

EMA HMA Big Data Stakeholder Forum | December 1st 2022



Health data sharing, a major priority for the European Commission and European health policy

Objective

remove obstacles to the smooth functioning of the data economy

Health data fragmentation



Diversity of access governance models

Multiple conditions for data use



Solutions

create an EU-wide governance framework for data access and use

2020

Data Governance Act proposal

2021

Joint Action TEHDAS "Towards a European Health Data Space"

2021

Pilot version of European
Health Data Space: call for
proposals financed up to 5m€

2022

Proposed European Health Data
Space legislation



The HDH, leader of a European consortium to build and operate a first version of the EHDS



HealthData@EUpilot

17 partners, 9 countries2 years5 million euros of European fundings



Create and test a beta version of the European Health Data Space



Build a network of data platforms on a European scale...



...tested by concrete crossborder use cases

































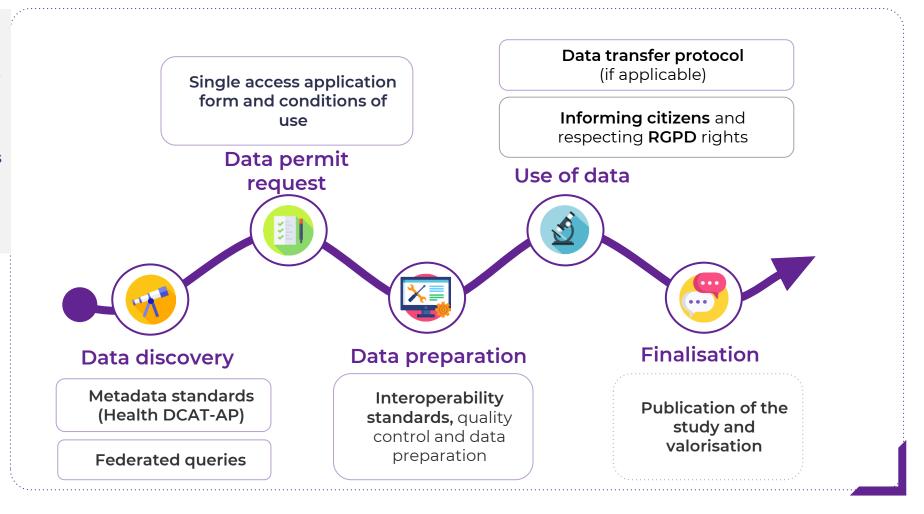


The project will cover important pieces of the overall EHDS user journey





... building on the IT infrastructure connecting the data platforms and EU central services in a network allowing information exchange (WP5)





The HDH, co-leader of building the technical backbone of the HealthData@EU pilot

WP5 builds a technical infrastructure allowing the exchange of information between

nodes and deploy a **technical**

infrastructure for the network of nodes and the link with central services

National platforms -Use European building blocks (eDelivery), **POC** nodes open source standards and establish security standards After a scoping phase, development of a National platforms -POC, then MVP and deployment of the other nodes network Ħ Central Access Metadata services **European agencies** Research nodes infrastructure nodes ecoc



Two work packages related to data discovery and interoperability



- Develop a standardised descriptive metadata (Health DCAT-AP)
 respecting the FAIR principles and User needs of the EHDS
- Implement Health DCAT-AP in the nodes
- Contribute to the implementation of a central search portal

