

Findata and the Finnish legislation on the secondary use of health data

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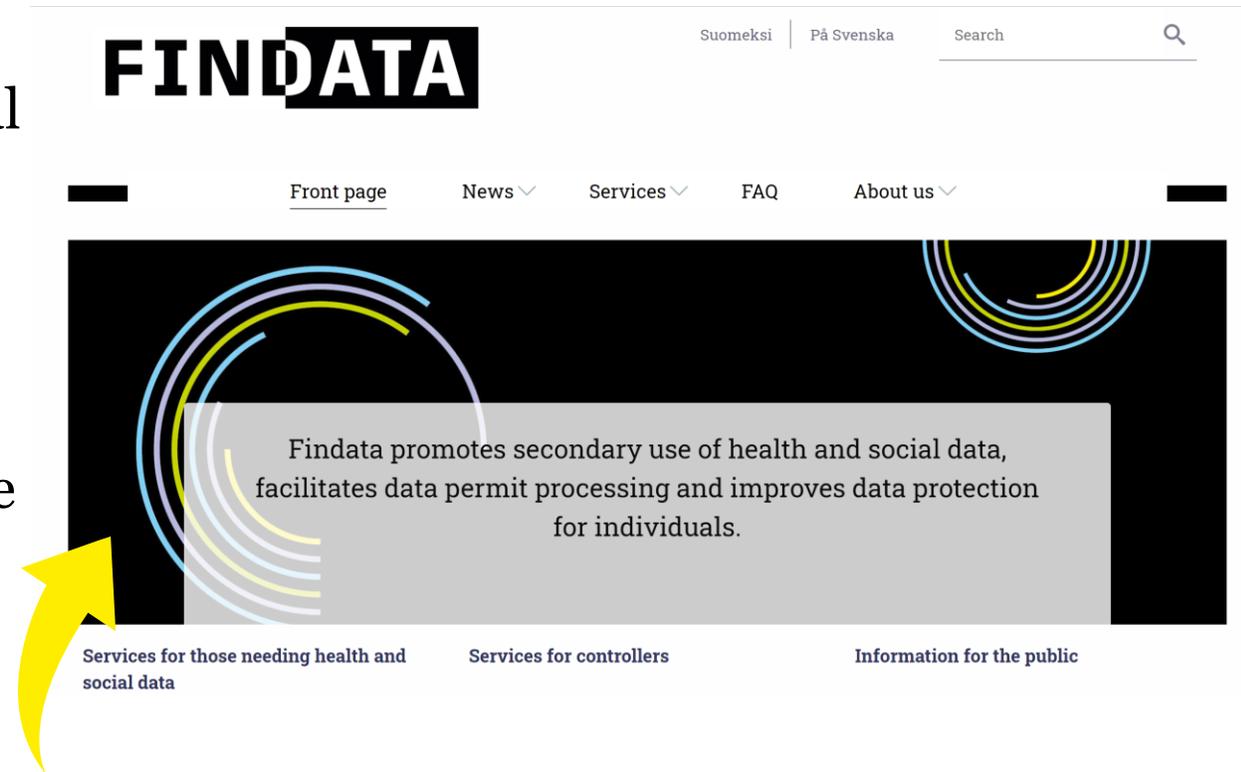
Sitra – the Finnish Innovation Fund

