FinHITS – Towards the Future of Secondary Use of Health Data

FINDATA

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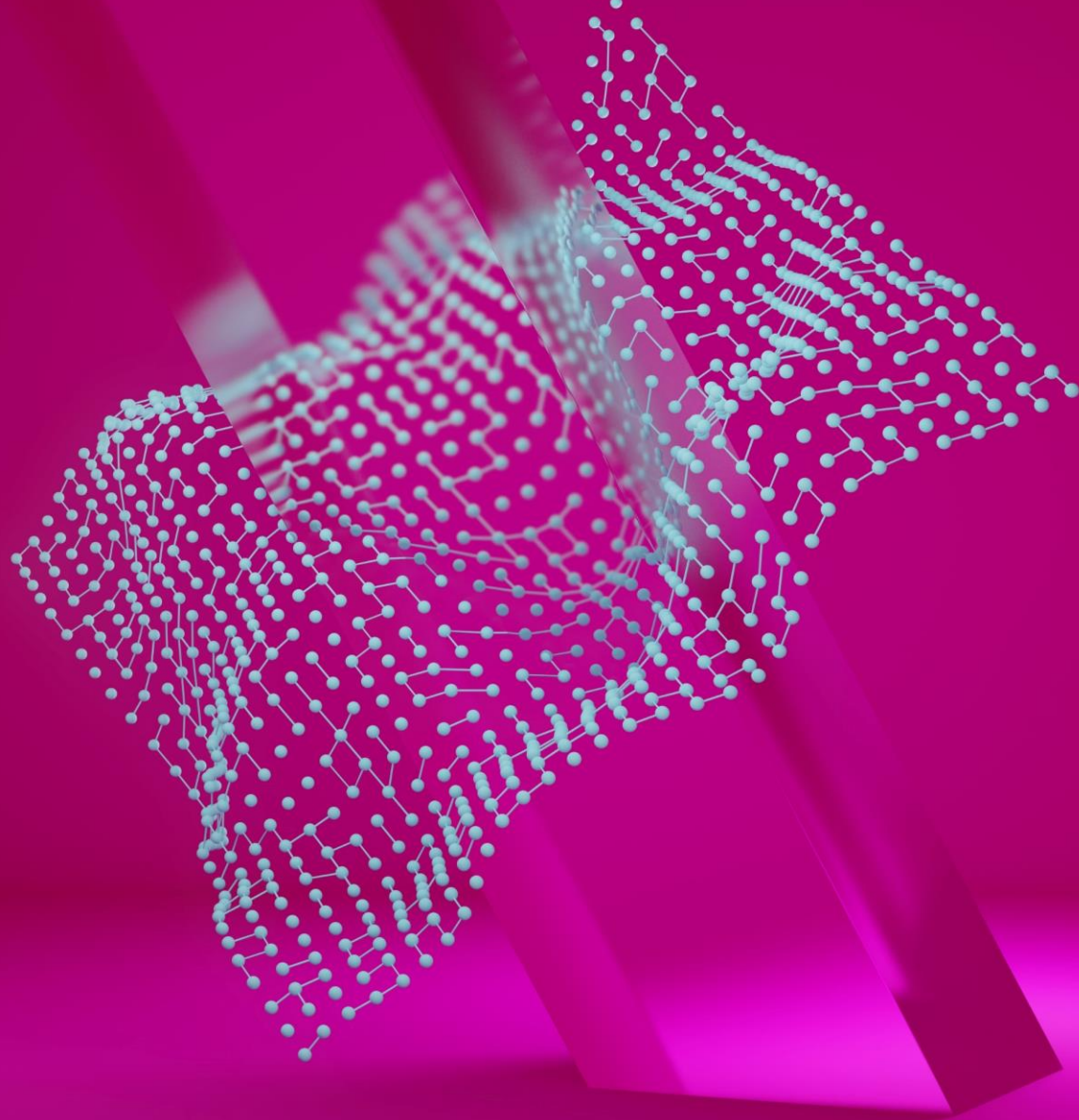
FinHITS-project

- Project Name: FinHITS – Strengthening Finnish Health Data IT for Secondary use

- Funding: EU4Health / Direct grants to Member States: for setting up services by Health Data Access Bodies - Secondary use of health data.

