

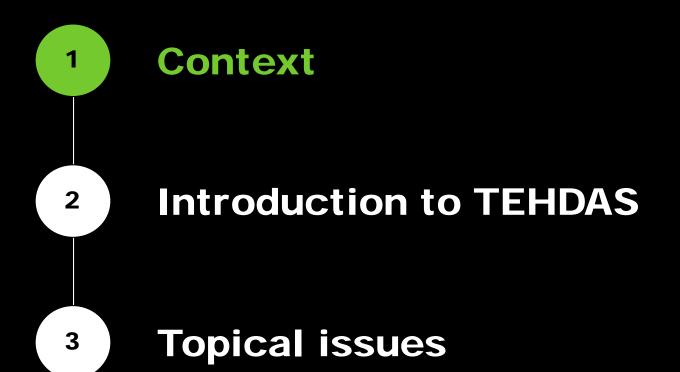
# **TEHDAS**

3.6.2021 Markus Kalliola, Project Director, Sitra TEHDAS Coordinator















#### Rich pool of data

with a varying degree of accessibility

#### Free flow of data

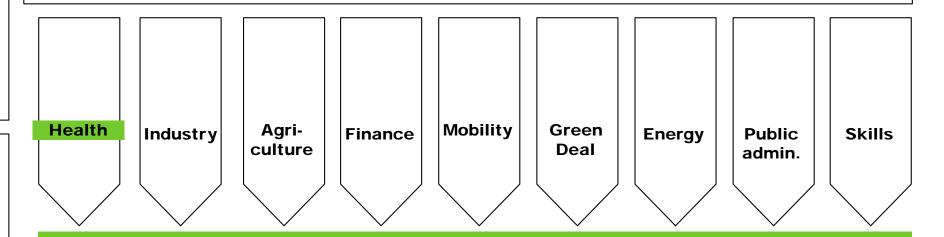
across sectors and countries

GDPR, DSA, DGA, AI, Data Act et al. and their full respect

### Horizontal framework

for data governance and data access

- Technical tools for data pooling and sharing
- Standards and interoperability (technical, semantic)
- Sectoral Data Governance (contracts, licenses, access and usage rights)
- IT capacity (cloud storage, processing, services)



#### **Cross-sectoral Personal Data Space**

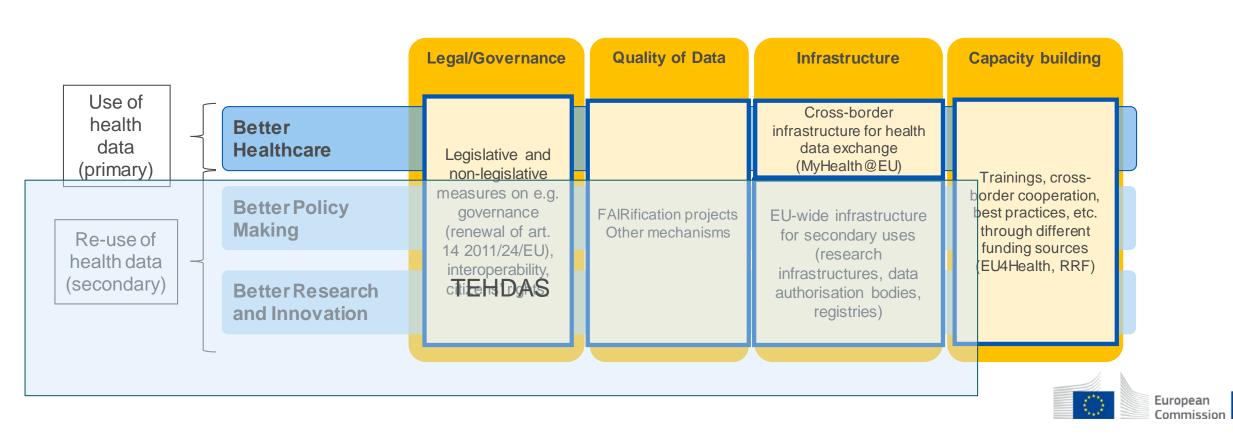
#### **Services**

Collecting, combining, enriching and refining data into information and insights

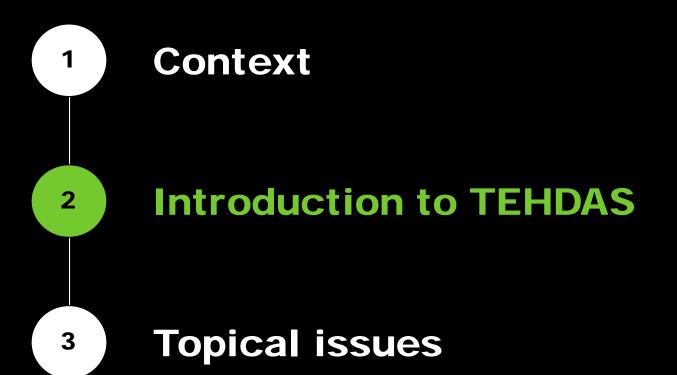




# Primary and secondary uses of health data













### **TEHDAS** in a nutshell

**Project coordinator** 

**Project acronym** 

**Start date** 

**Duration** 

**Participants** 

**Co-funding** 

Work packages

**Websites** 

**Contact** 

The Finnish Innovation Fund Sitra

**TEHDAS** 

1 February 2021

30 months

25 European countries

€4.16 M (EU €2.5 + MS €1.66)

8

www.tehdas.eu

tehdascoordination@sitra.fi







# Vision and mission







The Joint Action helps the Members States and the Commission in

developing and promoting concepts for sharing of data in secondary use for purposes

for citizens' health, public health, as well as health research & innovation in Europe.







