

# Innovating the secondary use of health data – the Finnish model

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*Sitra – the Finnish Innovation Fund*

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🐦 [@saara\\_malkamaki](https://twitter.com/saara_malkamaki)

# Sitra

1. An independent future house: a futurologist, visionary, developer, experimentalist, financier, partner, trainer, and networker.
2. The aim is the successful Finland of tomorrow, the vision is the next era of well-being – a fair and sustainable future.
3. Under the direct control of the Finnish Parliament.
4. Funded by returns on endowment capital and capital investments.
5. The vision is implemented by three themes and hundreds of projects.

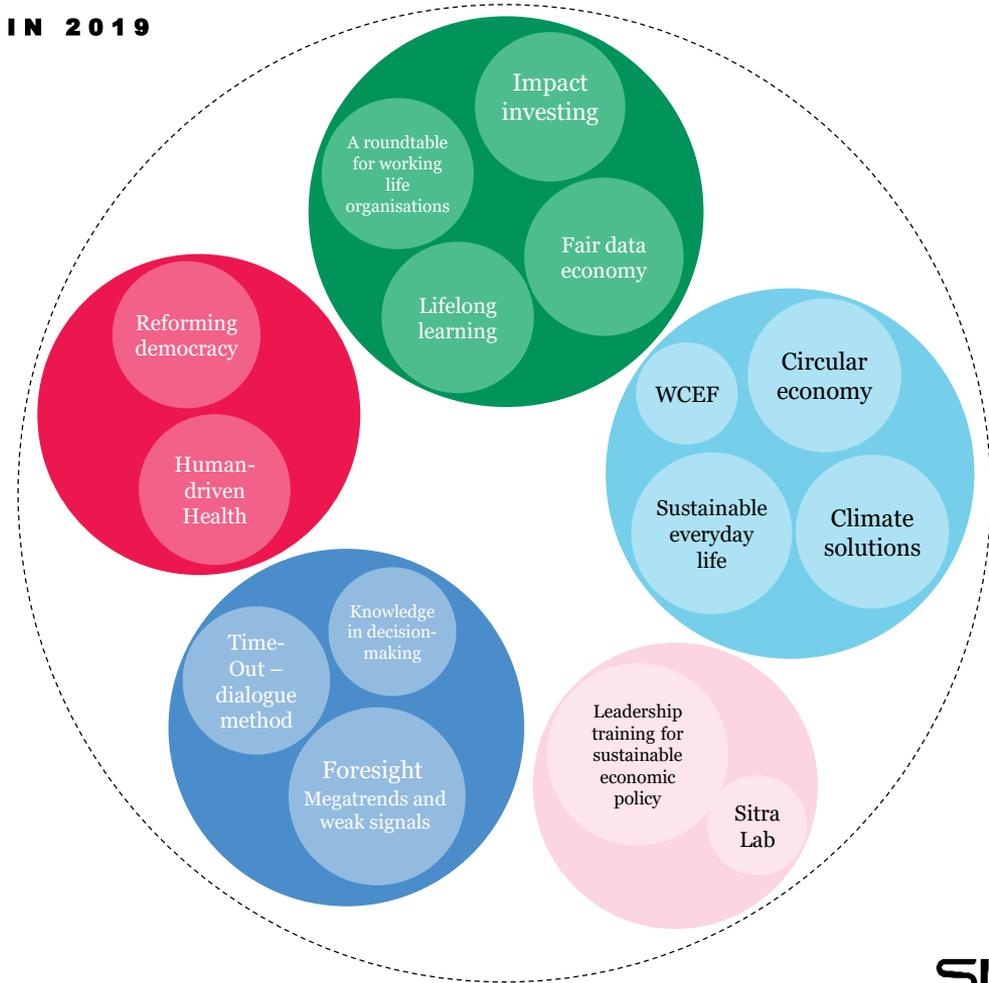
## + the most important of all

Building our future *together*.



## SITRA'S FUTURE-ORIENTED WORK IN 2019

-  **FORESIGHT**
-  **SOCIETAL TRAINING**
-  **A CARBON-NEUTRAL CIRCULAR ECONOMY**
-  **CAPACITY FOR RENEWAL**
-  **NEW WORKING LIFE AND A SUSTAINABLE ECONOMY**



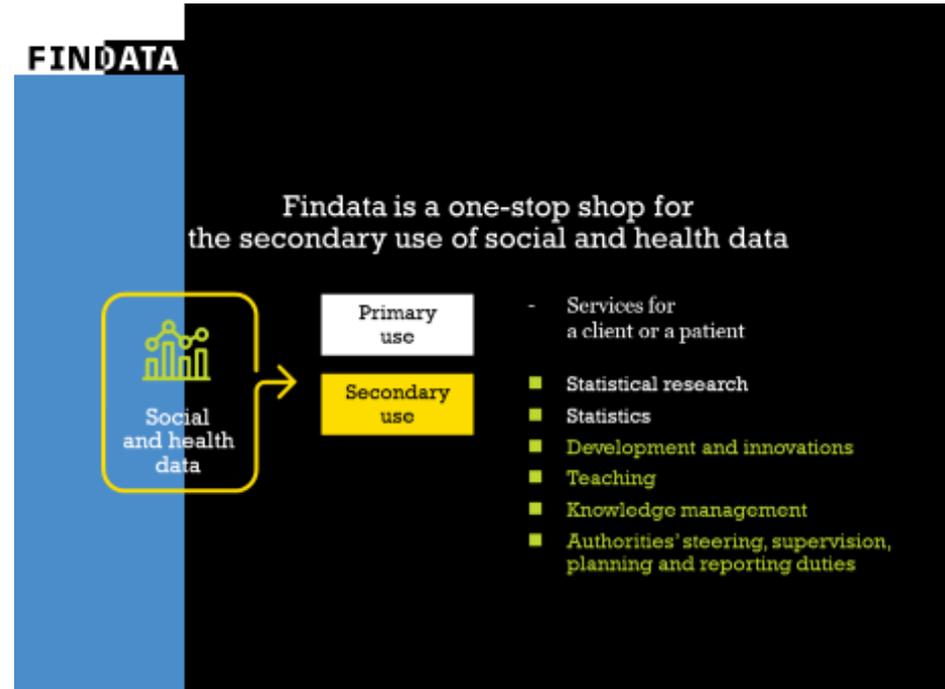
# **THE SECONDARY USE OF HEALTH AND SOCIAL CARE DATA**

Project Isaacus 2015-2018

Findata 2020-

# Great new from Finland!

- **New legislation** on Secondary Use of Social and Healthcare Data entered into force on 1 May 2019
- It enables the founding of the new national Social and Health Data Permit Authority **Findata** – a one-stop shop which offers permits, advisory and access to data for research, development and innovations.
- It opens up the national social and healthcare registers, but also data from the operational client and patient systems in primary care, specialist healthcare and social services.



