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Health data: where to find it? How to access it?

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

Health data: where to find it?

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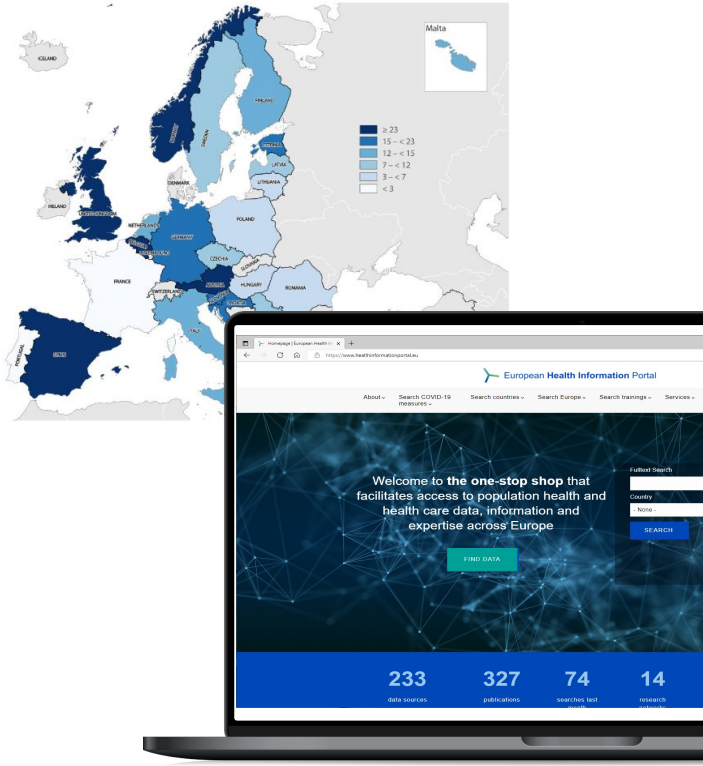
- **Landscape analysis of health-related data: FAIRness levels and feasibility of linking individual level data**
  - Survey and HealthyCloud FAIRness assessment tool
  - Collaboration with PHIRI Health Information Portal (>330 records)
  - Findings:
    - Heterogeneity of health data collections
    - Findings supportive of individual data linkage: individual level data, pseudonymisation, unique personal identifier
    - Findings not supportive of linkage: lack of interoperability
    - Variable FAIRness level

Figure 1: Map of Europe showing geographical coverage of data collections in the EU HIP metadata catalogue



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- **Guidelines to standardise metadata templates and assessment of FAIRness maturity levels**
  - Recommendations for metadata template standardisation and guidelines for FAIRness maturity levels assessment
  - Descriptive metadata record template compatible with the DCAT-AP standard

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Dedicated data infrastructures: **health data hubs**

- Analysis of data hub patterns of **governance**
- Current **discoverability** solutions and **FAIR** adoption level

