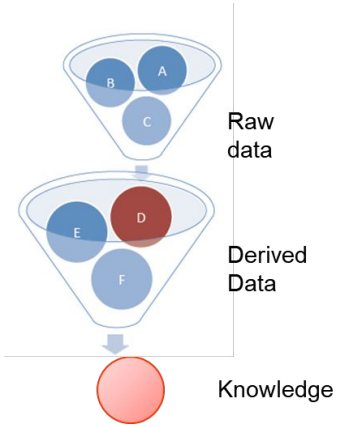
Improving data flow and secondary data use across teams and between disciplines

Increase **Flow of Information**

Support Collaboration

Increase knowledge

Team Science



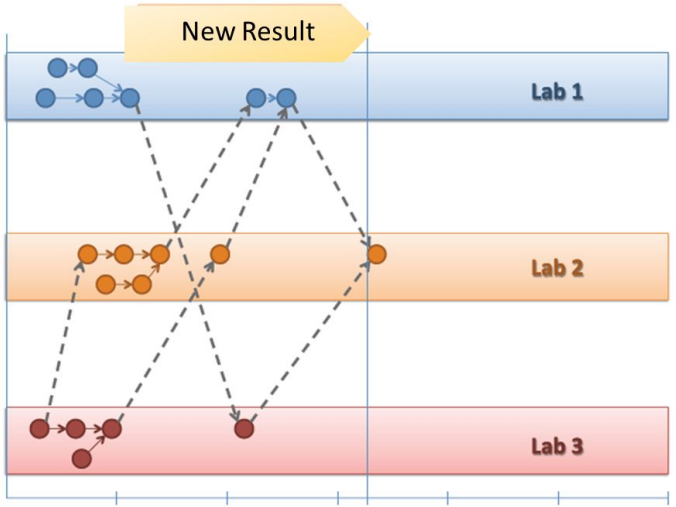


Figure: Knowledge Turning, Information Flow Josh Sommer, Chordoma Foundation, 2011

Goble, De Roure, Bechhofer, Accelerating Knowledge Turns, I3CK, 2013, isbn: 978-3-642-37186-8

We all produce as well as reuse (other people's) ~~data~~ digital objects

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- Documents (Thesis, Report, Conference Papers, Articles, Survey etc.)
- Slides
- Datasets
- Algorithms
- SOPs
- Codes
- Figures, Photos
- Software
- Workflows
- Databases

Deliverable 6.1 • "Expected user interactions"

Can data be truly shared?
… and mobilized?

HealthyCloud user story

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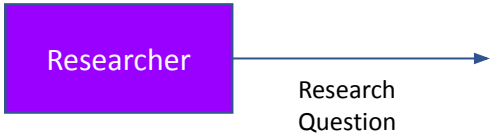
- Cancer
- Atrial fibrillation



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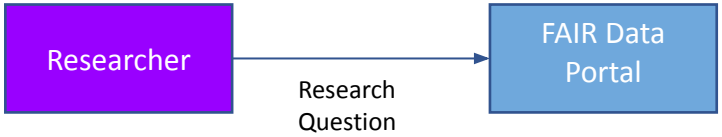

The FAIR Health Data Portal

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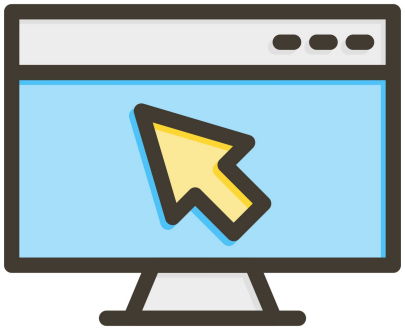
FAIR health data portal specifications

- Metadata catalogue of data hubs and data collections
- Metadata contribution guidelines
- Data access conditions
- Infrastructure providers for computational resources
- Guidance & knowledge hub



Deliverable 6.2 · "Specifications for the FAIR data portal"