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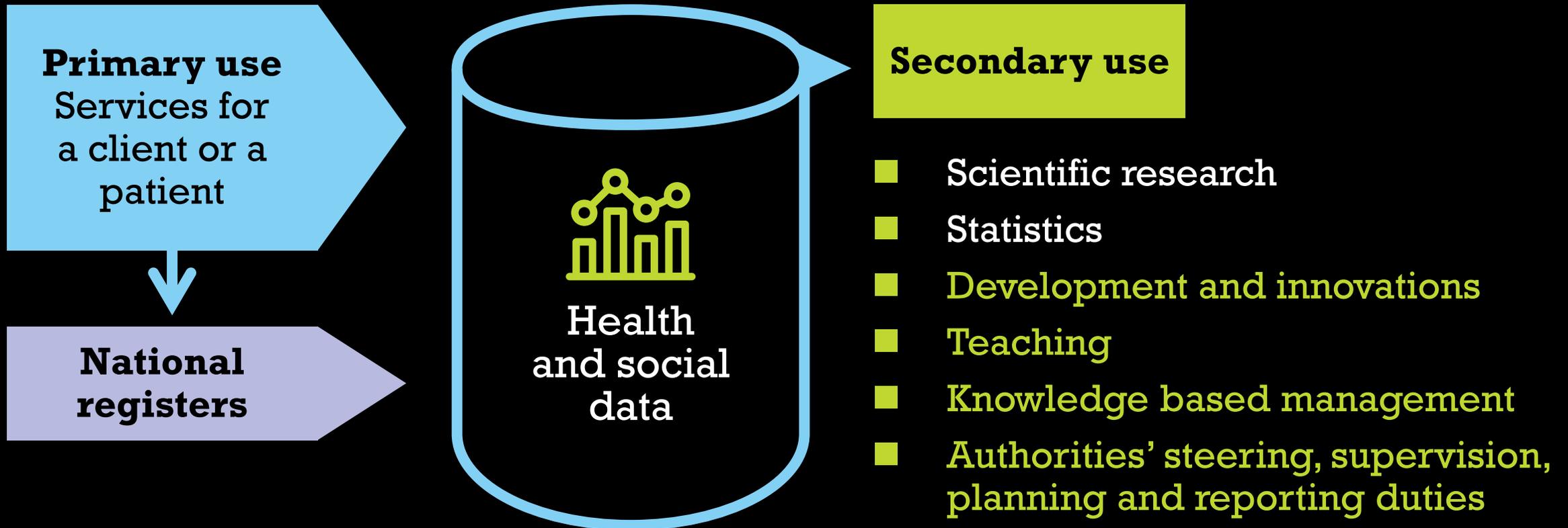
Finnish Legislation on Secondary Use of Social and Healthcare Data

- Entered into force **on 1 May 2019**
- It enabled the founding of a 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.