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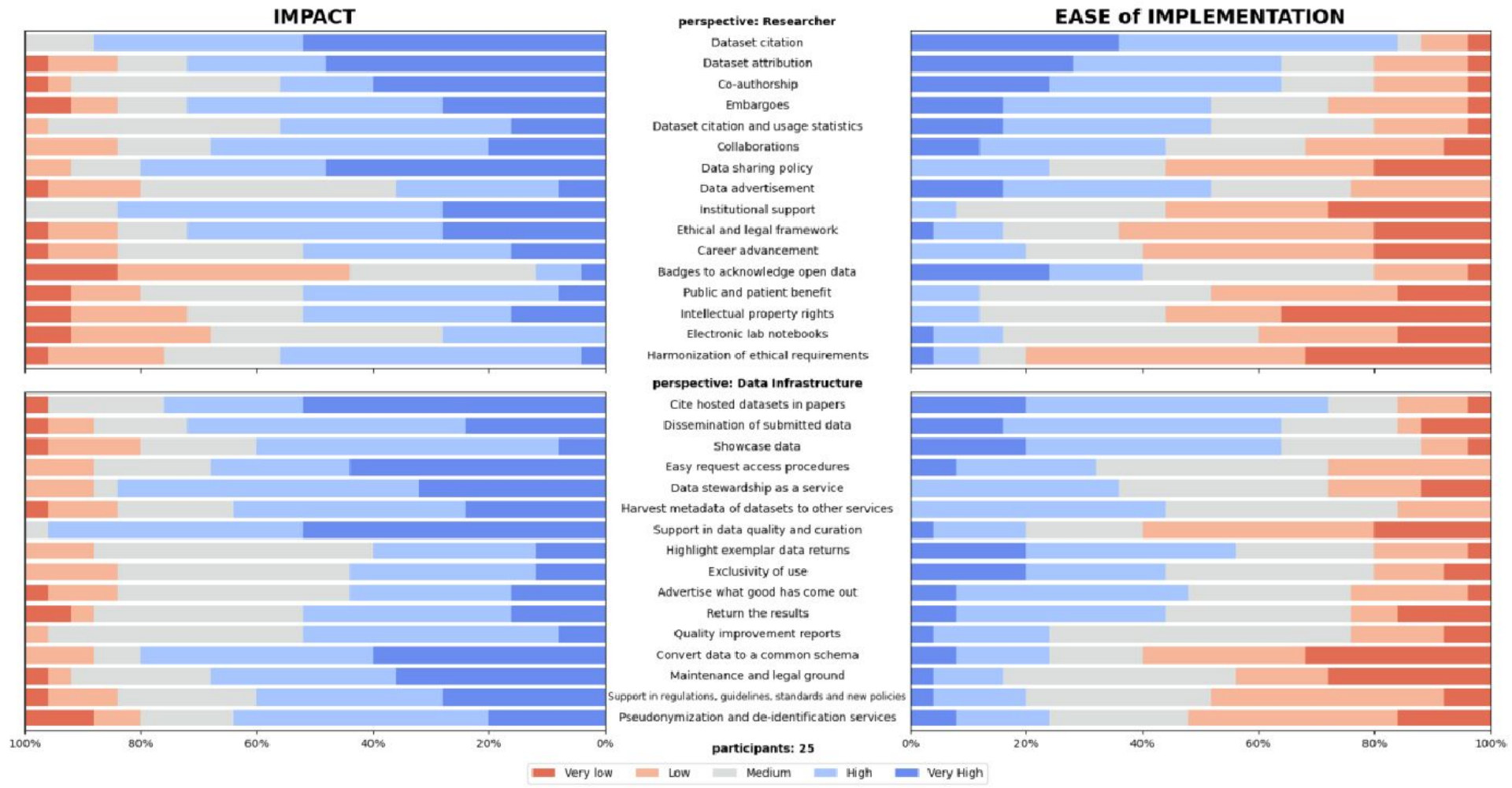
- **Usage and auditing data hubs indicators and incentive system**:

  - Measuring data usage and deposition in data infrastructures.
  - There are some incentives that could encourage data generators to share their data and data users to reuse data that is available in data hubs.
  - We have proposed that new HRIC shall recommend the use of common auditing systems and should advocate for active incentives.


IMPACT
EASE of IMPLEMENTATION
perspective: Researcher
Dataset citation
Dataset attribution
Co-authorship
Embargoes
Dataset citation and usage statistics
Collaborations
Data sharing policy
Data advertisement
Institutional support
Ethical and legal framework
Career advancement
Badges to acknowledge open data
Public and patient benefit
Intellectual property rights
Electronic lab notebooks
Harmonization of ethical requirements
perspective: Data Infrastructure
Cite hosted datasets in papers
Dissemination of submitted data
Showcase data
Easy request access procedures
Data stewardship as a service
Harvest metadata of datasets to other services
Support in data quality and curation
Highlight exemplar data returns
Exclusivity of use
Advertise what good has come out
Return the results
Quality improvement reports
Convert data to a common schema
Maintenance and legal ground
Support in regulations, guidelines, standards and new policies
Pseudonymization and de-identification services
100%
80%
60%
40%
20%
0%
0%
20%
40%
60%
80%
100%
participants: 25
Very low
Low
Medium
High
Very High

Contribution to HRIC

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- Health data availability, FAIRification and standardisation across Europe is essential for the future HRIC.

- Researchers need to know where to find diverse health-related data to be able to answer their research questions
  - Importance of **interoperable metadata catalogues**

- Gaps and needs remain in the practical application of the FAIR principles within health-related research and provided guidelines for FAIR metadata catalogues.
- The inclusion of data hubs with different data governance models across Europe is essential for the future HRIC.

Future directions

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Role of Research Infrastructures (RIs) in the HRIC:

- Systematic involvement of research infrastructures to support researchers

- Need to achieve alignment on vision of HRIC and link between RIs/EOSC/EHDS
  - How to enable researchers to get the most out of the services and tools provided in the EHDS2 and EOSC

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Thank you!