

Work in progress

Presentation in InfAct Assembly of Members

European Health DAta Space Joint Action, TEHDAS JA

25th June 2020

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The Finnish Innovation Fund



SITRA



A gift to Finland

The Finnish Parliament established Sitra as a gift celebrating the 50th anniversary of Finland's independence.

The public future-oriented organisation was given the mission to build the successful Finland of tomorrow.

The year was 1967.

SITRA

Sitra by the figures

Investments

by the Finnish State

1967: 16.8 M€

1972: 16.8 M€

1977: 16.8 M€

1981: 16.8 M€

1992: 16.8 M€

84.1 M€

Annual budget

30-40

million euros

179

employees

in 31 Dec. 2018

Market value

of endowment capital

M€

840 **776**

12/2017

12/2018

Average return

7,7% **-3,9%**

2017

2018

Founded

in **1967**

Working for
the future

over
years **50**

69 % women

31 % men

89 % higher education

11 % other education

Agenda

1. EC objectives and background
2. Administrative timeline for JA
3. Mission statement and participating countries
4. TEHDAS provision structure
5. More detailed view on the WPs and deliverables



Joint action for European Health Data Space

Martin Dorazil

Deputy Head of Unit, European Reference Networks and Digital Health, DG SANTE



*“We need to make the most of the potential of e-health to provide high-quality healthcare and reduce inequalities. I want you to work on the creation of a **European Health Data Space** to **promote health-data exchange** and **support research on new preventive strategies**, as well as on **treatments, medicines, medical devices and outcomes**. As part of this, you should ensure **citizens have control** over their own **personal data**.”*

*Mission letter of Stella Kiyriakides
Commissioner for Health*

Common European data spaces

Rich pool of data
(varying degree of
accessibility)

Free flow of data
across sectors and
countries

Full respect of GDPR

Horizontal
framework for data
governance and data
access



Health



Industrial &
Manufacturing



Agriculture



Finance



Mobility



Green Deal



Energy



Public
Administration



Skills

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

European Health Data Space

What?

Use of health data for:

- Better healthcare
- Better policy making
- Better research and innovation

How?

3 pillars of action:

- Data governance and rules
- Data quality and interoperability
- Infrastructure and technology

Joint Action Timeline

Invitation to Member States to nominate Competent Authorities:	Send out on 05 March 2020 - Nomination Platform
Deadline for nomination of competent authorities	28 May 2020 (Extended deadline due to COVID-19 crisis)
Webstreamed Infoworkshop for nominated Competent Authorities	03 June 2020 (nominated competent authorities will be invited and notified about the agenda and access details)
Invitations to nominated Competent authorities to submit proposals	June 2020
Deadline for applications:	October 2020
Evaluation:	November 2020
Information on evaluation results:	December 2020
Grant agreement signature:	February 2021
Starting date:	March 2021
Duration:	2 – 2,5 years
Budget:	€ 2.500.000.000 (€ 1.500.000 EC, € 1.000.000 MS)

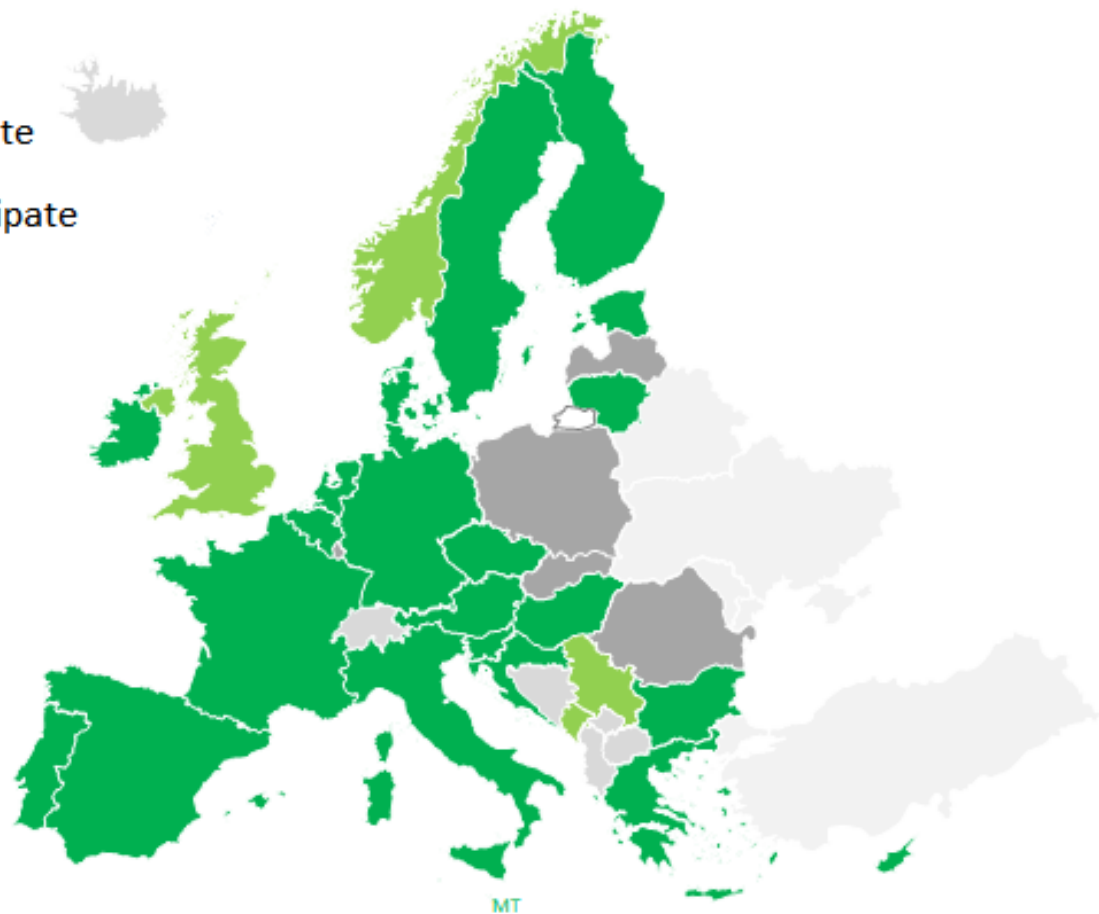
Mission statement

The Joint Action helps Members States and the Commission in developing **sharing of health data for citizen's health, public health, treatment, research and 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.**