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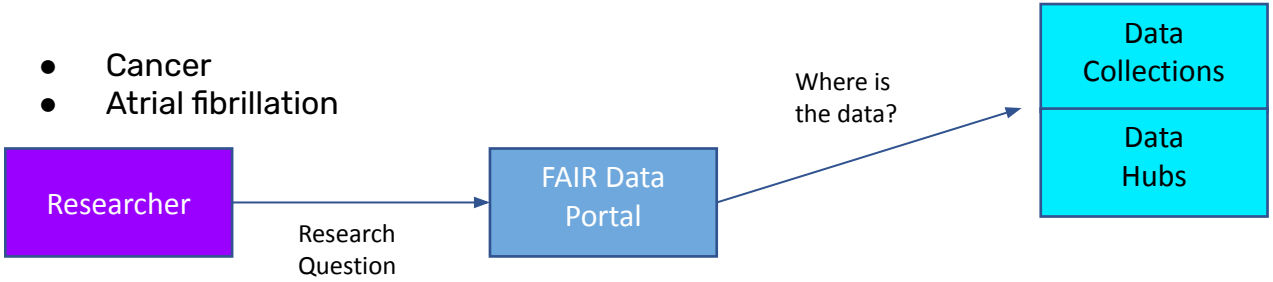
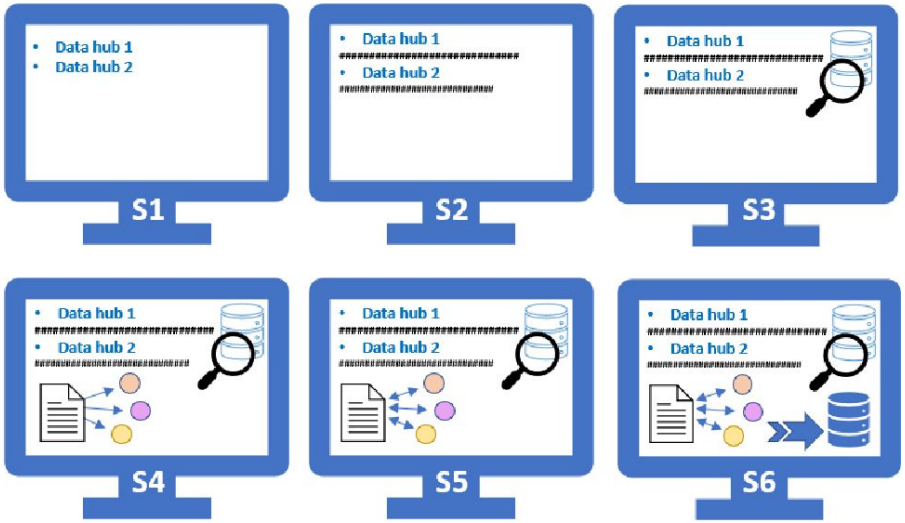


Specifications of data access



Data access scenarios, from very basic functionality to most advanced interaction (full provision)

- Considerations for data access (landscape)
  - Data characteristics
  - Organization of the data sources
  - Traditional vs machine-driven data access
- Identification of data access main steps and their characteristics based on the different scenarios
  - Data access application
  - Data access negotiation
  - Data access conditions
  - Implementation of data access

Specifications need to be flexible and are highly dependent on the level of complexity of the portal

Deliverable 6.3 • "Specifications for data access"