## Faster and improved access to data

### **Before**

Permits separately from each controller

A long process

### **From 2020**

Centralised access to permits and data sets

Time limits

### **Also**

Advice related to data sets/use

An electronic permit system

Secure user environment



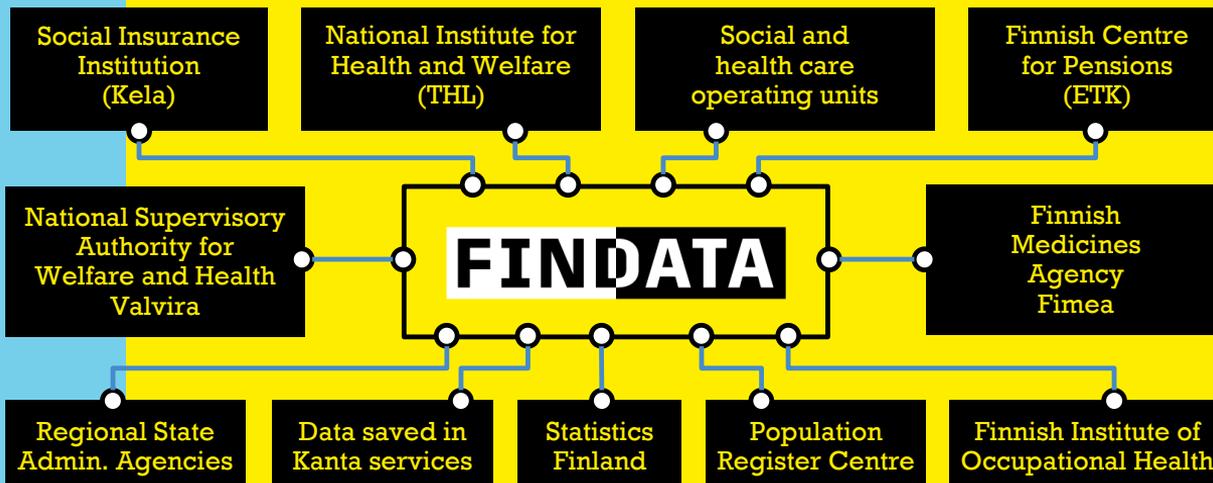
## More uses for social and health data

### Uses permitted under the Act

- Scientific research
- Statistics
- Development and innovation
- Steering and supervision by authorities
- Authorities' planning and reporting duties
- Teaching
- Knowledge management



The following controllers will provide access to data specified in the Act through Findata



## Data protection and information security are taken care of



- A secure remote use environment for individual level data sets
- Data sets will be made available without individual's direct identifying data
- The data permit authority Findata will see to anonymisation centrally

## Let the efficient and secure secondary use of social and health data begin!



STEPWISE  
ROLLOUT OF  
SERVICES

● **1 Nov  
2019**  
Advisory  
service and  
the website  
**findata.fi**  
launched

● **1 Jan  
2020**  
Access to  
statistical  
data  
subject to an  
information  
request

● **1 Apr  
2020** →  
Remote use  
of individual  
level data  
subject to a  
data permit  
request

### Further information:

Johanna Seppänen, Director, Findata  
firstname.lastname@thl.fi

# The Isaacus project

## **Isaacus project (2015–2018) at Sitra**

- Prepared the basic principles and an operating plan for Findata
- Piloted, tested and developed service models and processes, metadata descriptions, data lakes and co-operation models with authorities and stakeholders

# How we did it

State's supplementary budget proposes allocating 2.5 million euros for the year 2019 towards launching the operations of the data permit authority and the construction of a data-secure environment.

## REGULATION

## DATA PERMIT AUTHORITY

Working Committee prepares a new Act on the Secondary Use of Health and Social Data. Working term: April 2015 to December 2017.



Proposal submitted for the first hearing in August 2016.

Government proposes the new act (October 2017).

Parliamentary work, expert hearings and debates, and the social affairs and health committee suggests amendments in April 2018. Adjusted proposal returned to the committee in October 2018.

The new act is approved by Parliament (March 2019). Act enters into force on 1 May 2019.

Findata – new one-stop shop in operation. Helpdesk to open November 2019. Information requests to begin January 2020.

2016 -

2017 -

2018 -

2019 -

2020 -

## PROJECT ISAACUS

Project Isaacus starts in November 2015.

Eight pre-pilots begin with Sitra's funding support (of between 30 and 70%).

Isaacus phase 1 completed in September 2017. Pre-production pilots give an insight into future ICT services.

Sitra extends the project to ensure the impact of the work. Sitra funds Project Management Office to support the temporary Steering Group assigned by the Ministry of Social Affairs and Health.

## TEMPORARY STEERING GROUP

Temporary Steering Group prepares the launch of Findata operations.

# National Initiatives Network

The secondary use of well-being data

85

people

17

countries

51

organisations



Australia, Denmark, Estonia, Belgium, Finland,  
Germany, Hungary, Iceland, Ireland, Israel,  
Japan, Netherlands, Norway, Spain, Sweden,  
Switzerland, United Kingdom

# National Initiatives Network

To join, send an email to [saara.malkamaki@sitra.fi](mailto:saara.malkamaki@sitra.fi)

Two active subgroups:

**1** Synthetic data

**2** Metadata



# Further readings

- Blog post 5/2019
  - New legislation will speed up the use of Finnish health data <https://www.sitra.fi/en/blogs/new-legislation-will-speed-use-finnish-health-data/> (includes the act [in English](#))
- Press release 4/2019
  - Ministry of Social Affairs and Health
  - New act enables effective and secure use of health and social data [https://stm.fi/en/artikkeli/-/asset\\_publisher/uusi-laki-mahdollistaa-sosiaali-ja-terveystietojen-tehokkaan-ja-tietoturvallisen-kayton](https://stm.fi/en/artikkeli/-/asset_publisher/uusi-laki-mahdollistaa-sosiaali-ja-terveystietojen-tehokkaan-ja-tietoturvallisen-kayton)
- Sitra study “A Finnish Model For The Secure And Effective Use of Data”
  - Lessons learned from Sitra’s Isaacus project
  - <https://www.sitra.fi/en/publications/a-finnish-model-for-the-secure-and-effective-use-of-data/>



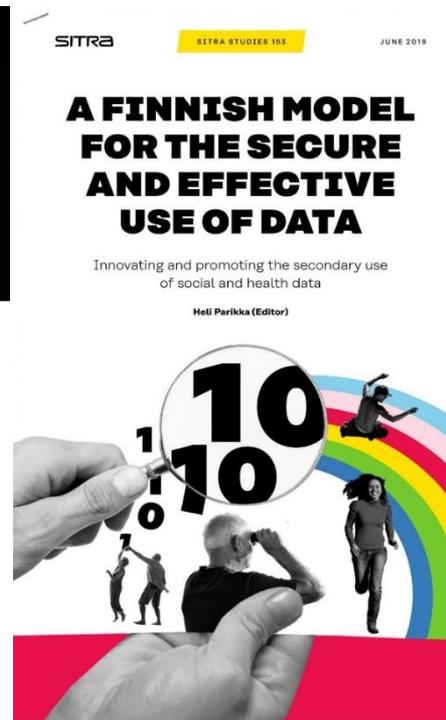
< WELL-BEING DATA

Photo: Miikka Pirinen

Published May 14, 2019

## New legislation will speed up the use of Finnish health data

Finland is showing the way by passing new enabling legislation on the secondary use of social and health data.



