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

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Health data: where to find it?

- 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
Health data: where to find it?

• 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
Health data: how to access it?

Dedicated data infrastructures: health data hubs

- Analysis of data hub patterns of governance
- Current discoverability solutions and FAIR adoption level
Health data: how to access it?

- 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.
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Contribution to HRIC

- 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

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
Thank you!