- Budget: Approx. 2.5 million € (37 million € available in the call) Funding approx. 1,5 million € (60 %)

- Duration: 1.11.2023–31.10.2027

- Objective: Improve the Finnish secondary use infrastructure from the perspective of the EHDS

- More information: findata.fi/finhits

Objectives

- Strengthen the Finnish data infrastructure to ensure efficient and secure secondary use of health data.

- Enable Finland to integrate seamlessly into the EHDS.

- Facilitate secure cross-border secondary use of health data.

- Support other member countries by bringing information about practical experiences.

FinHITS – Strengthening Finnish Health Data ICT for Secondary Use

Key areas of development

1. Enhance Findata's data access application management system.

2. Develop the national data resources catalogue.

3. Improve the secure processing environment to make it more efficient and versatile.

4. Participate in the development of technical solutions for cross-border data exchange between member states.

5. Promote the quality of health data.

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Work Packages and budget

Work Packages	Budget, €	Subcontract, %
WP1 Coordination	177 000	0 %
WP2 Dissemination	208 000	0 %
WP3 Evaluation	63 000	0 %
WP4 Sustainability	65 000	0 %
WP5 Data Access Application Management System	693 000	70 %
WP6 National Dataset Catalogue for health data (THL)	373 000	68 %
WP7 Secure Processing Environment for health data	333 000	56 %
WP8 Cross-border gateway	290 000	48 %
WP9 Health data quality	125 000	0 %
	Total 2 489 000	43 %

(WP1–WP4 bracketed as: Project management)

Project management (WP1–WP4)

Management and Coordination (WP1)
- National collaboration management
- Cross-border cooperation
- Monitoring and reporting
- Coordination

Dissemination, training and support (WP2)
- Dissemination of results
- Training activities (other authorities, data controllers, and users)
- Service desk and support

Evaluation (WP3)
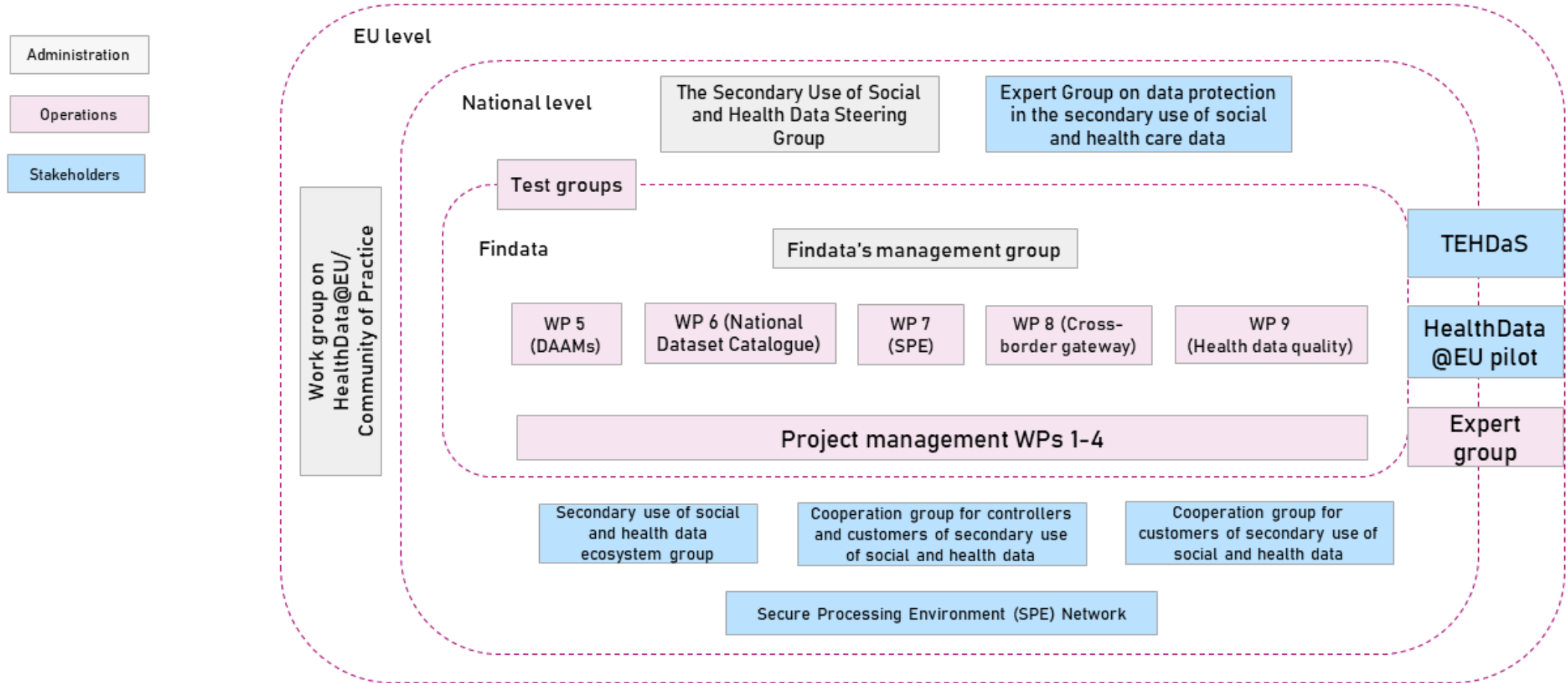- Performance monitoring
- Evaluation