HealthyCloud user story

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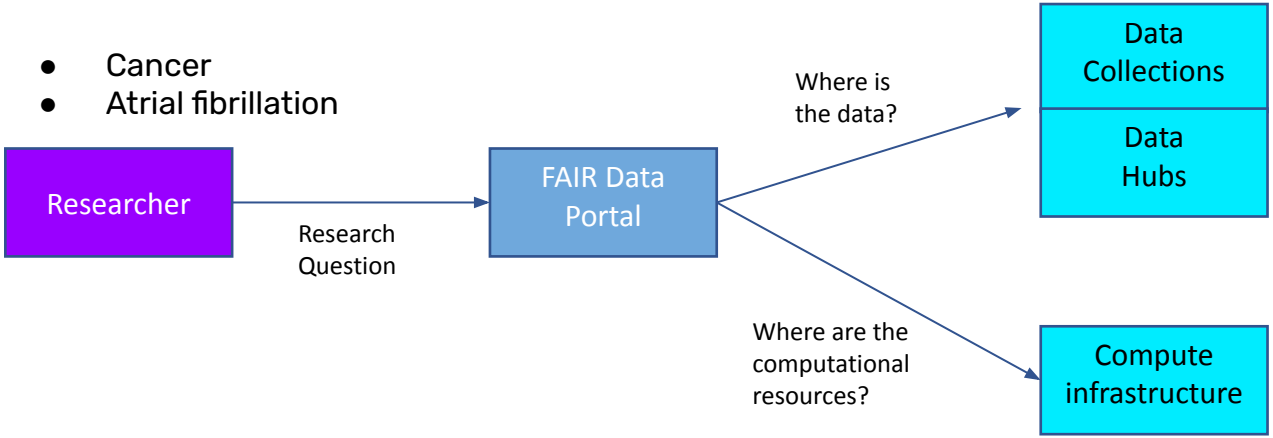

Compute infrastructure considerations
Can data be mobilized?

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Do I have enough computing capacity where I have the data?

- If YES, you are ready to analyse your data.
- If NOT consider using a **Secure Processing Environment** (SPE). If data cannot be moved (GDPR, confidentiality), the SPE has to be located in the same place (depending on national and institutional agreements) where the data is. If data can be moved (anonymized, public), a global SPE can be used.

Compute infrastructure considerations
Can data be mobilized?

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Do I need to use data from someone else?

- If computation is available and **data cannot be moved** → Federated analysis
- If computation is available elsewhere and **data can be moved** → Distributed analysis

Deliverable 5.2 · "Analysis of existing orchestration mechanisms for distributed computational analyses including a general overview to facilitate new developments"

Compute infrastructure considerations
A matter of trust…

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- **Safe projects**: is this use of the data appropriate?
- **Safe people**: can the research team be trusted to use this data appropriately?
- **Safe data**: is there a disclosure risk in the data itself?
- **Safe settings**: does the facility itself limit unauthorised access and use?
- **Safe outputs**: are all results removed from the safe setting non-disclosive?

Compute infrastructure considerations
Enabling health research

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- Define a capabilities maturity model for establishing different levels of engagement.
- Consider both perspectives: service providers and end-users, to facilitate expectation management.
- Look for alignment with parallel efforts, e.g. Gaia-X and EOSC.

Deliverable 5.5 • " Reference guidelines for the establishment of an ethically sound and legal compliant health data research ecosystem"

