

Towards the European Health Data Space

13 October 2022

Markus Kalliola

Project Director

TEHDAS coordinator



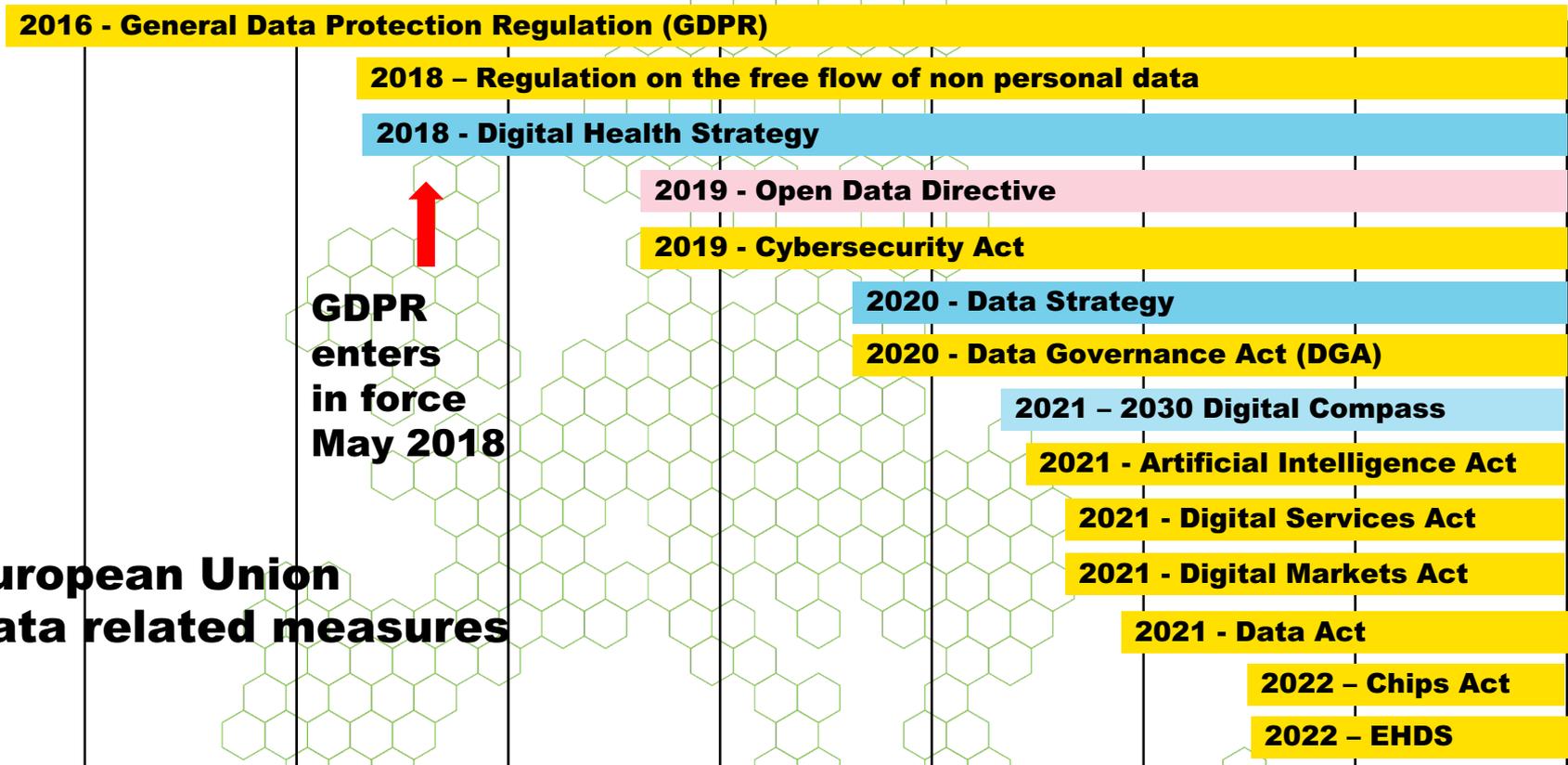
Agenda

European data policies and the European Health Data Space

Joint Action Towards the European Health Data Space (TEHDAS)