Website in English: www.findata.fi/en/

Primary and secondary use of personal data

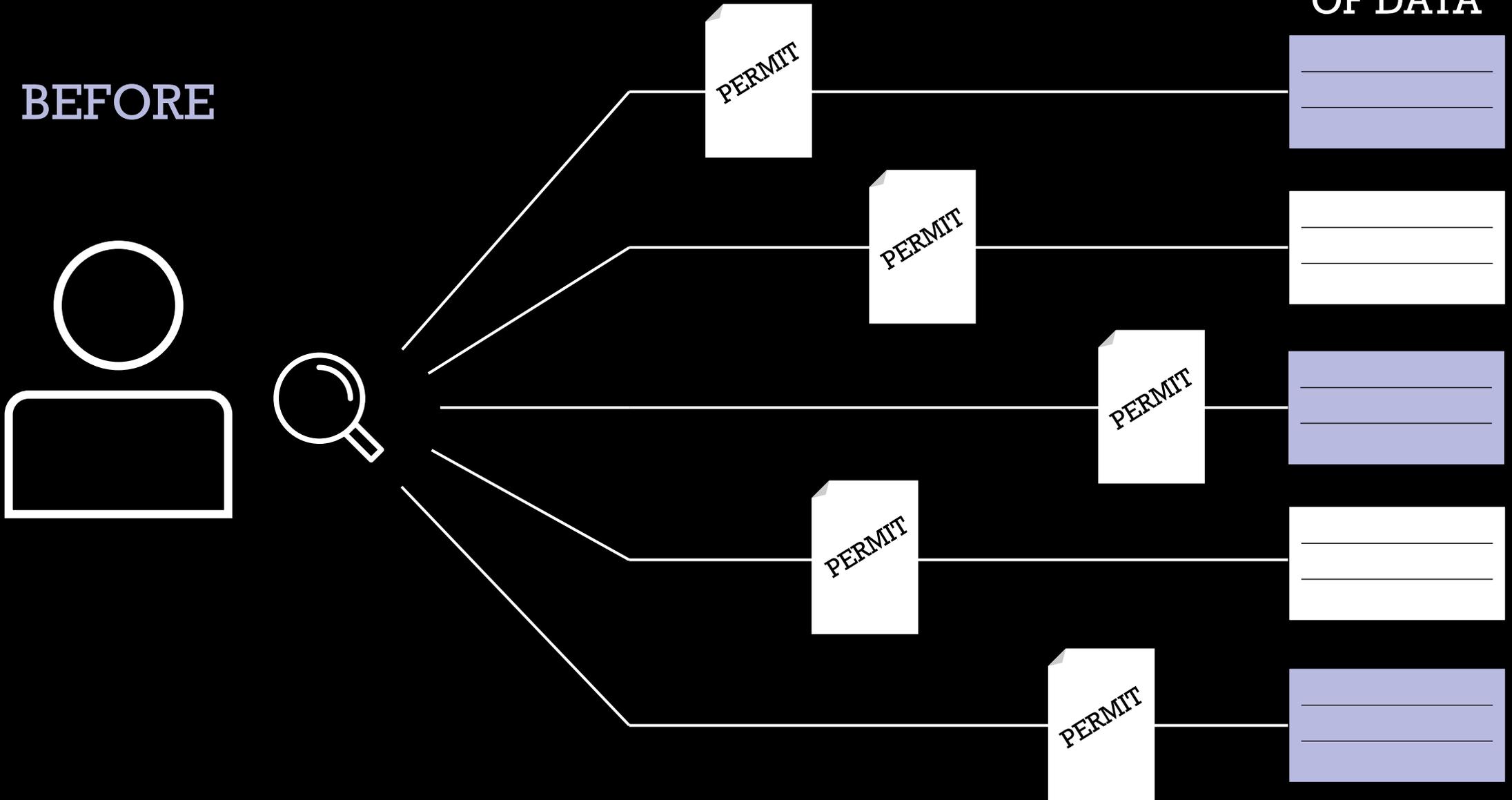


Based on the Act on the Secondary Use of Health and Social Data (552/2019)