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# **NEXT PHASE FOR VALUE CREATION – COMBINING REGULATED DATA WITH DATA COLLECTED BY INDIVIDUALS**

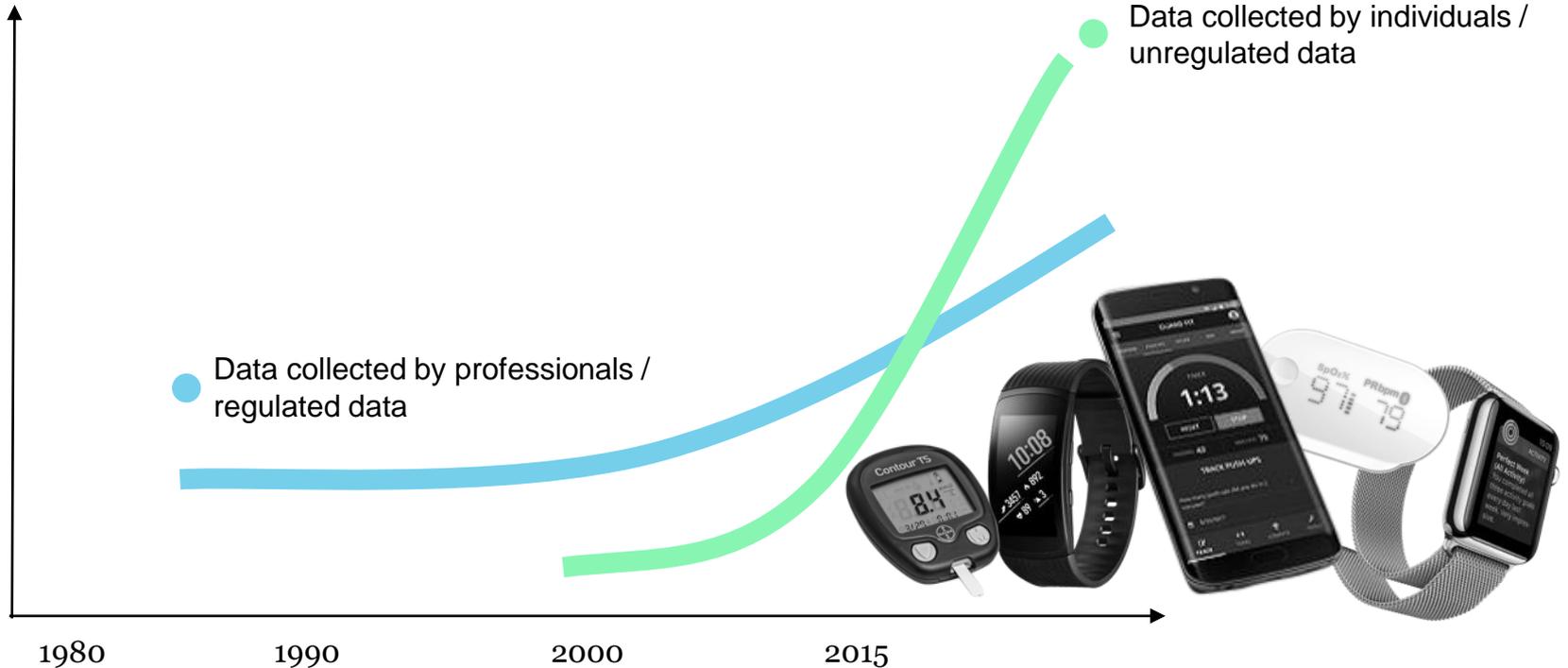
Project IHAN 2018–(2021)