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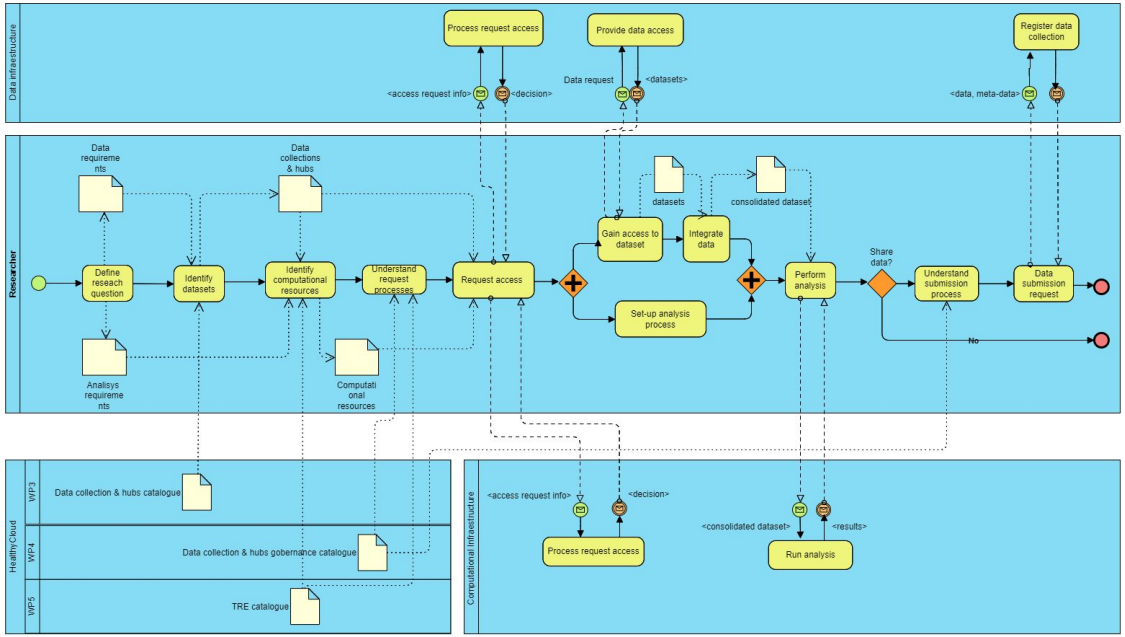

Deliverable 7.3 • "Validation of proposed solutions and gap analysis"

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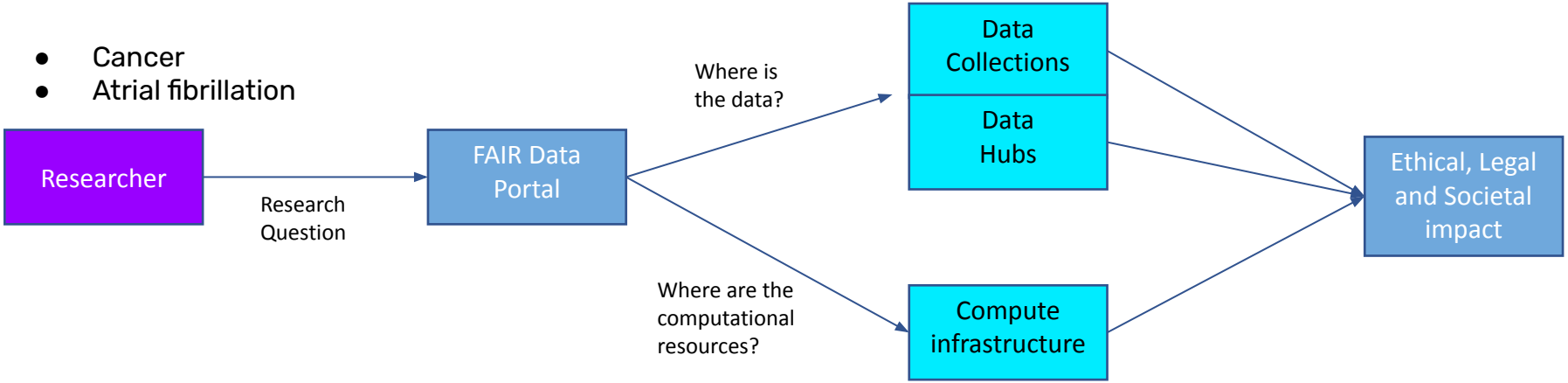

Conclusions

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- The **user journey** serves as a framework for identifying key stages for **systematically** using health-related data for research purposes across Europe.
- The **FAIR Health Data Portal** is an invaluable starting point for finding available both research data and computational resources.
- **Data access conditions** play an important role as they represent the implementation of the **data governance**.
- **Data processing** is conditioned by various factors, including computational capabilities and data granularity.
- **Collaborative alignment** with other initiatives is essential to ensure a coherent framework where researchers can use health-related data seamless.

Thank you!