Sustainability (WP4)
- Business continuity
- Sustainability of solutions

Project management and reporting

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Stakeholders and sections

FinHITS – Strengthening Finnish Health Data ICT for Secondary Use

FinHITS Advisory Group

Stakeholders

- Arho Virkki, The wellbeing services county of Southwest Finland (Varha)
- Jukka Lähesmaa, Ministry of Social Affairs and Health (STM)
- Markus Kalliola, Sitra
- Persephone Doupi, Finnish Institute for Health and Welfare (THL)
- Stella Rummukainen / Anna Silvola, Statistics Finland

Findata

- Johanna Seppänen (chair)
- Maari Parkkinen (secretary) (FinHITS, WP5)
- Satu Sandholm (WP1-WP4)
- Peija Haaramo (WP6 ja WP9)
- Hanna Tervonen / Hannu Vilpponen (WP7)
- Antti Piirainen (WP2)

EHDS2 Community of practice (CoP)
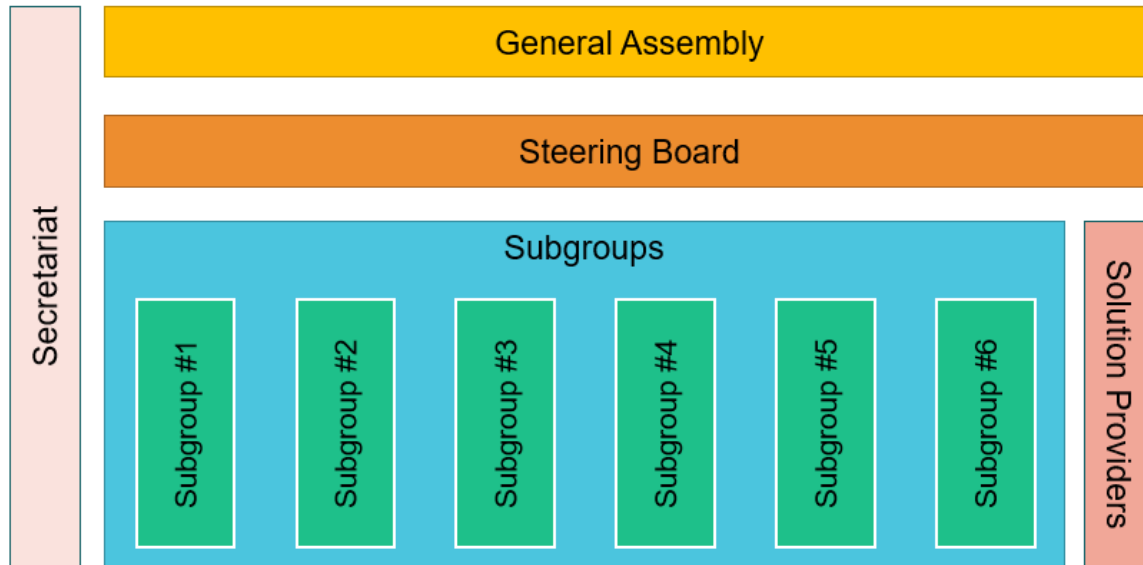
Representation of Findata:

General Assembly Johanna Seppänen (chair)

Subgroups:

1. **Data Access Application systems**
   - Maari Parkkinen (expert member)

2. **Health Datasets Metadata Catalogue and Data Quality and Utility**
   - Peija Haaramo (expert member)

3. **Secure Processing Environments**
   - Hannu Vilpponen (expert member)

4. **Cross-border Gateways**
   - Hannu Vilpponen (expert member)

5. **Deployment and Operations**
   - Satu Sandholm (expert member)

6. **Stakeholders' Fora**

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# Data Access Application Management System (WP5)

Challenges
- Current system doesn't support formation of data descriptions or communication between different parties.
- No real-time tracking of application status for customers.
- Lacks organization view and connections between organizations and individuals in the system.

