

Nordic Health 2030 Pockets

# **The Promise of Fair Data Economy**

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Our response to  
The European  
strategy for data

The part of the economy that focuses on creating services and data-based products in an **ethical** manner.

In the fair data economy data is shared between different parties with individuals' **consent** in a seamless and transparent way.

People use services that improve their well-being and everyday life, companies achieve growth through innovation, and the well-being of society increases

Vision is that Europe **has a well-functioning data market**, where companies that use data responsibly and open-mindedly succeed with **smart services**



~~FAIR  
DATA  
ECONOMY~~

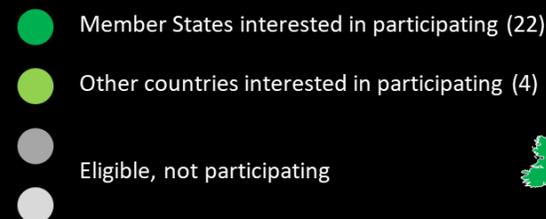




# Joint Action Towards European Health Data Space

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

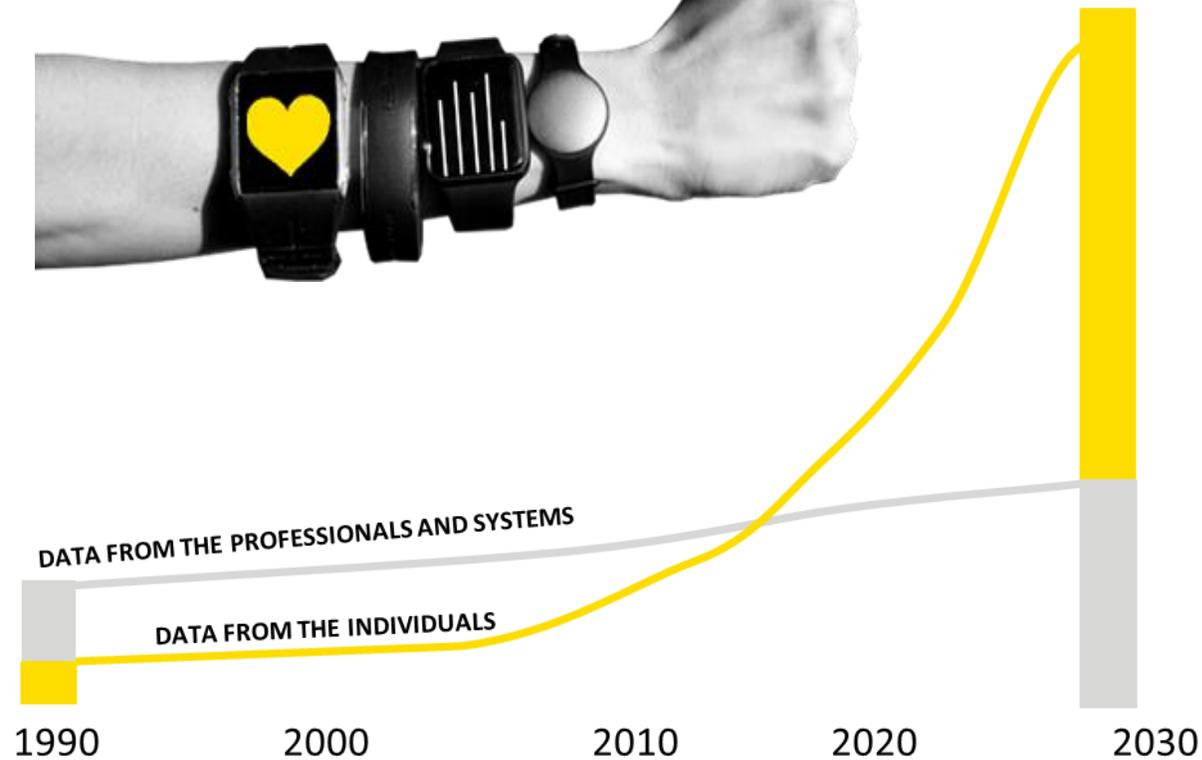
Contact: Markus Kalliola  
TEHDAS Coordinator



## Themes:

**Data Governance**  
**Guidelines on R&DI and ELSI evaluations**  
**Data Quality framework**  
**Interoperability guidelines**  
**Economics models**

# It's going to get a lot more personal!



**Emphasis on Professional Agents**

**Emphasis on Personal Agents**



Source: van der Kamp & Plochg: "The Health System Quartet" in: Sturmberg J (ed), Embracing Complexity in Healthcare, Springer 2019, pp. 113-123

**You are the key to  
preventive health**

**Data can enable  
preventive health  
for you and the  
system**

**You as the  
primary point of  
care**

Source: Nordic Health 2030 Vision  
CIFIS [www.CIFIS.dk](http://www.CIFIS.dk)



# **TOWARDS TRUSTWORTHY HEALTH DATA ECOSYSTEMS**

How the reuse of data can create new services  
for the benefit of all

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Data can improve patient outcomes, foster research and accelerate the development of new health services only if it is shared between stakeholders and reused while respecting privacy, strengthening people's control over their data and guaranteeing transparency.