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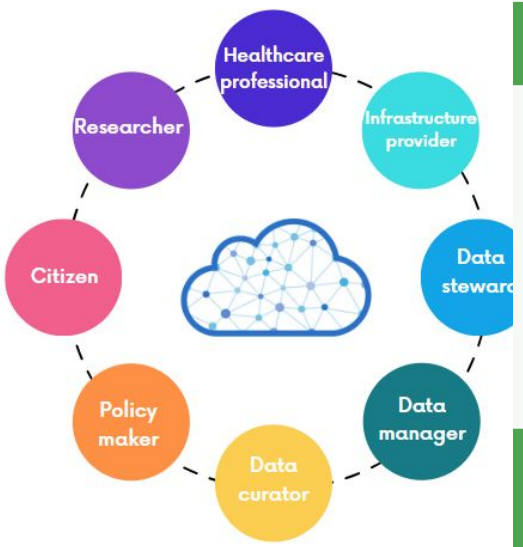
Highlights

Expected users' interactions



Contribution to HRIC

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- **Service 2**: Identification of gaps for data governance
- **Service 3**: Identification of gaps for data interoperability
- **Service 4**: A health research community interface service, with the EOSC

Lessons learned (1)

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- What would you have done differently?
  - **A broader participants expertise in the workshops**
  - **In-person workshop/s to validate the findings on the user profiles**
  - **Better definition of data and computational resources access**
  - **Better definition of access conditions of the expected for the FAIR health data portal**

Lessons learned (2)

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- Which have been the missing discussions?
  - **Collaboration with data related work packages to elaborate on services required by end-users, e.g. data anonymization, adoption of the FAIR principles, data quality assessment.**
  - **Discussions about the accessibility of computational resources**

Future directions

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- What is the missing expertise in the consortium?
  - **User experience and engagement experts**
  - **End-users of the HRIC**
  - **Broader EOSC and EHDS representatives**

Use cases scenario

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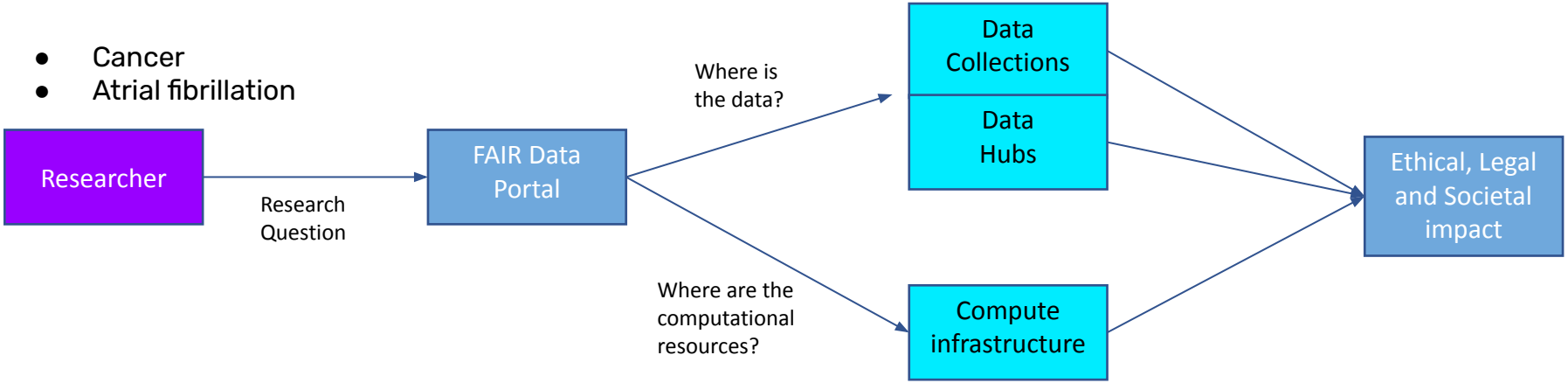