Solutions
- Data description tool and processing of data descriptions in structured format, collaboration with data controllers.
- Improved portal to facilitate data flow (status information, better user management).

Outcome
- Smoother and more efficient service.
- Processing times in line with EHDS requirements.
- Reduced extraction errors.
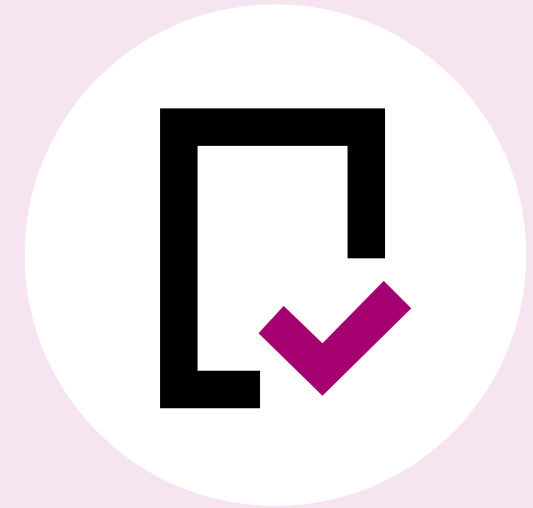
We are developing and enhancing the service portal.

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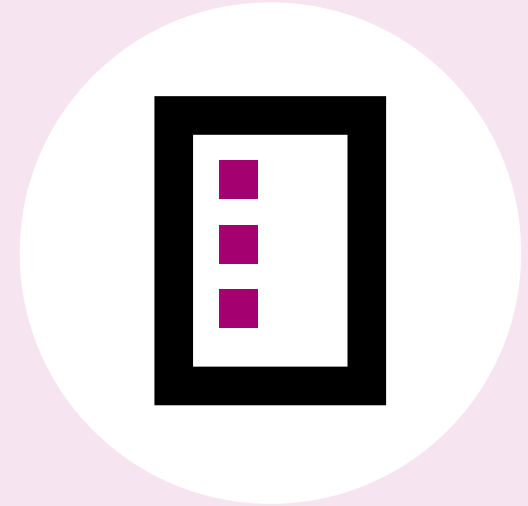# National Dataset Catalogue for health data (WP6)

Challenges
- Does not meet the needs of growing user base and international clients.
- Not EHDS compliant.

Solutions
- Improving usability.
- Considering international clients.
- Integration with the Findata's e-service.

Outcome
- Smoother dataset retrieval.
- Usable for international customers.
- Fulfills EHDS requirements for national dataset catalogue, including the use of applicable standards.

We are developing the data resource catalogue in collaboration with THL and ensuring its international usability.

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Secure Processing Environment for health data (WP7)

Challenges
- Does not support the growing number of users, handle very large datasets, or utilize advanced methods.

Solutions
- Increasing computing power (GPU).
- Enhanced license management.
- Anonymization tool and tools for verifying anonymization.
- Federated analysis.

Outcome
- Smoother and faster process for verifying the anonymity of results.
- More suitable for large-scale data projects.
- Potential new requirements.

We are strengthening our SPE in terms of capacity, usability, and information security.

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Cross-border gateway (WP8)

Challenges
- No technical solution for the cross-border transfer of health data for secondary use.

Solutions
- Connect to the HealthData@EU infrastructure to enable cross-border workflows for secondary use of electronic health data at EU-scale.

Outcome
- Integration into the cross-border gateway infrastructure in compliance with EHDS, leveraging the outcomes of the HealthData@EU Pilot.

We are establishing a connection to the HealthData@EU infrastructure.

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Health data quality (WP9)

Challenges
- Due to lack of time and resources, Findata has been unable to update tools and guidelines for improving data quality.