The working paper from the Finnish Innovation Fund Sitra provides guidelines for the future strategic use of sensitive data within European health systems. It addresses ethical, legal and self-regulatory frameworks for balanced data ecosystems, discusses the current challenges and establishes a set of recommendations for a new health and well-being data paradigm.

# How to go beyond GDPR

## GDPR - the regulation point of view

1. Right to be Informed
2. Right to Access
3. Right to Rectification
4. Right to Erasure



## The Fair Data Economy - individual's point of view

1. Open, clear and proactive customer communications about data use, benefits and problems with data from the very first click. Two-way interaction encouraged and supported with easy-to-use tools.
2. Easily found and easy-to-use online tools to access data 24/7 via phone app or browser.
3. Ability to ask for rectification via phone, app or browser. The ability to correct data self, real-time. Guidelines and online help easily available
4. Easily found and easy-to-use tools to erase data 24/7 via phone app or browser. Guidelines and online help easily available

# IHAN® - building trust-based data sharing ecosystems

## Rulebook for a Fair Data Economy

Rulebook Template for Data Networks

Versio 1.1 en

30.6.2020

## European Data Economy Testbed

Beta launch in June 2020

Develop solutions on global data markets



Data

Governance

Technology

TRUST

People

Organisations



Finnish government rolls out digital projects to support SMEs

ComputerWeekly.com

Source: Towards a European-governed Data Sharing Space, Enabling data exchange and unlocking AI potential  
BDVA Position Paper, V2 11-2020

[https://www.bdva.eu/sites/default/files/BDVA%20DataSharingSpaces%20PositionPaper%20V2\\_2020\\_Final.pdf](https://www.bdva.eu/sites/default/files/BDVA%20DataSharingSpaces%20PositionPaper%20V2_2020_Final.pdf)

# Imagine 2025

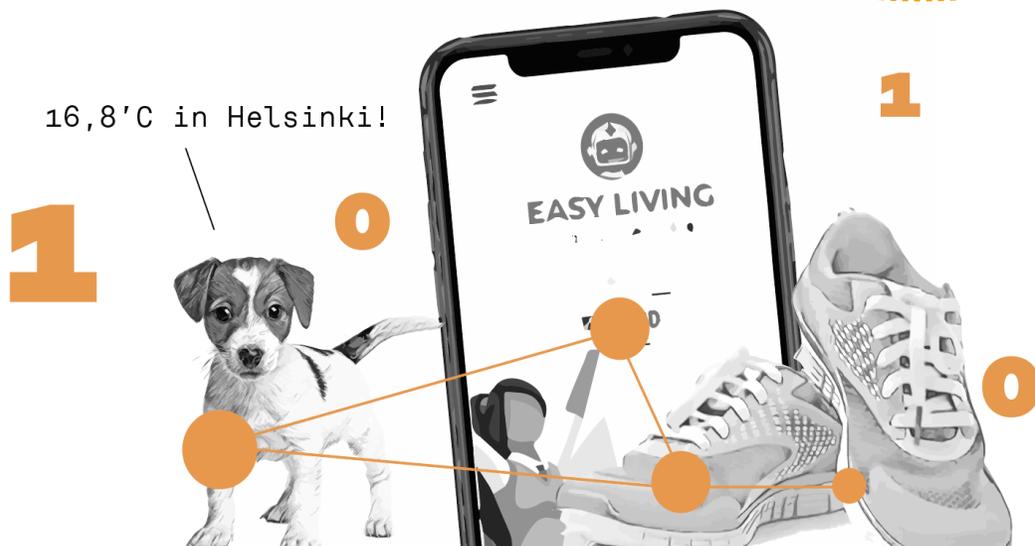
Lately, your energy levels have been low, and you have found a need for a change in lifestyle. Your friend told you about a new **Live Better** app.

When taking a closer look at the new app, you notice that it has a **Fair™ label** on it. Now you know that the service uses your personal data in an ethical and safe way.

You grant the service the permission to connect your **purchase data** from your neighbourhood store with your health data from the **Kanta service**, and your data collected by the **Sports Tracker** app.

When making the payment, you notice that your insurance company offers the service to you free of charge.

It is the year 2025, and you are living in a world with a data economy that is fair and benefits all.



16,8°C in Helsinki!

**Thank you!**

