Innovating the secondary use of health data – the Finnish model

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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.


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

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<thead>
<tr>
<th>Before</th>
<th>From 2020</th>
<th>Also</th>
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<tbody>
<tr>
<td>Permits separately from each controller</td>
<td>Centralised access to permits and data sets</td>
<td>Advice related to data sets/use</td>
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<tr>
<td>A long process</td>
<td>Time limits</td>
<td>An electronic permit system</td>
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<td>Secure user environment</td>
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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

- Social Insurance Institution (Kela)
- National Institute for Health and Welfare (THL)
- Social and health care operating units
- Finnish Centre for Pensions (ETK)
- National Supervisory Authority for Welfare and Health Valvira
- Finnish Medicines Agency Fimea
- Regional State Admin. Agencies
- Data saved in Kanta services
- Statistics Finland
- Population Register Centre
- Finnish Institute of Occupational Health
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

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

**REGULATION**


Proposal submitted for the first hearing in August 2016.

- **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.

**TEMPORARY STEERING GROUP**

Temporary Steering Group prepares the launch of Findata operations.

**DATA PERMIT AUTHORITY**

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.


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.


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.
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

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

- Sitra study “A Finnish Model For The Secure And Effective Use of Data”
  - Lessons learned from Sitra’s Isaacus project
NEXT PHASE FOR VALUE CREATION – COMBINING REGULATED DATA WITH DATA COLLECTED BY INDIVIDUALS

Project IHAN 2018–(2021)
Who creates the data in the future?

Lots of new data sources – health data being one example

Data collected by individuals / unregulated data

Data collected by professionals / regulated data
Combining regulated data with data collected by individuals leads to next phase for value creation.
Europe’s role in data economy?
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® 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® works

Service provider

Consent to My Personal Data

Requests for data

Data providers

Service

Consumer/Patient

Data
IHAN – enabling framework

Data “Plumbing System”
IHAN®

work packages and outcomes

**Business Model**

- IHAN fair data ecosystem principles
- Overall Business Model for Fair Data Economy
- Organization level Ecosystem Model
- ICT Proposal Day
- My Data
- Playbook and References XYZ
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**Mindset Change**

- Vision Europe thought piece
- EU Framework for Data Economy
- Citizen Survey: Use of Digital Services
- Digital Behavior Profiles
- Company Survey
- Gartner Analysts ❤️ IHAN
- IHAN Blueprint
- IHAN Pilots as Technical Proofs
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**POLICIES**

- Green Paper
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**CONSUMERS**

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**Enabling Technology**

- Fair Data Economy in EC Workplans and Funding Programs
- Governance Framework and Organisational Readiness
- Specifications for IHAN Standard
- Inventory of Governance Models
- National Steering Board organised

**Governance**

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Overall Business Model for Fair Data Economy

Value Chain -> Platforms and Value Networks -> Open Ecosystems (decentralised)
An organisational level model that shows the value from open ecosystems.
Rulebook describes companies’ legal, business, technical and governance framework in the data ecosystems.

Uudistamo and Playbook renew business models and guides companies:
1) to understand the advantages and value potential in fair data economy
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
Policy Brief: A Roadmap for a Fair Data Economy for EU policy makers with the Brussels-based think tank and policy network Lisbon Council

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

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)

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

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

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

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

Conducted 12/2018

EUROPEANS’ ATTITUDES TOWARDS THE USE OF PERSONAL DATA

Survey results.

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?”

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

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

Finnland  30%
Netherlands  37%
Germany  43%
France  31%
What is the effect of data leaks on people’s behaviour?

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.
has requested access to their own personal information

Finland 7%
Netherlands 11%
Germany 9%
France 8%
Lack of trust is an obstacle

Data plz?

Strongly agree, agree

Finland 43%
Netherlands 38%
Germany 48%
France 39%
“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…”

<table>
<thead>
<tr>
<th>Information</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Information about my wealth and spending</td>
<td>40%</td>
</tr>
<tr>
<td>Personal data or data about my personal history</td>
<td>35%</td>
</tr>
<tr>
<td>Information about my health or genetics</td>
<td>30%</td>
</tr>
<tr>
<td>My spatial data, devices I use or the way I use devices</td>
<td>27%</td>
</tr>
<tr>
<td>Information about my values or beliefs</td>
<td>27%</td>
</tr>
<tr>
<td>Information about my consumption habits or my purchases</td>
<td>17%</td>
</tr>
</tbody>
</table>
“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

<table>
<thead>
<tr>
<th>Country</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>Finland</td>
<td>71%</td>
</tr>
<tr>
<td>Netherlands</td>
<td>63%</td>
</tr>
<tr>
<td>Germany</td>
<td>70%</td>
</tr>
<tr>
<td>France</td>
<td>61%</td>
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</table>
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.
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.
The results of a data economy business survey conducted in Finland, France, Germany and the Netherlands will be published in 19 September 2019.
A way to identify, certificate or reward fair data actors

IHAN approved?, Fair Data Label?, Fair Data Award?
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/
Business Model

- IHAN fair data ecosystem principles
- Organisation level

Mindset Change

- Citizen Survey: Use of Digital Services
- Company Survey
- Digital Behavior Profiles

POLICIES

Geographical Framework and Organisational Readiness

CONSUMERS

- EU Framework for Data Economy

- Green Paper

COMPANIES

- IHAN Blueprint

- Fair Data Economy as a Theme for EU Presidency

- Vision Europe thought piece

- My Data ICT Proposal Day

- Gartner Analysts

- IHAN Ethical Guidelines

- Fair Data Label

- IHAN Pilots as Technical Proofs

Governance

- National Steering Board organised

- Inventory of Governance Models

- Specifications for IHAN Standard

- CEN-CENELEC WS

Enabling Technology

- 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

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.

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.

Guidance, commitment and national coordination.

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

Enabling Technology
H1 - 2019

- IHAN fair data ecosystem principles
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H2 - 2019

- Enabling Technology
- Citizen Survey: Use of Digital Services
- Digital Behavior Profiles

2020 -

- Governance Framework and Organisational Readiness
- Governance Home base for IHAN components and outputs after Sitra’s project ends
- Fair Data Economy in EC Workplans and Funding Programs

Business Model

Mindset Change

POLICIES

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- Citizen Survey: Use of Digital Services
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- ICT Proposal Day
- Fair Data Economy as a Theme for Vision Europe
- My Data

Governance

INVENTORIES

- Governance Models
- Inventory of Governance Models

National Steering Board organised

ICT

- CEN - CENELEC Specifications for IHAN Standard

Sitra

- IHAN Pilots as Technical Proofs
- IHAN Blueprint

ICT

- Green Paper
- Gartner Analysts

ICT

- CONSUMERS
- COMPANIES
- POLICIES

My Data

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ICT
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.

RISE TO SHINE!