**Introduction to Sitra's IHAN®**

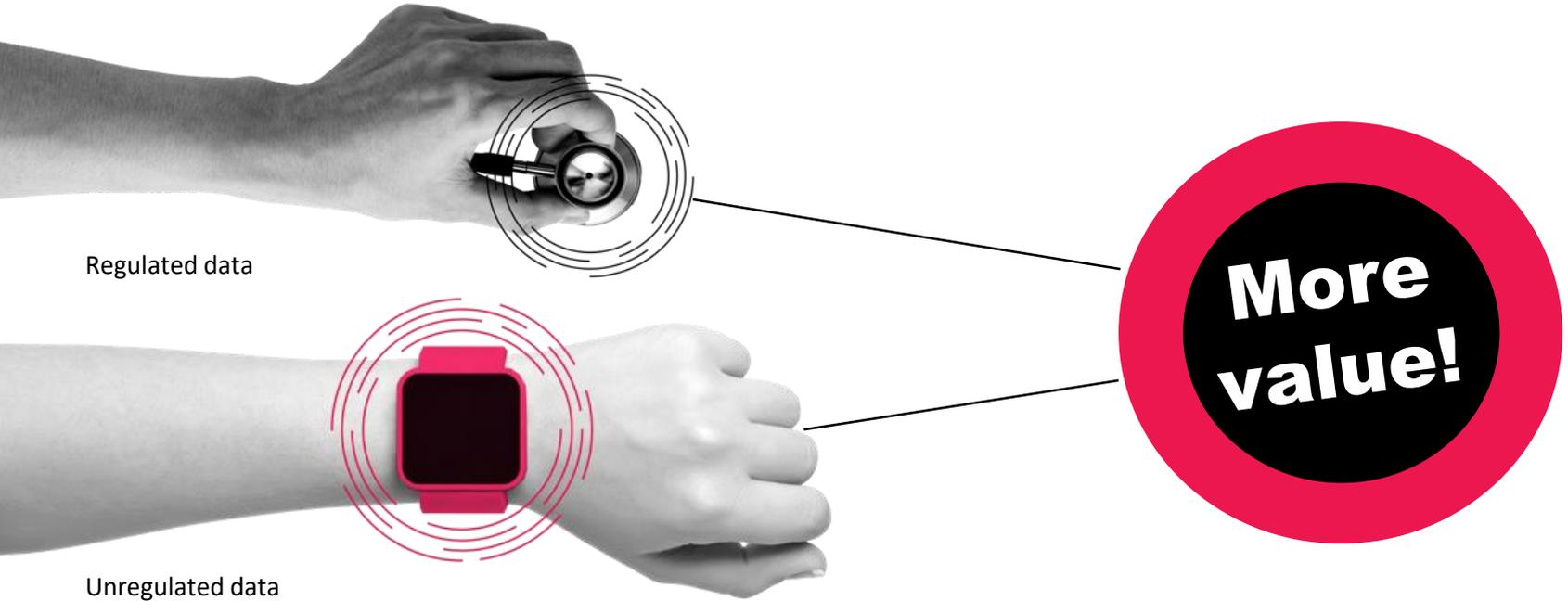
**FAIR DATA  
ECONOMY**

**Lots of new data sources**  
- health data being one example

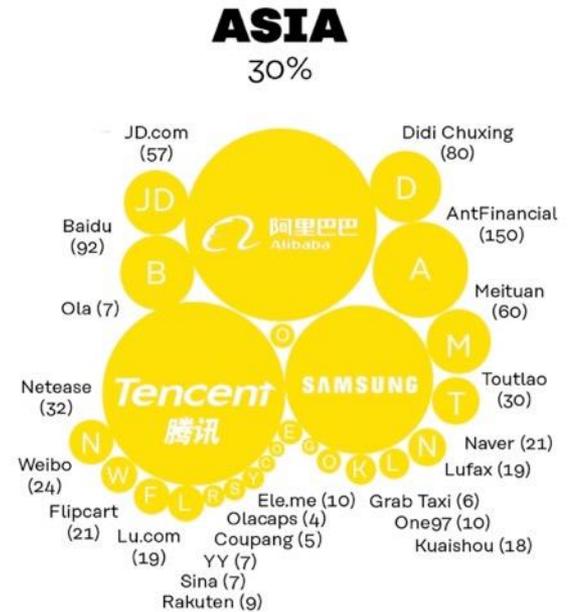
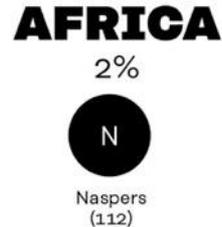
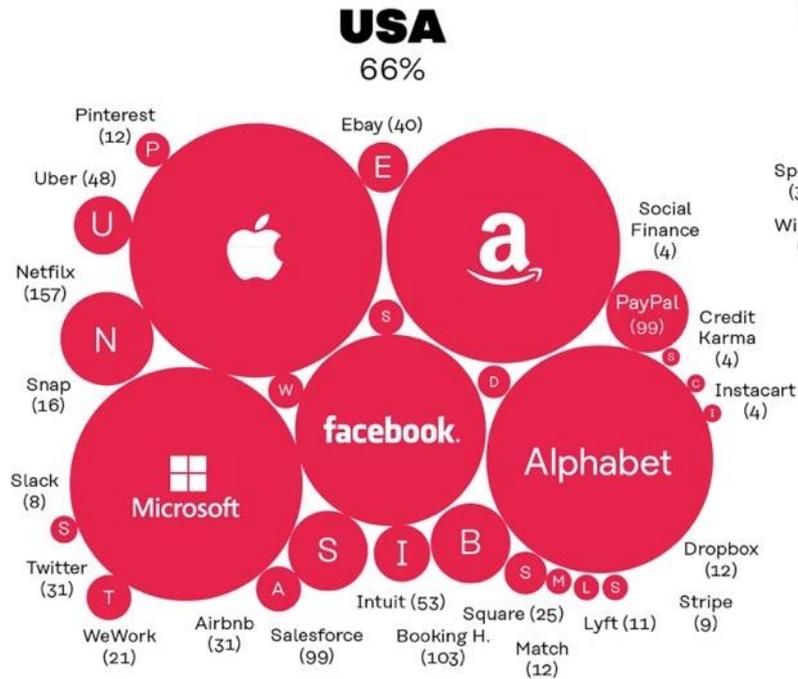
# Who creates the data in the future?



