TEHDAS Joint Action
Towards the European Health Data Space

Joint Action for the European Health DAta Space

Workshop on the application of the General Data Protection Regulation (GDPR) in the area of health and Secondary Use of Data for Medicines and Public Health Purposes

29 September 2020

Markus Kalliola
TEHDAS Coordinator

SITRA

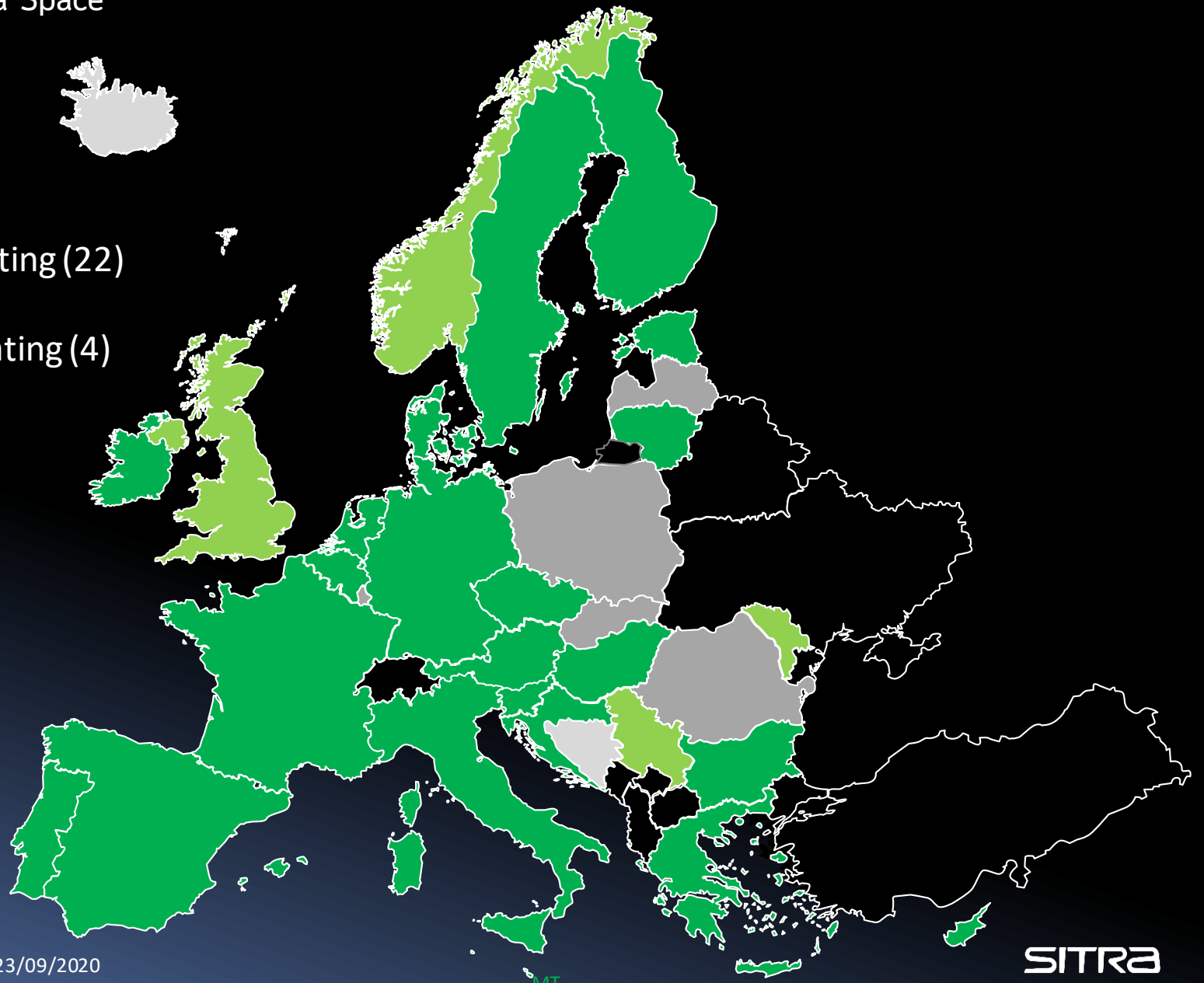
Joint Action Towards European Health Data Space

Project Coordinator:	Finnish Innovation Fund Sitra, Finland
Project Acronym:	TEHDAS JA
Starting Date:	01/02/2021 (estimated)
Project Duration:	30 months
Participants:	26 - 22 Member States, 4 other countries
Co-funding:	3rd EU Health Programme (2014-2020)
Budget:	€4.16 mill.
	EU €2.5 mill. + MS €1.66 mill.