Solutions
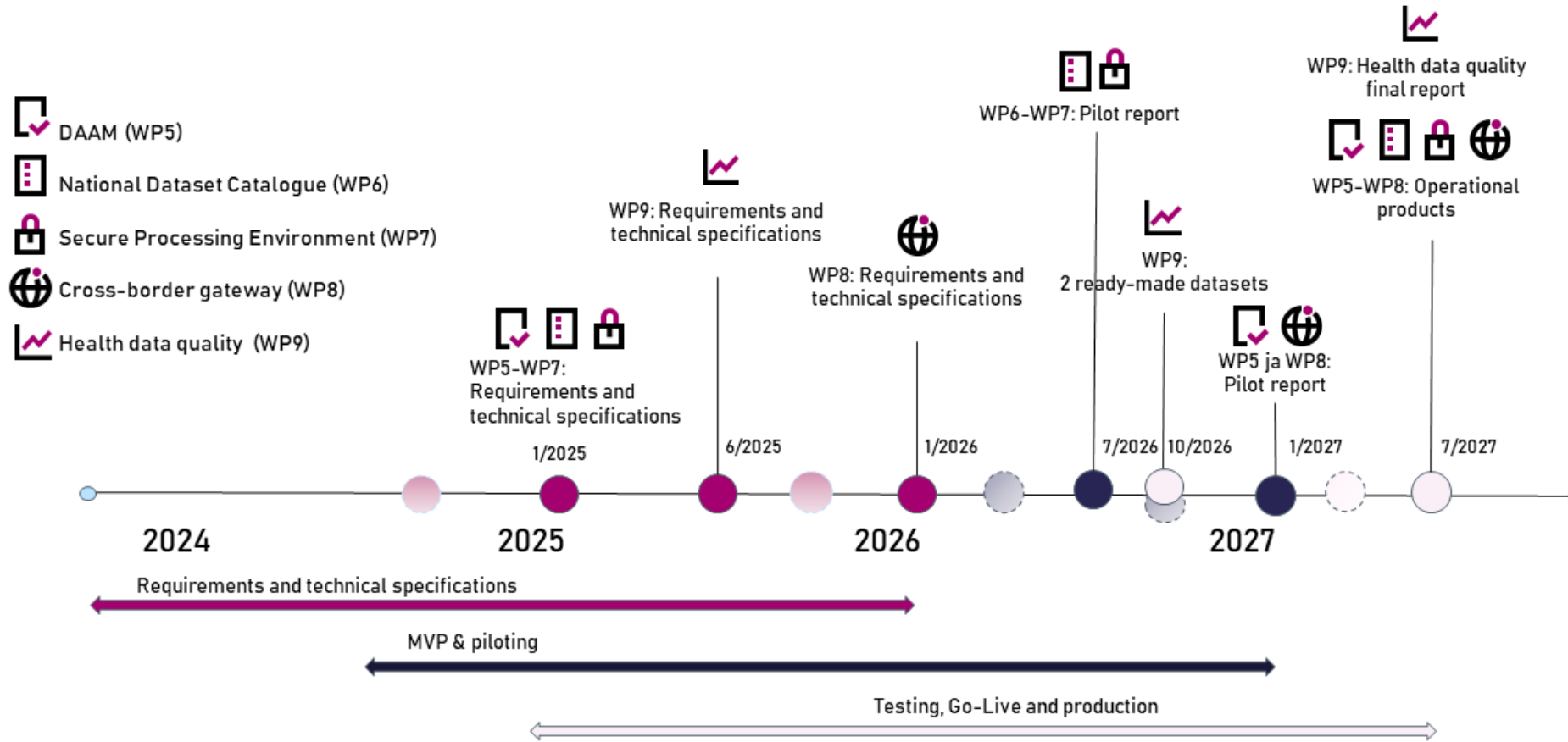- Provide solutions and instructions to enhance the quality.
- Two ready-made datasets.