# Combining regulated data with data collected by individuals leads to next phase for value creation

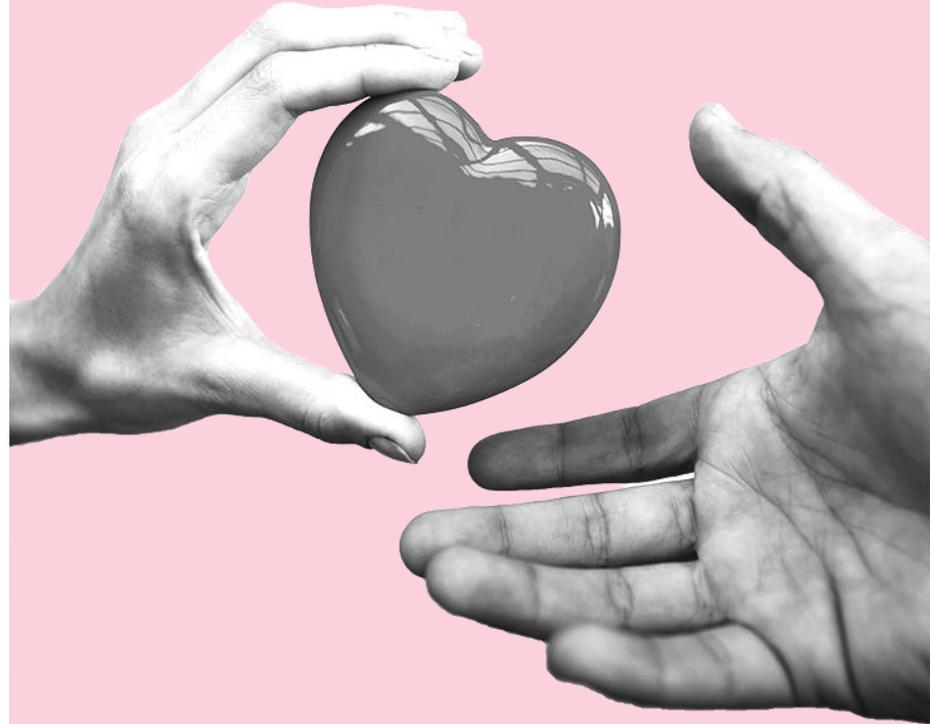


# Europe's role in data economy?

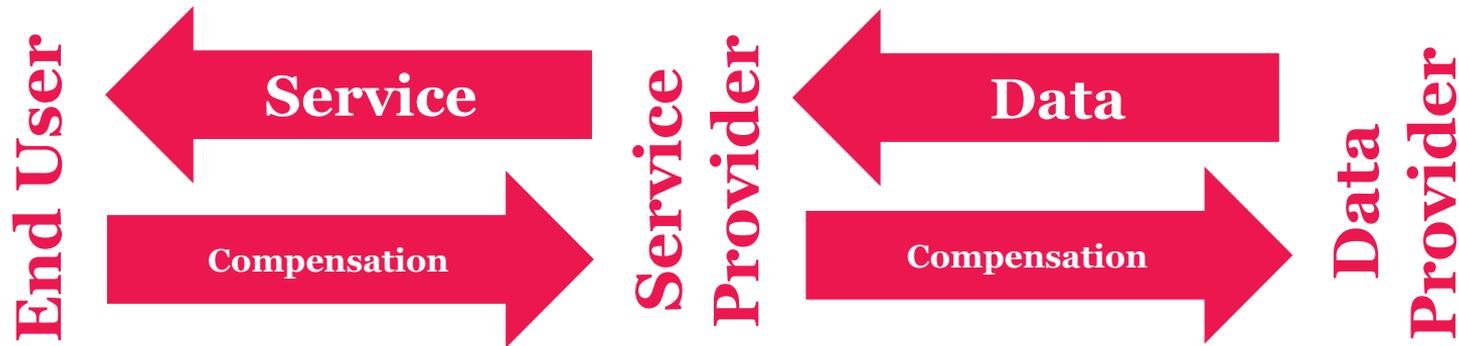


Quelle: Netzoeconom.de/platformeconomy.com Idee: Peter C. Evans

**Maintaining trust –  
Europe's biggest  
opportunity?**



**Data economy  
must be FAIR for**  
**End User**  
**Service Provider**  
**Data Provider**



**Great  
timing!**



**#GDPR**

General Data Protection Regulation  
and especially Article 20

**#PSD2**

Payment Services Directive

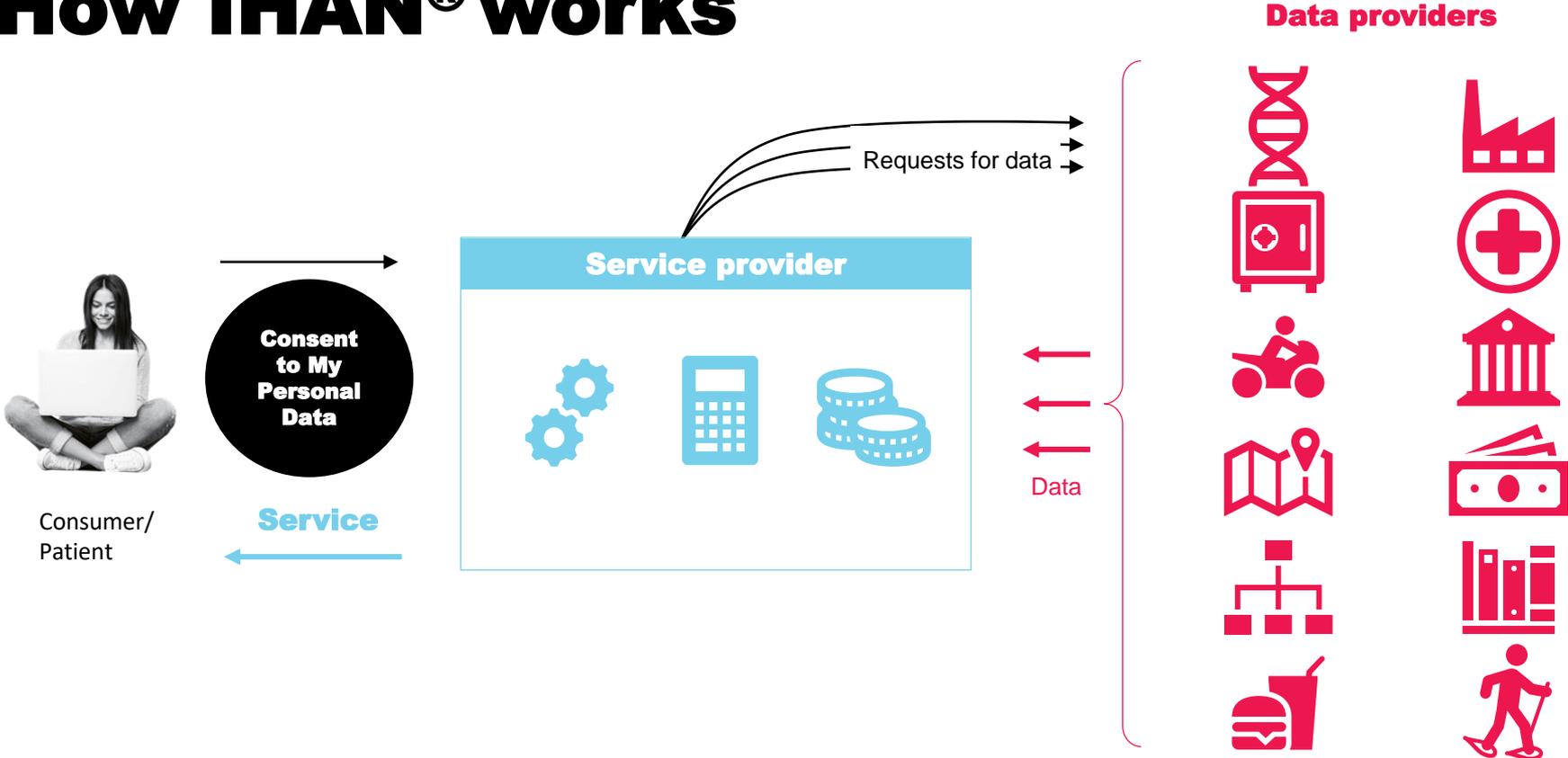
**#eIDAS**

EU regulation on electronic  
identification and trust services for  
electronic transactions

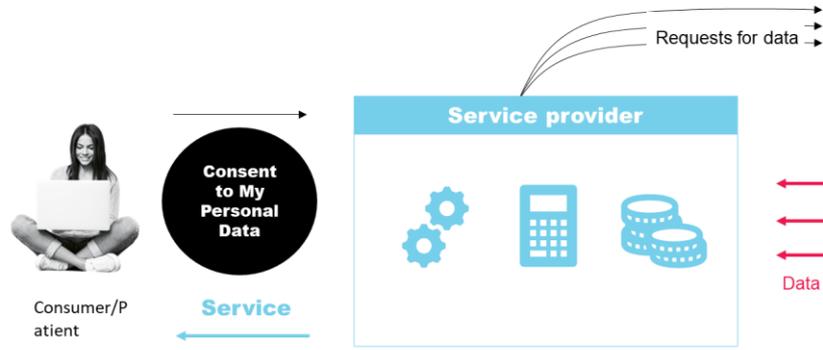
# IHAN<sup>®</sup> project

- Building the foundation for a **fair** and functioning **data economy** and creating a **method for data exchange**.
- Setting up **European level rules and guidelines** for fair use of data.
- **Piloting** new concepts based on personal data in **collaboration** with pioneering **businesses**.
- Project runs until 2021