Classified as internal/staff & contractors by the European Medicines Agency

TEHDAS Joint Action

Towards the European Health Data Space



Participant Countries

18 June 2020

23/09/2020

SITRA

Joint Action is expected to produce as its outputs options for

- Data Governance for the European Health Data Space (EHDS), complementing the horizontal European Data Spaces framework, including functions and responsibilities of the relevant actors.
- Guidelines on using health data for research and policy making
- Guidelines on Ethical, Legal and Social issues in the European Health Data Space
- Data Quality framework encompassing semantic interoperability and FAIR principles, as well as anonymization and pseudomisation techniques.
- Infrastructure architecture and technical interoperability guidelines to enable European Health Data Space services
- Economics models focused on the sustainability of European Health Data Space

Adapted from CHAFEA Ares(2020)1379455 - 05/03/2020:
Policy expectation for the joint actions 2020

Classified as internal/staff & contractors by the European Medicines Agency

TEHDAS Joint Action

Towards the European Health Data Space

Work in progress - plans

23/09/2020

SITRA

Provisional Mission statement

The Joint Action helps the Members States and the Commission in developing concepts for sharing of data 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 available regardless where it is stored.

Classified as internal/staff & contractors by the European Medicines Agency

Draft - Specific objectives

1. Producing elements and options for an (operational) framework and governance for the exchange and secondary use of health data between (European) countries, respecting the principles of transparency, trust, FAIRness*, citizen empowerment and a common good.
2. Provide solutions on quality, interoperability and fairification for the trustworthy secondary use of health and health care data with a view to fostering the digital transformation of the European health systems.
3. Provide a catalogue of services to support the secondary use of health data across through the EHDS as well as the architecture and infrastructure options required to its deployment.
4. Provide a European perspective to improving citizen capacity to engage with data and improve citizen trust in data sharing and strengthen the health data governance mechanisms at EU level and in the Member States relevant for cross-sector data use and for data use in the common sectoral data spaces.
5. Ensure the sustainability and implementation of the proposals of the Joint Action by suggesting concrete ways to integrate them into the national and European health data landscape.

Classified as internal/staff & contractors by the European Medicines Agency

TEHDAS JA - Draft description of the Work Packages 4-8*

WP	Name	Contents	Leader
WP4	Sustainability and linking to other EU processes	The Joint Action will build on the previous initiatives and ensure the links to stakeholders and propose ways to make data sharing sustainable.	Belgium
WP5	Sharing Data for Health	The work package will develop options for the creation of the European Health Data Space, for the governance of the secondary use, working on the consistent application of the GDPR and management of the secondary use of health data.	Sweden & Netherlands
WP6	European Excellence for Quality of Data	What can we do and how to incentivize quality of data and its interoperability?	Open
WP7	Connecting the Dots	The health systems need new investments, in Member States and at EU level. The proposed EU4Health, together with other EU level instruments, brings new impetus to building infrastructures in the EU.	Spain
WP8	iCitizen	What happens when data is not in the hands of professionals or healthcare? MyData is in citizens' hands.	France & Hungary

* WP1 Coordination and WP2 Dissemination are led by the Coordinator (Finland). Leader of WP3 Evaluation is led by Portugal.

Classified as internal/staff & contractors by the European Medicines Agency

TEHDAS and stakeholders

- TEHDAS JA offers a way to plan policy and implementation for sharing of data cross-borders in the EU and beyond and engage both Members States and stakeholders in the process.
- The JA Partners are the policy guardians or bodies specifically designed in their Member States, which ensures the close link to the policy adoption process in the EU and between Member States.
- The European Health Data Space integrates various health data related efforts in the EU. It is important to build on synergies of previous initiatives and prevent data silos.
- TEHDAS will form dialogue with other projects and activities, and a mechanism to involve stakeholders and field their expectations, knowledge and experience in its outputs.

Classified as internal/staff & contractors by the European Medicines Agency

TEHDAS Joint Action

Towards the European Health Data Space

Contact information

Markus Kalliola

TEHDAS Coordinator

Markus.kalliola@sitra.fi

+358503591499

@markuskalliola

SITRA