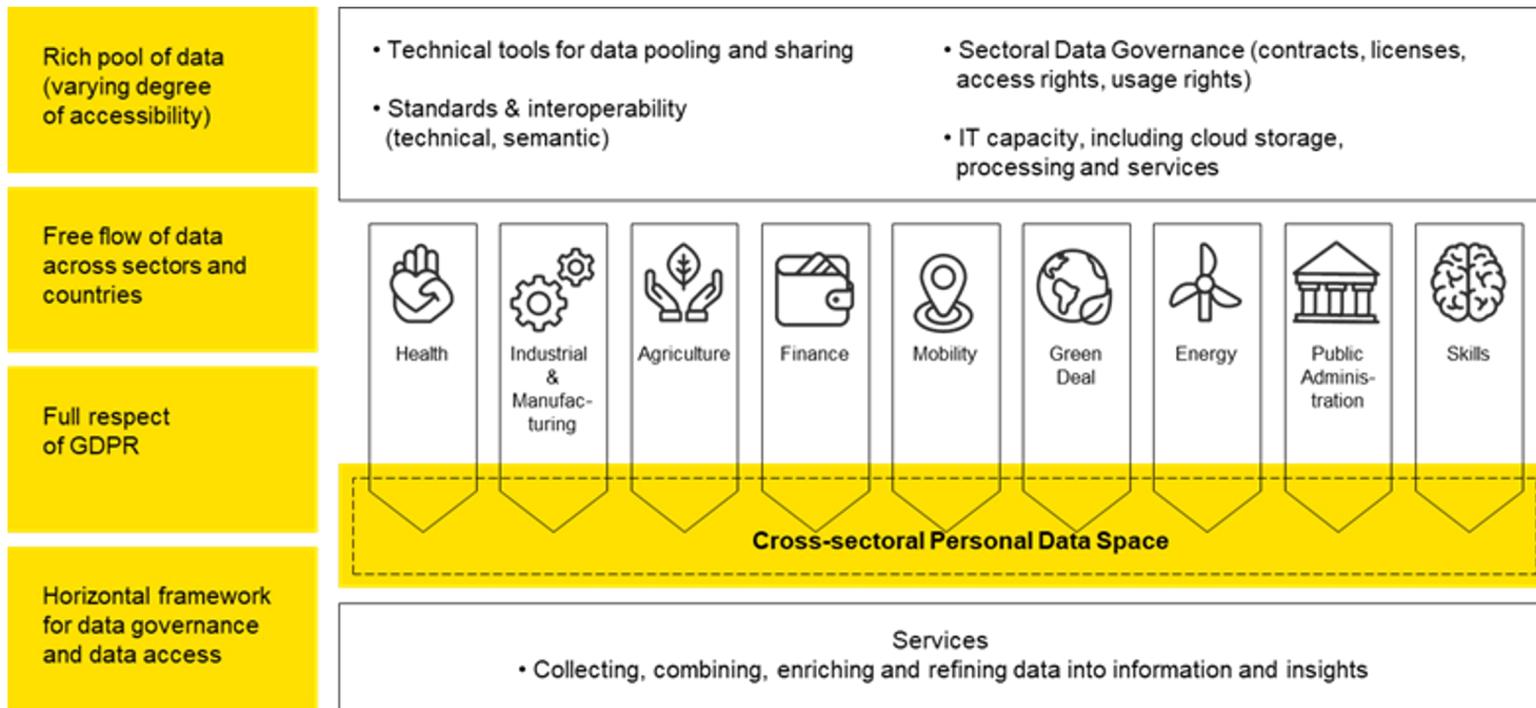
2016 2017 2018 2019 2020 2021 2022 2023



GDPR enters in force May 2018

European Union Data related measures

EU data strategy and Data Spaces



The European Health Data Space is a health specific ecosystem comprised of rules, common standards and practices, infrastructures and a governance framework

EHDS Proposal published 03/05/2022

EHDS proposal in a nutshell

- 1 Chapter 1: General provisions (Art. 1 -2)**
- 2 Chapter 2: Primary use of electronic health data (Art. 3 - 13)**
- 3 Chapter 3: EHR systems and wellness applications (Art. 14 - 32)**
- 4 Chapter 4: Secondary use of electronic health data (Art. 33 - 58)**
- 5 Chapter 5: Additional actions (Art. 59 - 63)**
- 6 Chapter 6: European governance and coordination (Art. 64 - 66)**