FIND DATA

CONTROLLERS OF DATA

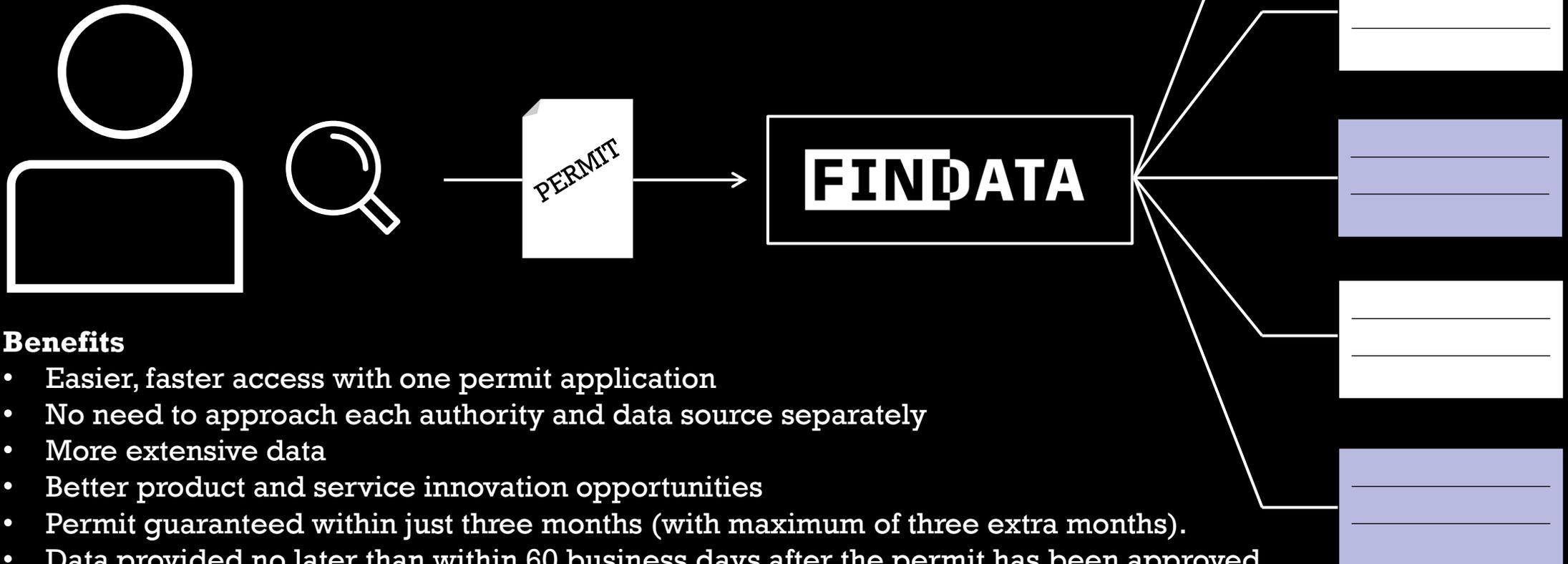
BEFORE



FINDATA

CONTROLLERS OF DATA

AFTER



Benefits

- Easier, faster access with one permit application
- No need to approach each authority and data source separately
- More extensive data
- Better product and service innovation opportunities
- Permit guaranteed within just three months (with maximum of three extra months).
- Data provided no later than within 60 business days after the permit has been approved

Services

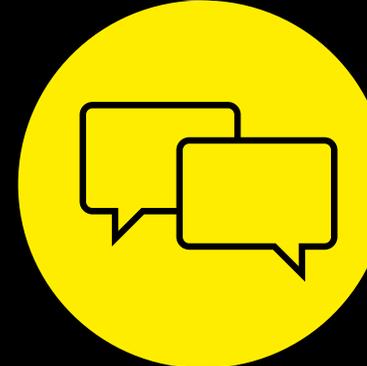
One-stop shop
for the
secondary use
of health and
social data

Operates directly under
the Ministry of Social
Affairs and Health

Grant data permits when data are requested from multiple registers



Help Desk for data users



Collect and process the data



Provide the data in a secure IT-environment for data users



What kind of data is available?

Individual level data

Data Permit

- Scientific research
- Statistics
- Teaching
- Authorities' steering, supervision, planning and reporting duties
- *Knowledge based management (organisations can use their own data sets without a permit from Findata)*

Statistical level data

Data request

- **All of the above**
- Development and innovations
- Reference data for knowledge based management

A data utilisation plan is always required to access data sets

How to access data sets

Individual
level
data



- Findata started receiving data permit applications 1.4.2020
- Available in a secure remote use environment for a set period
- Data sets are only available without individual's direct identifiers
- For the purposes specified in the Act

Statistical
level
data



- Findata started receiving data requests 1.1.2020
- Delivered to the customer
- Free use for the purposes specified in the Act

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

National Institute for Health and Welfare (THL)

- Cancer register
- Infectious disease register
- Hospital discharge register
- National vaccination register
- Medical birth register
- Register of induced abortions
- Register of congenital malformations
- etc.