Outcome
- Two new ready-made datasets available for customers to access and extract data from.
- Findata's role in supporting data quality throughout its lifecycle is clear.
- Produced support materials on data quality.
- Update the national guidelines and instructions on data descriptions as needed to comply with EHDS regulations, including data quality aspects.
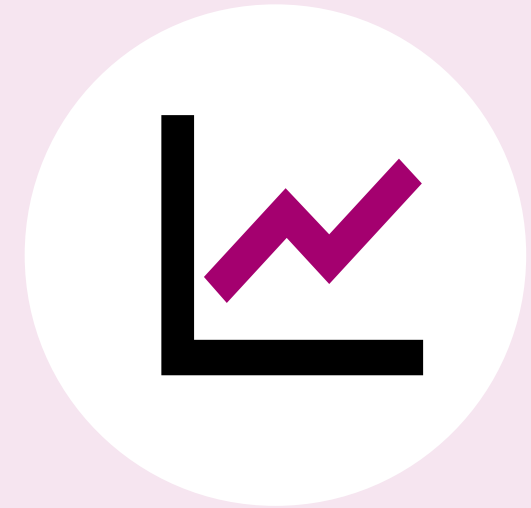
We improve data quality by developing tools, providing support, creating guidelines, and compiling ready-made datasets.

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Timeline

DAAM (WP5)

National Dataset Catalogue (WP6)

Secure Processing Environment (WP7)

Cross-border gateway (WP8)

Health data quality (WP9)

WP5–WP7: Requirements and technical specifications

WP9: Requirements and technical specifications

WP8: Requirements and technical specifications

WP6–WP7: Pilot report

WP9: 2 ready-made datasets

WP5 ja WP8: Pilot report

WP9: Health data quality final report

WP5–WP8: Operational products

1/2025 6/2025 1/2026 7/2026 10/2026 1/2027 7/2027

2024 2025 2026 2027

Requirements and technical specifications

MVP & piloting

Testing, Go-Live and production

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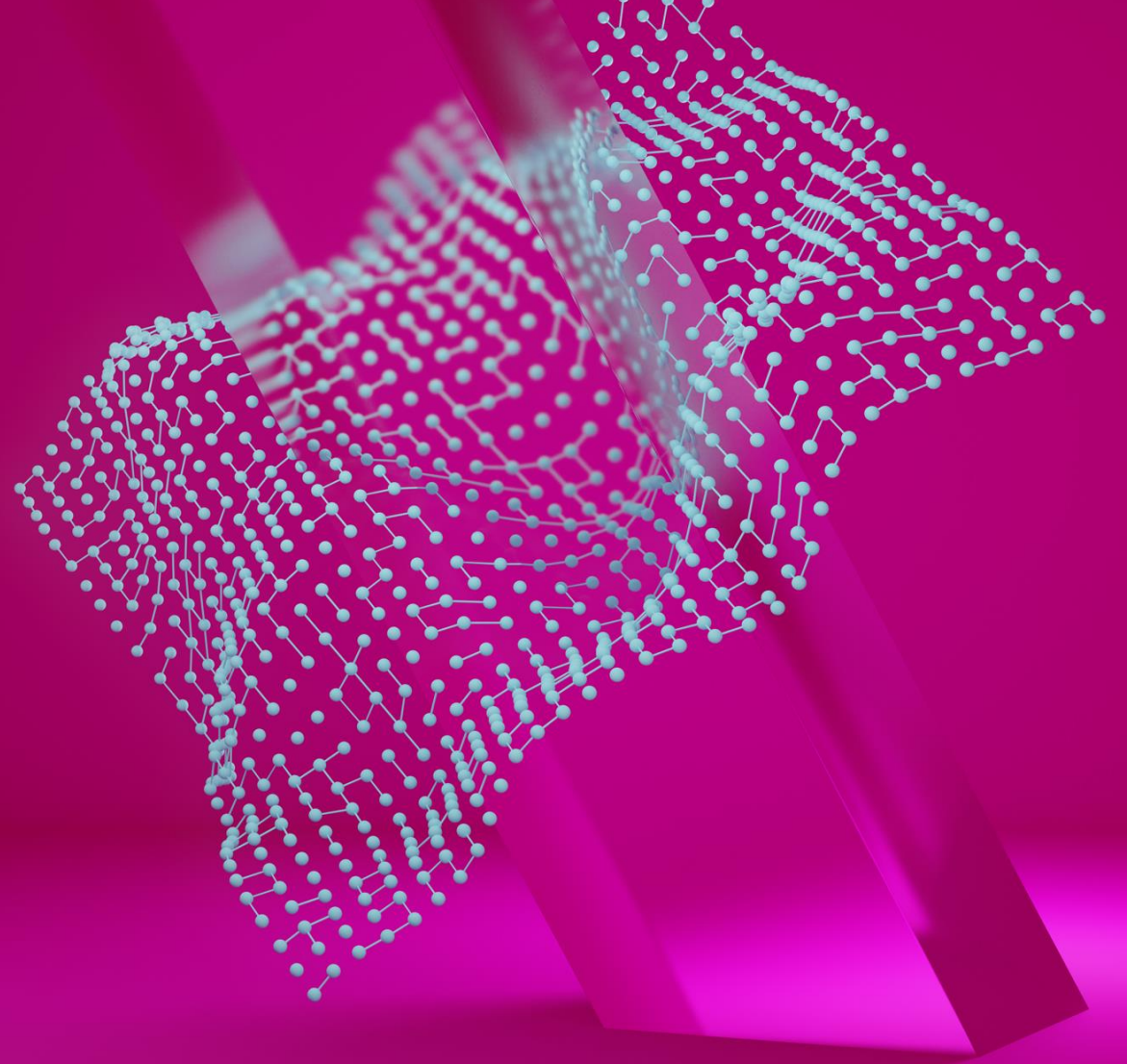
Let's develop digital services together!