7-9

**Chapter 7-9: Delegation, Miscellaneous, Deferred application
(Art. 67 - 72)**



European Health Data Space (EHDS)

OBJECTIVES

Effective use of health data

SCOPE & EXPECTED IMPACT

Use of health data
(primary,
MyHealth@EU)

- Empower individuals to control their data
- Standardization and mandatory certification of EHR systems
- Voluntary labelling of wellness apps
- European Electronic Health Record Exchange Format

Single market for health data, data protection, free movement of people, digital goods and services

Re-use of health data
(secondary,
HealthData@EU)

- Health data access bodies
- Purposes for use and forbidden use
- Data permits, secure environments, no identification

Facilitated Research & Innovation
Better Policy Making

MEANS

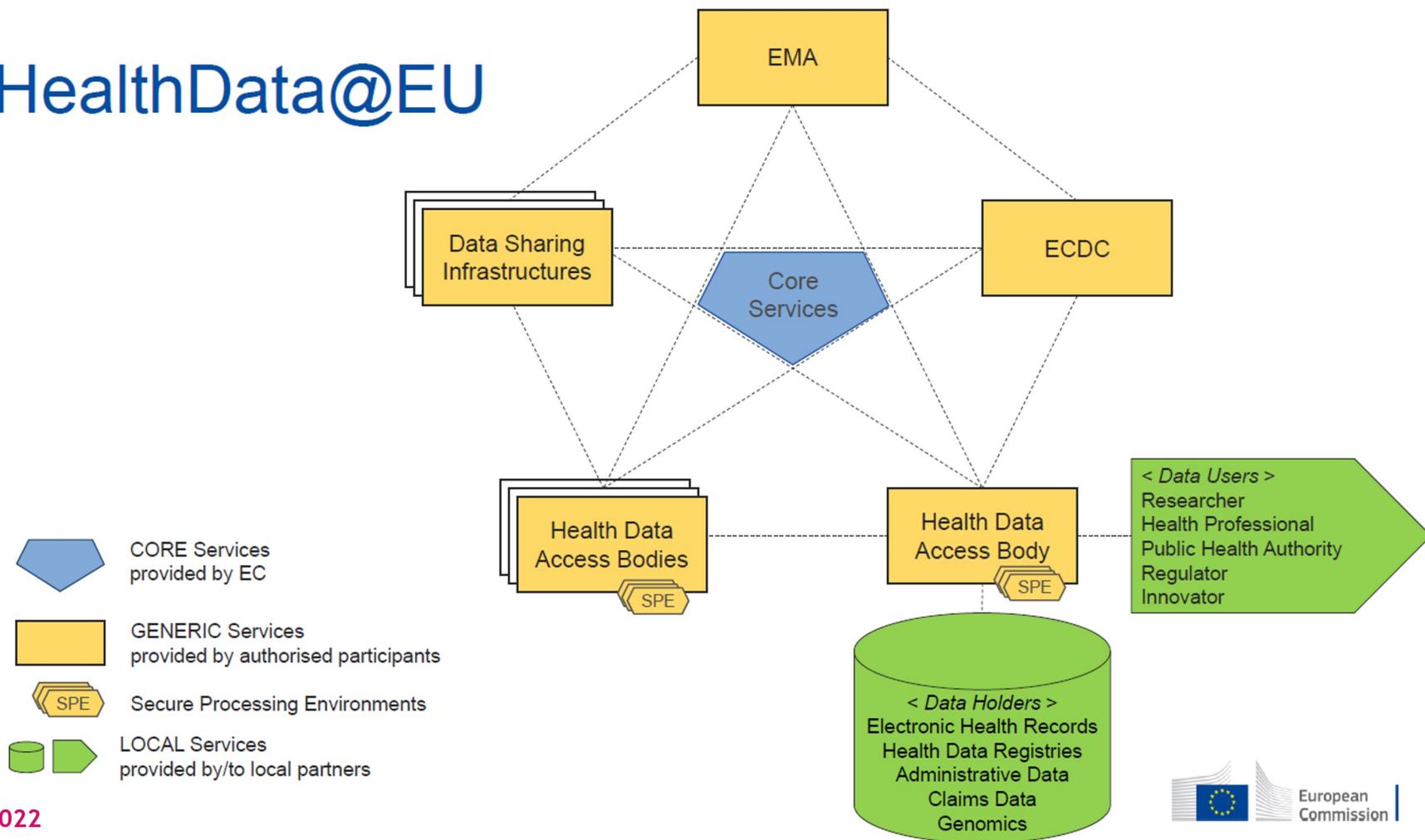
Legal / Governance

Quality of data

Infrastructure

Capacity building/digitalisation (MFF)