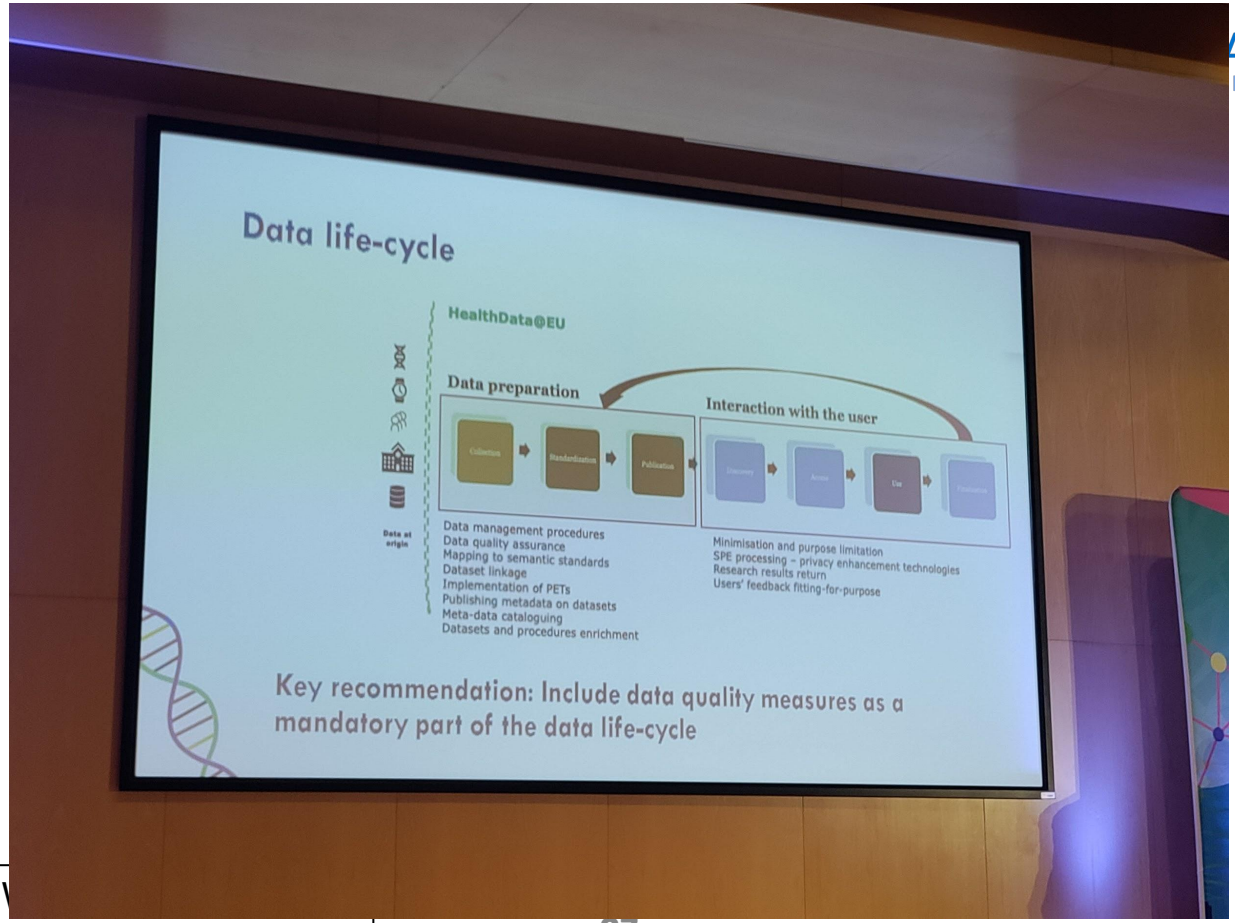

Include the V
logo in the Master Slide

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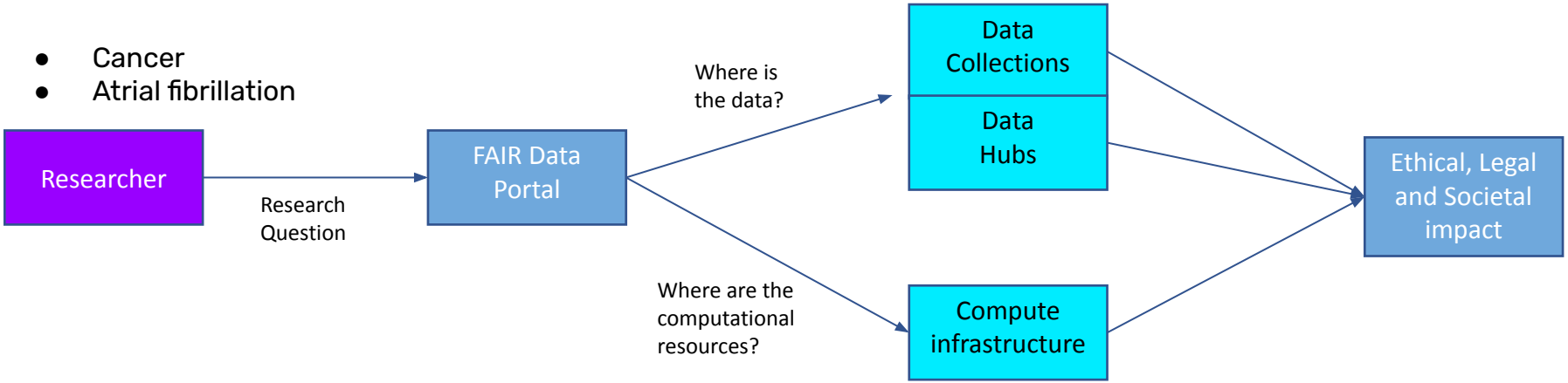