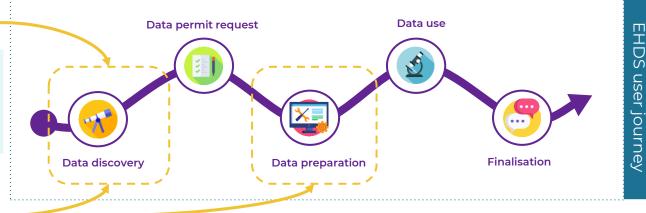


Sciensano



Norwegian Directorate of eHealth





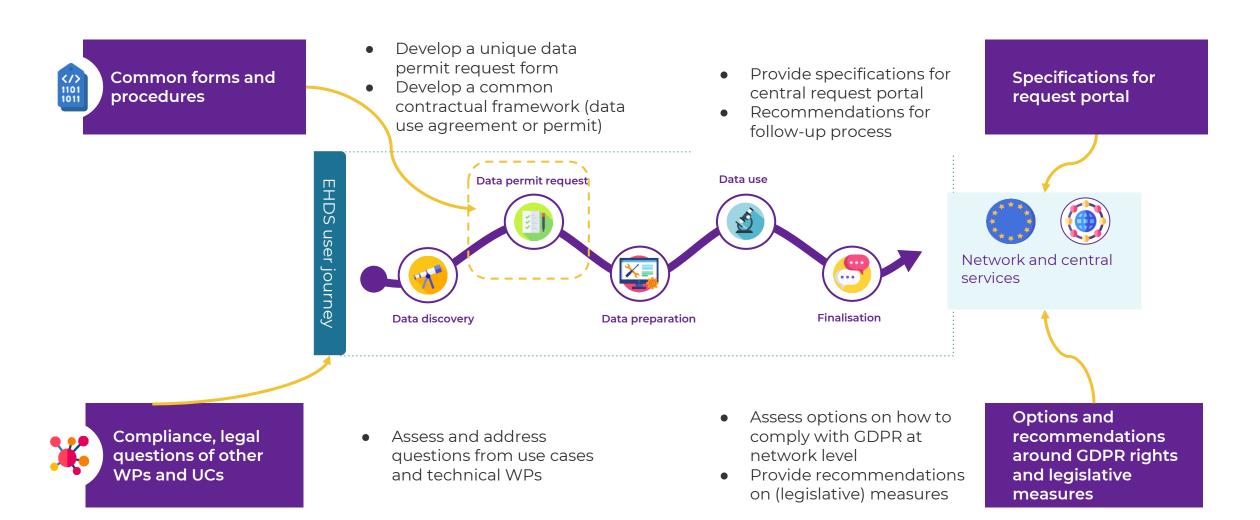


- Provide guidelines for data standards to address semantic interoperability, including data quality assurance and the definition of security prerequisites for transfer
- Investigate, and if feasible, test **solutions for query** (data discovery)
- If applicable, definition of data transfer protocol for the use cases





WP7, normative laboratory of the project





Link with IV-4 and IV-5 of the EHDS proposal

Establishment of the HealthData@EU infrastructure (art. 52)

Adoption of **delegated and implementing acts** (52-7; 52-13) around HD@EU operations

Management of access requests (art. 53-3): unique access form, permit template, contractual arrangements, etc.

Minimum dataset description (metadata) for the catalogue (art. 55-2)

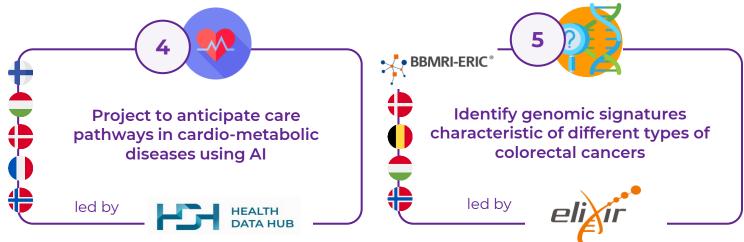
HealthData@EU datasets cataogue (art. 57)

Data quality and utility label (art. 56-4/5)



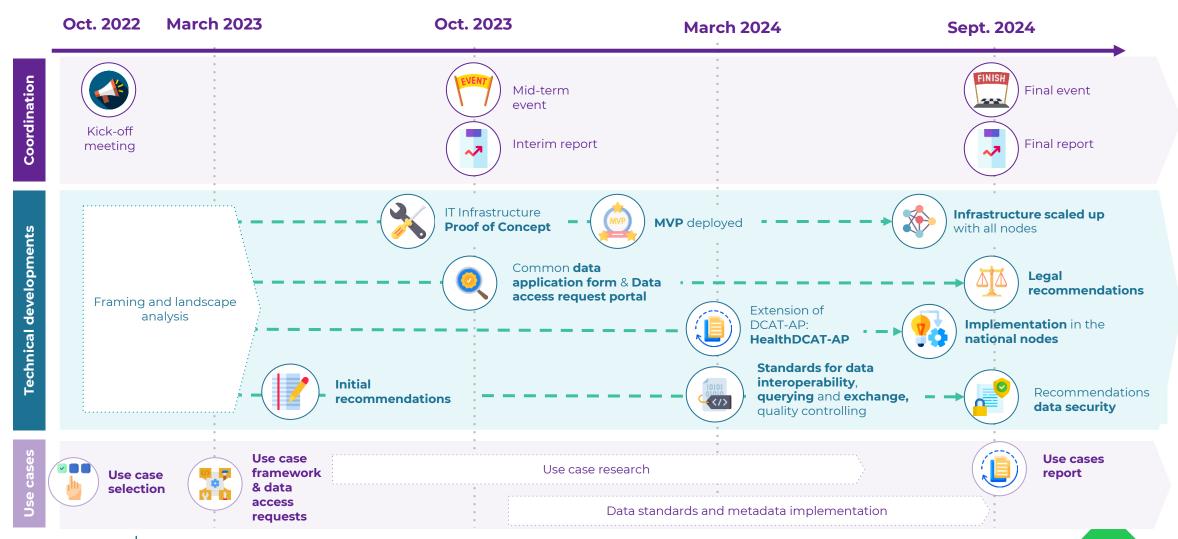
5 cross-border use cases will show the added value of HealthData@EU







Project partners have committed to an ambitous 24-month timeline





Opportunities to engage with the project



Over the 24-month project timespan, there will be multiple opportunities to engage with us!



Open call for our **External advisory Board** (Dec-22/Jan-23)



Stakeholder meetings to present and discuss project activities and outcomes



Stakeholder roundtable discussions



Interactions with the community of HDABs (working on the direct grant for HDABs)



Multiple presentations, round table discussions and forums





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