HealthData@EU



Funding

Overall funding for EHDS and its infrastructures

- Around € 800 mil

Earmarked funding: € 330 mil

- EU4Health: € 280 mil
- DEP: € 50 mil

Complementary funding: ≥ € 480 mil

- DEP: €140 mil
- CEF: €130 mil
- HE: € 210 mil

Funding for national investments

- RRF: € 12 bn
- ERDF
- InvestEU

Agenda

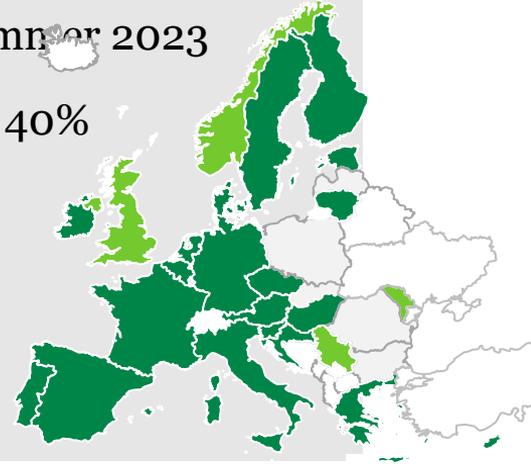
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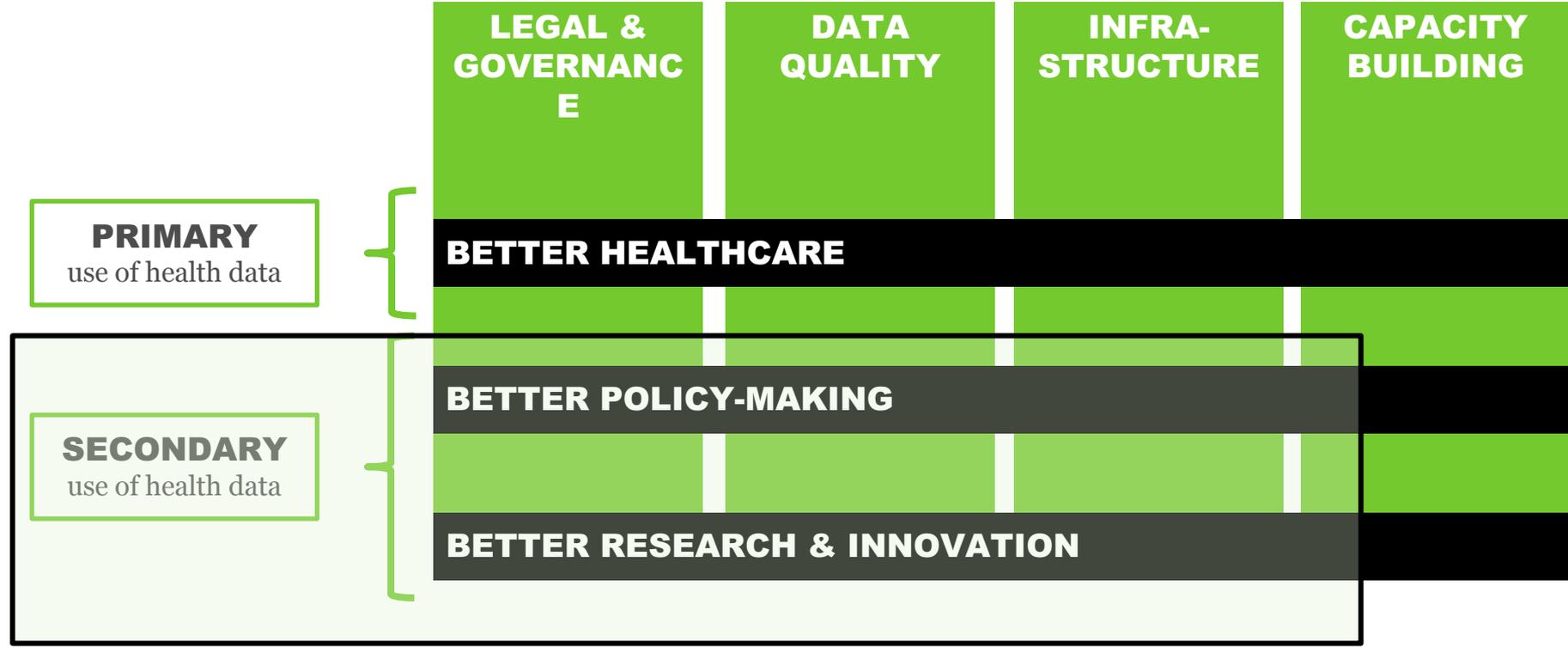