In the future Europe, citizens, communities and companies benefit from a protected and secure access to seamless health data regardless where it is stored.

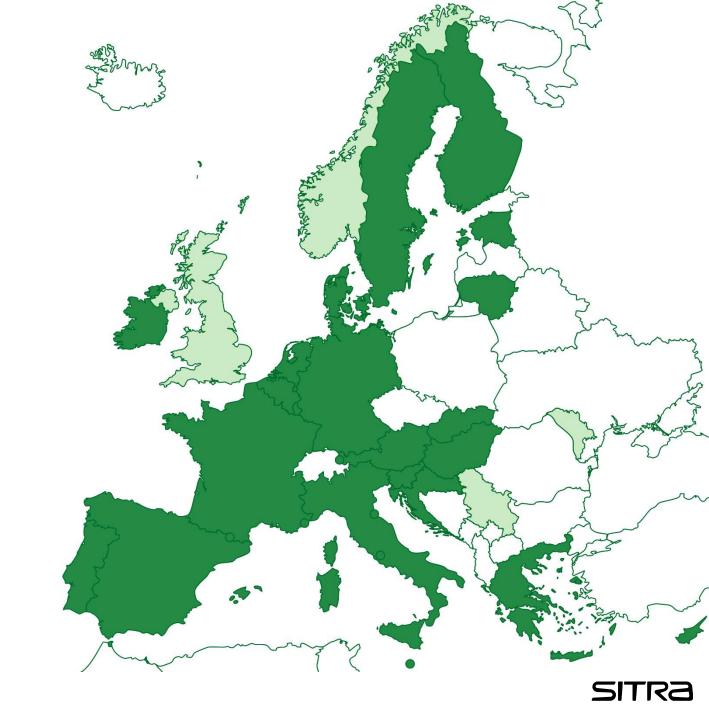






### **Participants**

- EU member states (21)
- Non-EU member states (4)
- Non-participating states





#### What TEHDAS is

- 1. Creates concepts for the secondary use of health data in Europe
- 2. A preparatory body
- 3. A project between beneficiaries nominated by Member States
- 4. Co-funded by the EU Health Programme
- 5. Clear scope with defined Deliverables and timeline

## Co-funded by The Health Programme of the European Union

#### What TEHDAS is not

- 1. Creates concepts for primary use of health data in Europe
- 2. A legislative/executive body
- 3. Defines the EHDS
- 4. Builds working IT solutions
- 5. Pilots use-cases / exchange data
- 6. Part of Horizon Europe
- 7. Creates a code of conduct for health data usage



The needs, expectations and views of stakeholders on economic sustainability

Sustainability

Governance

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

Definitions, good practices and use cases of GDPRcompliant data altruism

Data altruism

Secondary use of health data

**Data quality** 

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

Citizen perception of health data and data-sharing practices

Citizen engagement

Infrastructure

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







### First result out in June!

- Why Health is a Special Case for Data Governance? (June)

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1 Context

Introduction to TEHDAS

Topical issues







2020-09-16, Commission President von der Leyen, State of the Union

"We need common data spaces - for example, in the energy or healthcare sectors. This will support innovation ecosystems in which universities, companies and researchers can access and collaborate on data."

2020-10-02, European Council, Summit Conclusions

• "The European Council welcomes the creation of common European data spaces in strategic sectors, and in particular invites the Commission to give priority to the health data, which should be set up by the end of 2021."

2020-10-19, Commission work programme 2021

• Plan: Legislative proposal for the European health data space, incl. impact assessment, Articles 114 and 168 TFEU, Q4 2021

2020-11-11, Commission Communication on building a European Health Union

• "The set-up of the European Health Data Space will be an integral part of building a European Health Union..."

2021-03-30 President of the European Council and the Director-General of the WHO

World leaders call for new international treaty to improve pandemic response. "..enhancing international cooperation to improve, for example, alert systems, data-sharing, research.."

**2021-04-20, Angela Merkel** 

"EU 'probably' needs treaty changes, especially for health policy"

2021-04-21, Commissioner Stella Kyriakides

• "We're putting the structures in place," "We cannot work with ad-hoc solutions anymore."







# **EHDS Consultation open**

03 May 2021 - 26 July 2021

https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12663-A-European-Health-Data-Space/public-consultation\_en

# **TEHDAS Stakeholder Forum**

October in Helsinki – Stay tuned!







### Join the dialogue!

We encourage you to participate in a dialogue about the European Health Data Space. Follow us on Twitter @tehdas and tag us in your tweets.

Sign up to our TEHDAS Newsletter via our website tehdas.eu/contact.

Markus Kalliola

**Project Director** 

**TEHDAS Coordinator** 

Markus.Kalliola@sitra.fi

+358503591499

@markuskalliola

### www.tehdas.eu

@tehdas

tehdascoordination@sitra.fi

**#TEHDAS** 

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