Joint Action EHDS

- MS interested to participate
- Other interested to participate
- .
- .



TEHDAS - Provisional Structure

TEHDAS consists of eight Work Packages (WPs): four mandatory and four thematic WP's.

Mandatory

- WP 1 Coordination of the project
- WP 2 Dissemination of the project
- WP 3 Evaluation of the project
- WP 4 Sustainability

Thematic

- WP 5 Sharing data for health
- WP 6 European Excellence
- WP 7 Connecting the dots
- WP 8 iCitizen

Deliverables consist of

- Study: Material collection and review
 - Analysis: Analysis of specific topic
 - Guidance: Overall guidance how to improve a specific topic
 - Options: Provide alternative options for a specific actor to move forward
-
- M = Milestone
 - D = Deliverable

What TEHDAS is not about

- IT development
- Funding of other projects
- Final decision making body -> instead options for EC/MS

Better health

**Better policy
making**

Better R&D&I

WP.1 Coordination

WP.2 Dissemination

WP.3 Evaluation

WP.4 Sustainability

WP.5 Sharing data for health

WP.6 European Excellence

WP.7 Connecting the dots

WP.8 iCitizen

Deliverables

WP 5: SHARING DATA FOR HEALTH

Needed skills: Legal, organisational

Sharing health data for care of citizens as well as for public health, research, development an innovation is increasingly important. The work package will develop options for next steps in EU policy by building on existing initiatives and mobiliseng new ideas from the Member States.

WP 5: Ideas for deliverables

- D 5.1. Options for governance models including functions and responsibilities for cross-border collaboration in the secondary use of health data taking into account use cases:
 - M 5.1.1 A network of national authorities responsible for the secondary use of health data
 - M 5.1.2 Scientific research
 - M 5.1.3 Statistics
 - M 5.1.4 Development and innovation activities
 - M 5.1.5 Steering and planning activities of national authorities
 - M 5.1.6 Data quality governance
 - M 5.1.7 Teaching
 - M 5.1.8 Public health surveillance
 - M 5.1.9 Open data
- D 5.2. Options to harmonise GDPR implementation
 - M 5.2.1 Study of national GDPR implementation in secondary use of health data
 - M 5.2.2 Analysis of the differences in national GDPR implementation concerning the secondary use of health data

WP 6: EUROPEAN EXCELLENCE

Needed skills: Quality, semantics, interoperability, economics

What can we do and how to incentivize quality?

WP 6: Ideas for deliverables

- D 6.1. Data quality framework
 - M 6.1.1 Study of currently used data exchange formats and common data models (Patient Summary, OMOP, i2b2)
 - M 6.1.2 Study of current means to harmonise EHR data from multiple sources commercial and non-commercial (TrinetX, BC Platforms, Darwin etc.)
 - M 6.1.3 Analysis of data exchange formats and best practises used in the markets to harmonise data
 - M 6.1.4 Analysis of the fairification of health data, how to make data FAIR, Findable, Accessible, interoperable and reusable. (Metadata catalogues, federated availability queries etc.)
 - M 6.1.5 Study of health data categories (identifiable, pseudonymised, anonymised, syhthetic, fabricated)
- D 6.2 Analysis of economic models of data exchange

WP 7: CONNECTING THE DOTS

Needed skills: Technical, architecture, investments

The Commission said health systems need €70 billion of extra investments. The new EU4Health is €9,4 billion.

WP 7: Ideas for deliverables

- D 7.1. Technical framework
 - M 7.1.1 Study of the potential of current infrastructures to support European wide collaboration on the secondary use of health data (eHDSI, ERN CPMS, EMA Darwin, EMBL Covid19dataportal.org, EWRS etc.)
 - M 7.1.3 Analysis of centralised, decentralised, federated architectures models usage in health
 - M 7.1.4 Guidance How to benefit from cross-sectoral infrastructures in health (Gaia-X etc.)
 - M 7.1.5 Guidance How to take into account EU cross-border exchange and EU secondary use of health data when investing into healthcare IT
 - M 7.1.6 Options how to build European Health Data Space to facilitate AI/Big data innovations
- D 7.2 Investment framework
 - M 7.2.1 Options for the European Commission to fund in
 - Horizon Europe
 - Digital Europe and
 - The next health programme

WP 8: iCITIZEN

Needed skills: Home diagnostics, citizen science, personal medical devices, consent

What happens when data is not in the hands of the authorities, healthcare or professionals?

WP 8: Ideas for deliverables

- D 8.1 Options for the European Commission to move forward to create a European Health Data Space where citizens are active participants
 - M 8.1.1 Study of current market where health data is out of reach for authorities
 - M 8.1.2 Analysis of current means to access the data or grant access to the data
 - M 8.1.3 Guidance on how to use citizen controlled health data to prevent/track future epidemics

Thank you!

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