Joint Action Towards the European Health Data Space - TEHDAS

Joint Action	Supports the Member States and the Commission Develops and promotes concepts for sharing of data in secondary use
Participants	Nominated authorities from 25 European countries
Duration	30 months from February 2021 – Summer 2023
Co-funding	€4 million - EU 60%, Member States 40%
Project coordinator	Sitra, Finnish Innovation Fund



Four pillars of the European Health Data Space



The needs, expectations and views of stakeholders on economic sustainability



Options for governance models for data-sharing at EU level, in particular networking for secondary use

Definitions, good practices and use cases of GDPR-compliant data altruism



Secondary use of health data



Availability of comparable high-quality health data for research and innovation

Citizen perception of health data and data-sharing practices



Shared European data infrastructures across the EU (cf. eHDSI)



A steady flow of outputs in 2021-2023

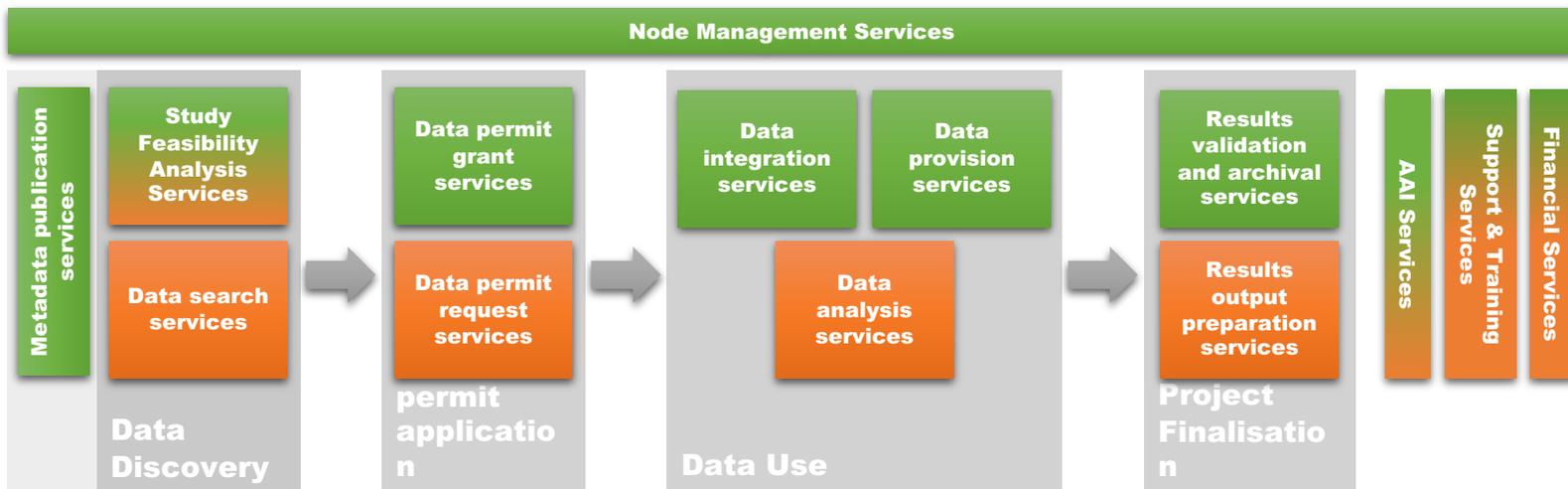


Barriers on cross-border sharing of health data for secondary use and options to overcome these