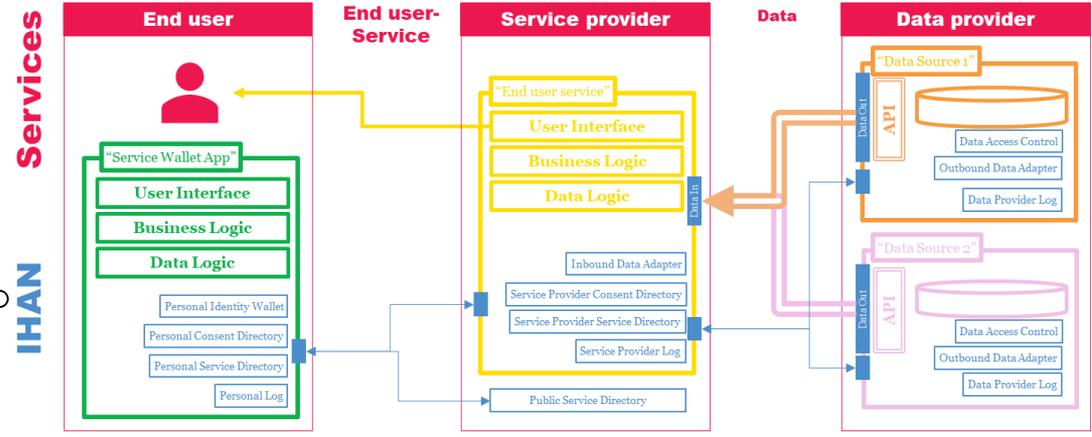
# How IHAN<sup>®</sup> works



# IHAN - enabling framework



Data "Plumbing System"

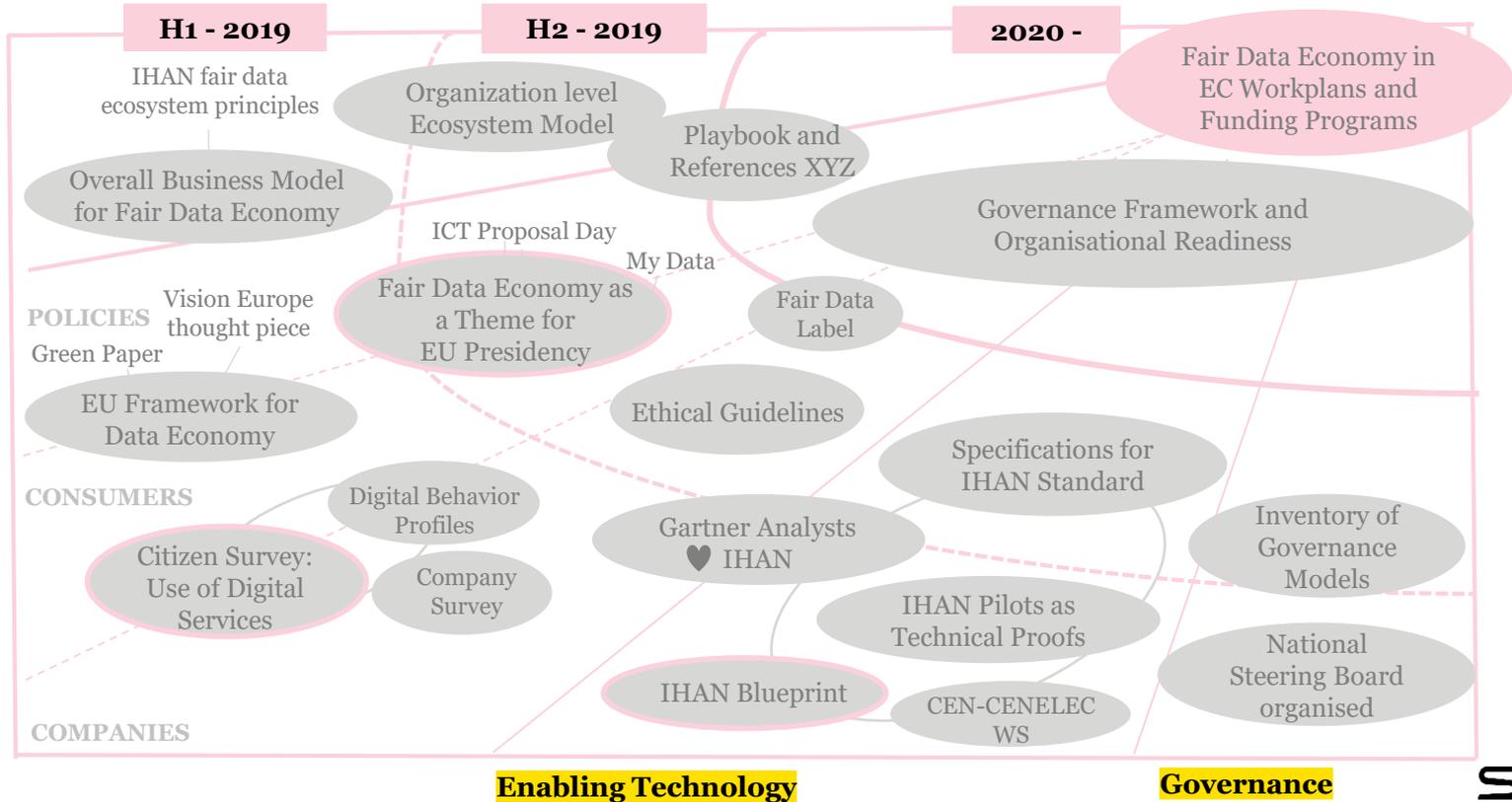


# IHAN<sup>®</sup>

## work packages and outcomes

**Business Model**

**Mindset Change**



**H1 - 2019**

**H2 - 2019**

**2020 -**

IHAN fair data ecosystem principles

Organization level Ecosystem Model

Playbook and References XYZ

Fair Data Economy in EC Workplans and Funding Programs

**Overall Business Model for Fair Data Economy**

Governance Framework and Readiness

**POLICIES**

Vision Europe thought piece

EU Framework for Data Economy

ICT Proposal Dev

Data E  
EU

**CONSUMERS**

Citizen Survey: Use of Digital Services

Digital Behavior Profiles

Company Survey

**Value Chain -> Platforms and Value Networks -> Open Ecosystems (decentralised)**

Inventory of Governance Models

**COMPANIES**

IHAN Blueprint

CEN-CENELEC WS

National Steering Board organised

**Enabling Technology**

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Governance Framework and Organisational Readiness

**POLICIES**

Vision Europe thought piece Green Paper

EU Framework for Data Economy

An organisational level model that shows the value from open ecosystems

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ICT Proposal Day

Fair Data Economy as a Theme for EU Presidency

Rulebook describes companies' legal, business, technical and governance framework in the data ecosystems.