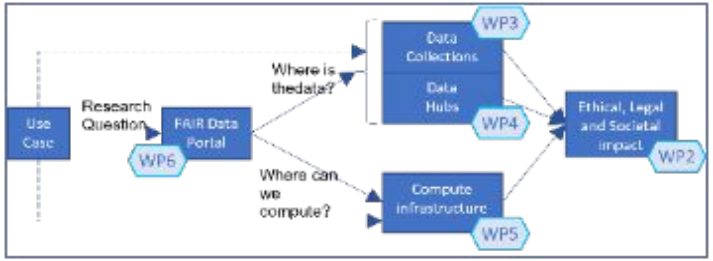
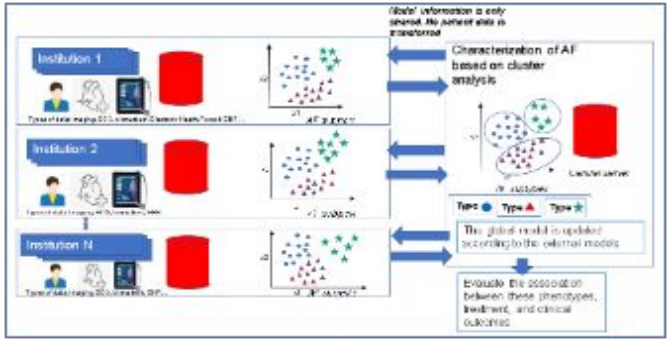
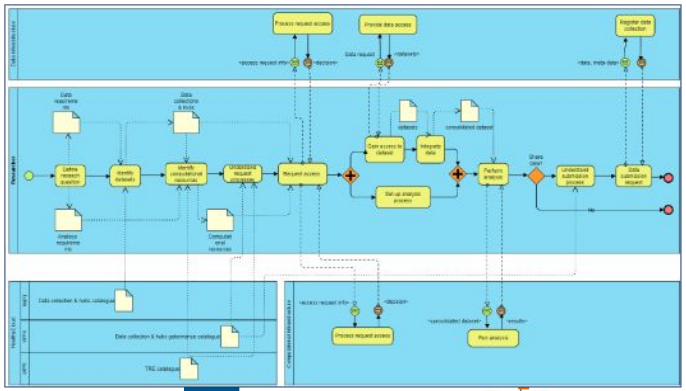


Uses cases driven analysis

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