- 47 papers reviewed by 4 reviewers to identify barriers
- from 89 barriers 20 went through detailed analysis and 11 barriers were prioritized
- 23 European countries provided 113 case studies to give real-life examples of the 11 barriers on impact, issues and solution
- 6 were legal
- 3 were data/semantic related
- 1 infrastructure
- 1 trust

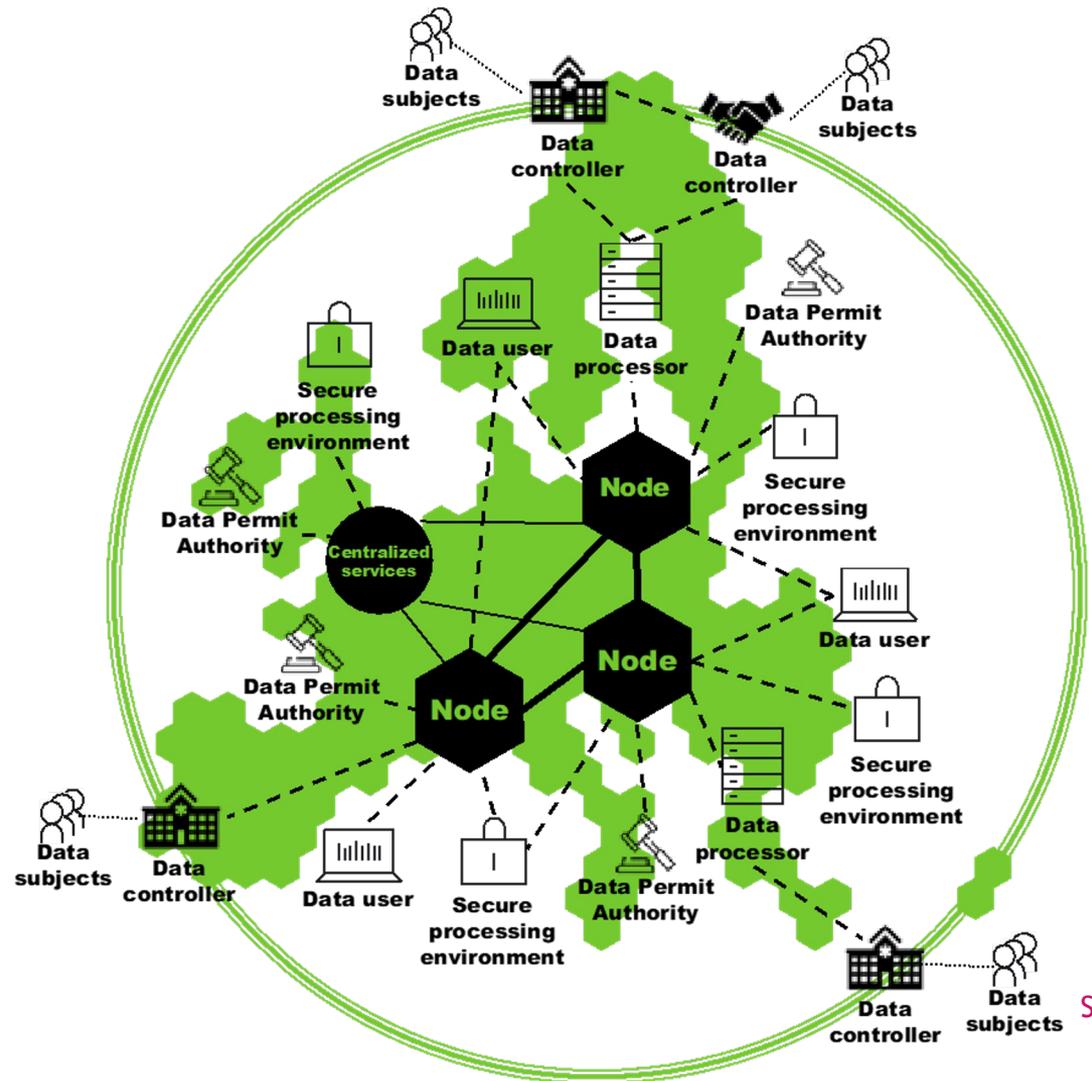


User's Journey Services



- Infrastructure services**
- Services with data user interaction**

Overall architecture



@markuskalliola  

Markus.Kalliola@sitra.fi

+358503591499



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Audience Q&A Session

① Start presenting to display the audience questions on this slide.