**POLICIES**  
Green Paper

Vision Europe thought piece

EU Framework for Data Economy

Uudistamo and Playbook renew business models and guides companies:  
1) to understand the advantages and value potential in fair data economy  
2) 2) to assess company's current state and identify new business model(s)  
3) to understand which capabilities and technologies are needed  
4) to design the transformation journey

**CONSUMERS**

Digital Behavior Profiles

Citizen Survey: Use of Digital Services

Company Survey

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My Data

Fair Data Economy

Fair Data

Vision Europe thought piece

**POLICIES**  
Green Paper

EU Framework Data Economy

Policy Brief: A Roadmap for a Fair Data Economy for EU policy makers with the Brussels-based think tank and policy network Lisbon Council

ifications  
IHAN  
standard

Inventory of Governance Models

**CONSUMERS**

Citizen Survey: Use of Digital Services

<https://www.sitra.fi/en/publications/roadmap-fair-data-economy/>

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ICT Proj

Vision Europe dialogue and a workshop with think tanks about fair data economy

Network and Readiness

**POLICIES**  
Green Paper

Vision Europe thought piece

EC

Partners: Bertelsmann Stiftung (Gütersloh, Germany), Bruegel (Brussels, Belgium), Calouste Gulbenkian Foundation (Lisbon, Portugal), Chatham House (London, UK), Compagnia di San Paolo (Torino, Italy), Notre Europe Jacques Delors Institute (Paris, France), CASE – Center for Social and Economic Research (Warsaw, Poland) and Sitra (Helsinki, Finland)

EU Framework for Data Economy

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Fair Data Economy as a Theme for EU Presidency

Collaboration with an international non-profit organisation MyData Global that aims to enhance people's rights concerning their personal data

**POLICIES**  
Green Paper

Vision Europe thought piece

EU Framework for Data Economy

Ethical Guide

Sitra is a founding member and Jaana Sinipuro was elected in November 2018 to the board of directors

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ICT Proj

Network and Readiness

Survey results of Europeans' attitudes towards the use of personal data

8,004 responses from 4 countries: Finland, Netherlands, Germany, France

Conducted 12/2018

<https://www.sitra.fi/en/publications/use-digital-services/>

**POLICIES**  
Green Paper

Vision Europe thought piece

Fair Data Economy as a Theme in the EU Presidency

EU Framework for Data Economy

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# EUROPEANS' ATTITUDES TOWARDS THE USE OF PERSONAL DATA

Survey results.

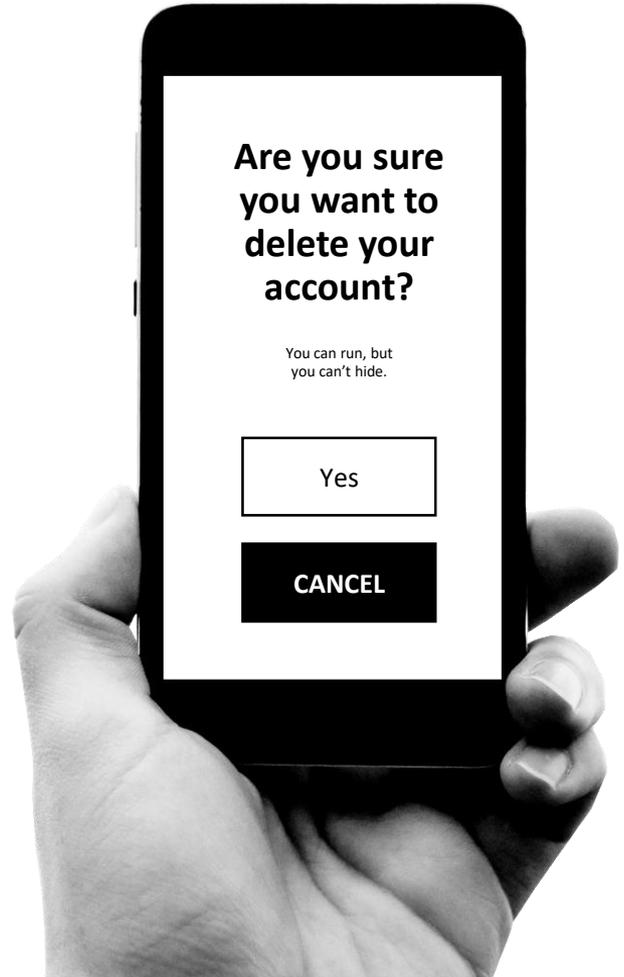
<https://www.sitra.fi/en/publications/use-digital-services/>



# Survey details

- **8,004 responses.** Finland 2,000, Netherlands 2,000, Germany 2,004, France 2,000.
- **Respondents aged 18-65**
- **Survey data was collected** in November and December 2018.
- **The study was carried out** using the Kantar TNS online panel.
- **The questions were designed by Sitra** in co-operation with Kantar TNS.

# How well people know GDPR.



**“What rights do you believe you have concerning personal data the service provider has gathered on you?”\***



GDPR rights 🔍

**58%**

**The right to know how and for what purpose my personal data is used**

**58%**

**The right to have access to any personal data the service provider has collected on me**

**54%**

**The right to have any personal data collected on me erased**

**21%**

**The right to move any personal data from one system to another**

**\*The figures are averages for the surveyed countries**

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TRICK  
QUESTION!

1/3

**The right to receive a notification  
from the service provider when  
my personal data is being sold or  
handed over to a third party**



Finland	<b>30%</b>
Netherlands	<b>37%</b>
Germany	<b>43%</b>
France	<b>31%</b>

# What is the effect of data leaks on people's behaviour?



**70%**

**30%**

**Unaffected by the news**

**27%**

**Have changed privacy settings on some services**

**8%**

**...on all services**

**24%**

**Have reduced the use of some services**

**15%**

**Have stopped using some services**

**\*The figures are averages for the surveyed countries. The respondents were allowed to choose multiple responses.**

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# 1/10

**has requested  
access to their own  
personal information**

Finland	<b>7%</b>
Netherlands	<b>11%</b>
Germany	<b>9%</b>
France	<b>8%</b>



# Lack of trust is an obstacle

**2/5**

Data plz?