- Assessing stakeholder needs and wishes: Satisfaction survey, kickoff event, and workshops.

- Stakeholder engagement plan Fall 2024.

- In November 2024, a virtual event: presentation of project plans.

- Piloting and testing of developed tools from 2025 to 2026.

- Final seminar and presentation of solutions in 2027.

- Other FinHITS-related events and training sessions are also planned for the years 2024–2027.

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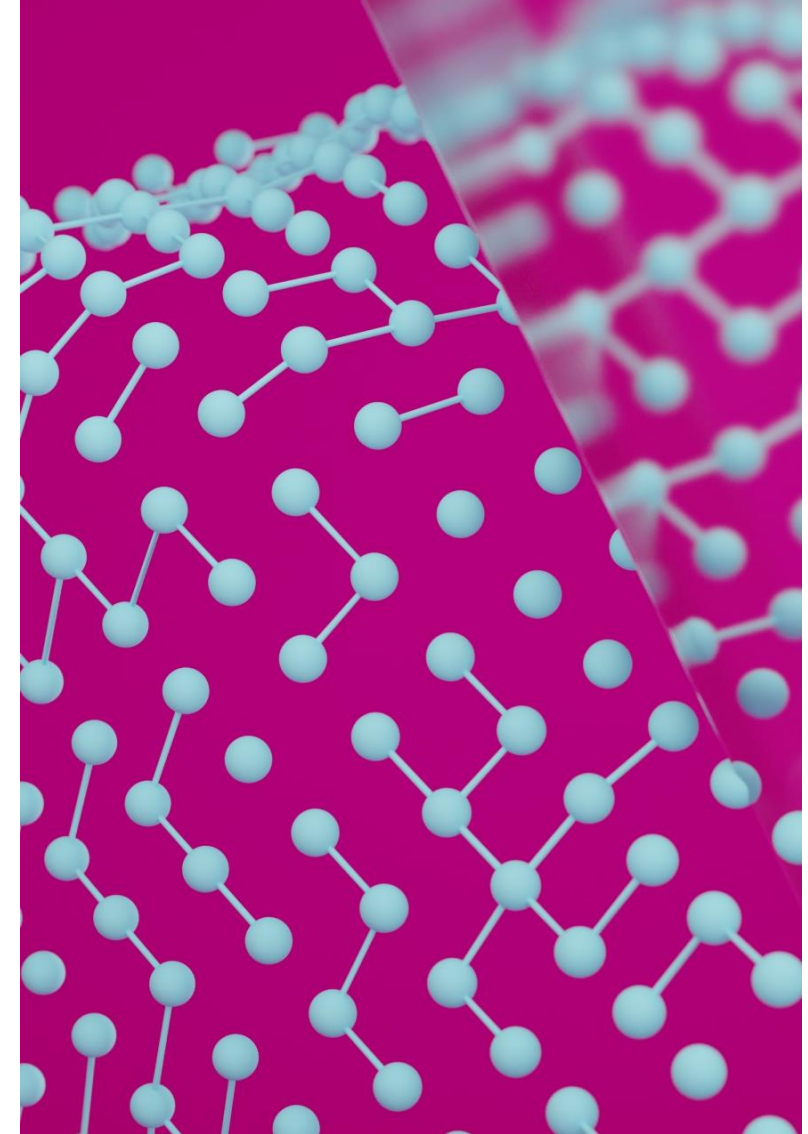
Thank you!

findata.fi/finhits
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