**Strongly agree, agree**

Finland	<b>43%</b>
Netherlands	<b>38%</b>
Germany	<b>48%</b>
France	<b>39%</b>

**“I am **not willing** to provide or allow access **under any conditions** about myself or my family to a service provider when it comes to...”**



	<b>ALL</b>
Information about my wealth and spending	<b>40%</b>
Personal data or data about my personal history	<b>35%</b>
Information about my health or genetics	<b>30%</b>
My spatial data, devices I use or the way I use devices	<b>27%</b>
Information about my values or beliefs	<b>27%</b>
Information about my consumption habits or my purchases	<b>17%</b>

**“How much do the following features increase your trust towards a service provider...?”**



**“I can accept or forbid the selling of my data to a third party”**

**56%**

**Very much, somewhat**

**Having the power to make decisions is important to people.**



**“Consumer goods have the Fair Trade label. Do you believe a similar label is important for services that use data fairly?”**



**66%**

**Very important, somewhat important**

Finland	<b>71%</b>
Netherlands	<b>63%</b>
Germany	<b>70%</b>
France	<b>61%</b>

# HIGHLIGHTS

Let's recap...



**GDPR rights are quite well-known and the change of actions has already started.**

**The lack of trust is an obstacle.** It prevents people from using digital services.

**Data leaks have had a big effect on people's behaviour.** Approx. 70 % have either changed privacy settings and reduced or stopped using some services.

**Two out of three respondents want fair digital services to be identifiable.**

**Having the power to make decisions is important to people.**

**H1 - 2019**

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**2020 -**

IHAN fair data ecosystem principles

Organization level Ecosystem Model

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Fair Data Economy as a Theme for EU Presidency

Fair Data

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Green Paper

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EU Framework for Data Economy

Digital profile challenge – an online test for citizens to find out what kind of a digital user they are and how they could improve their digital behavior

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The results of a data economy business survey conducted in Finland, France, Germany and the Netherlands will be published in 19 September 2019

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Fair Data Label

A way to identify, certificate or reward fair data actors  
IHAN approved?, Fair Data Label?, Fair Data Award?

**Mindset Change**

Guidelines

Specifications for IHAN Standard

Inventory of Governance Models

Partner Analysts ❤ IHAN

IHAN Pilots as Technical Proofs

National Steering Board organised

IHAN Blueprint

CEN-CENELEC WS

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H1 - 2019

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Fair Data Economy in EC Workplans and Funding Programs

**Business Model**

IHAN blueprint document describes functional and non-functional business and technical requirements to be used in technical pilot projects.

It is our understanding of how components can be built according to IHAN requirements.

The IHAN Blueprint 2.0 will be further developed in technical workshops.

<https://www.sitra.fi/en/articles/ihan-blueprint/>

**Mindset Change**

Playbook and references XYZ

data

Fair Data Label

al Guidelines

artner Analysts  
♥ IHAN

Governance Framework and Organisational Readiness

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Fair Data Economy in EC Workplans and Funding Programs

IHAN fair data

Organization level

13 ongoing pilots:

Farmidata Distributed Ledger  
Sandbox of Trust  
MyTravelHealth

Blood sugar monitoring on diabetic children  
Citizen-centric diabetes data on PHR platforms  
Generalizing consent for blue-button based data services

Fairdrop consent receipt management for personal data exchange

Minerva – Your Digital Wallet  
MyCelia Creative Passport  
Lifelong battle fit

Data-platform for top athletes  
Open Supply Space

<https://www.sitra.fi/en/projects/ihan-pilot-projects/>

Governance Framework and Organisational Readiness

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Governance Framework and Organisational Readiness

Fair Data Label

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IHAN Pilots as Technical Proofs

National Steering Board organised

CEN-CENELEC WS

Sitra and SFS Finland organize a series of workshops in accordance with the rules and processes of the European Committee for Standardization CEN-CENELEC to refine the technical requirements of the IHAN architecture's key concepts through an open process.

Results are published as a CEN or CENELEC Workshop Agreement (CWA). The ultimate goal is to further develop CWA by either as a technical committee document or even as a European Standard (EN).

Kick-off meeting was held in January 2019.

<https://www.sitra.fi/en/projects/ihan-standardisation-workshops/>

Business Model

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IHAN fair data ecosystem principles

Organization level  
Ecosystem Model

Fair Data Economy in EC Workplans and Funding Programs

Overall Business Model for Fair Data Economy

Realising Finland as an IHAN testbed, utilising EU chair 2019 country status, engaging ministries, taking fair data economy on the EU roadmap and funding programmes to enable scaling IHAN to all Europe.

Framework and  
National Readiness

**POLICIES**  
Vision Europe thought piece  
Green Paper

Fair I  
as EU

Guidance, commitment and national coordination.

ns

EU Framework for Data Economy

**CONSUMERS**

Digital Be  
Profil

Ministry of Transport and Communications, Ministry of Economic Affairs and Employment, Ministry of Finance, Business Finland, Technology Industries of Finland, Population Register Centre, The State Development Company Vake Oy

Inventory of Governance Models

Citizen Survey: Use of Digital Services

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National Steering Board organised

**COMPANIES**

**Enabling Technology**

**Governance**

**Business Model**

**Mindset Change**

**H1 - 2019**

**H2 - 2019**

**2020 -**

IHAN fair data ecosystem principles

Organization level Ecosystem Model

Playbook and References XYZ

Fair Data Economy in EC Workplans and Funding Programs

Overall Business Model for Fair Data Economy

Governance Framework and Organisational Readiness

ICT Proposal Day

My Data

Fair Data Economy as a Theme for

Fair Data

**POLICIES**  
Vision Europe thought piece  
Green Paper

EU Framework for Data Economy

**CONSUMERS**

Citizen Survey: Use of Digital Services

Digital Pr

Home base for IHAN components and outputs after Sitra's project ends

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Inventory of Governance Models

National Steering Board organised

**COMPANIES**

**Enabling Technology**

**Governance**

**SITRA**

**Business Model**

**Mindset Change**

# Make data work for people's health! – A Webinar for Pioneers in data-driven Health Innovations on 16 September

As experts in digital health, Sitra and EHTEL are pleased to invite you to a joint webinar around the IHAN approach for trustfully personalised health services.

[JOIN SKYPE](#)

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🕒 September 16, 2019 at 3:00 pm - 4:30 pm (webcast 15:00 - 16:30)

📍 Online

<https://www.sitra.fi/en/events/ihan-webinar-in-data-driven-health-innovations/>

**RISE TO  
SHINE!**