Finnish Institute of Occupational Health

- Occupational illnesses
- Occupational exposures

Digital and Population Data Services Agency

- Population data
- Families
- Residence
- Building information

Social Insurance Institution (Kela)

- Prescriptions
- Social benefits

Statistics Finland

- Register on causes of death

Finnish Centre for Pensions (ETK)

- Benefits and incomes
- Diagnoses

Social and health care operating units (public and private)



Data saved in Kanta services (National electronic health record system for citizens and health care professionals)

- “My Kanta Pages” for citizens (medical records and prescriptions)
- (e-)Prescription service
- Pharmaceutical Database
- Patient Data Repository
- Archiving of old patient data
- Client data archive for social welfare services
- Sharing of medical certificates

National Supervisory Authority for Welfare and Health Valvira

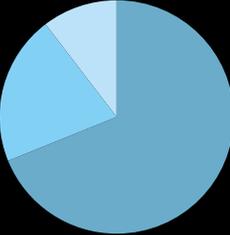
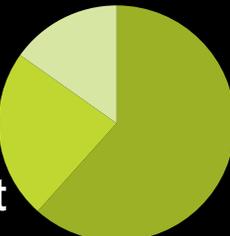
Finnish Medicines Agency Fimea

Regional State Administrative Agencies (AVI)

Operations have started on schedule set by the Act

- A lot of legal interpretation and guidelines
 - Solution-focused and agile way of working
- Demand for advice
 - Advice calls 2-10 in a day (average 5 per day)
 - Approx. 1,000 incoming e-mails

Statistics

- Applicant organisations
 - 69 % public
 - 21 % private
 - 10 % individual
- 202 applications received (14.9.2020)
 - 63 % data permit
 - 22 % data request
 - 15 % application for amendment

Sitra's Isaacus project 2015-2018

- 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 open in November 2019. Information requests from January 2020.

2015 -

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.

Further readings

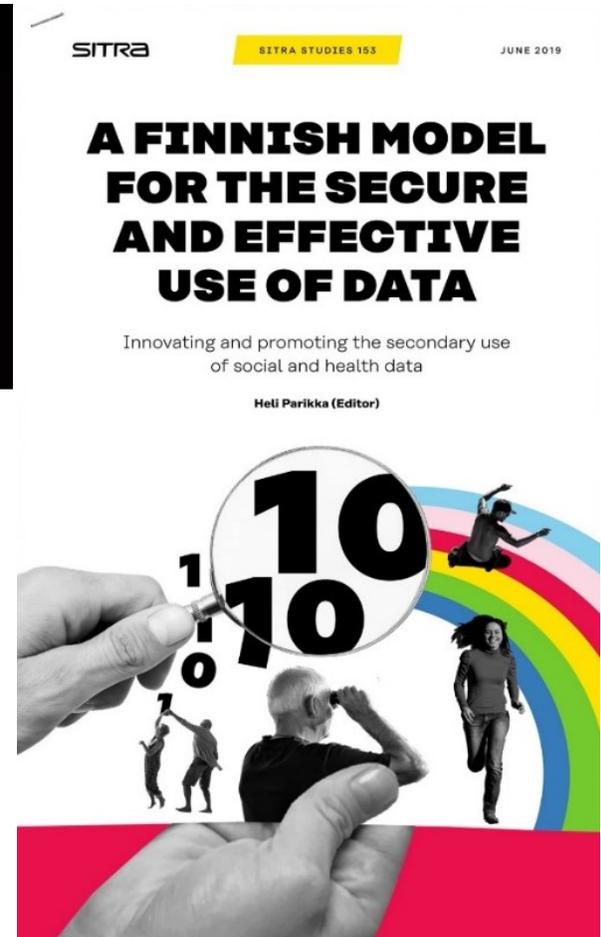
- Findata website
 - <https://www.findata.fi/en/>
- Blog post 5/2019
 - New legislation will speed up the use of Finnish health data <https://www.sitra.fi/en/blogs/new-legislation-will-speed-use-finnish-health-data/> (includes the act **in English**)
- Sitra study “A Finnish Model For The Secure And 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

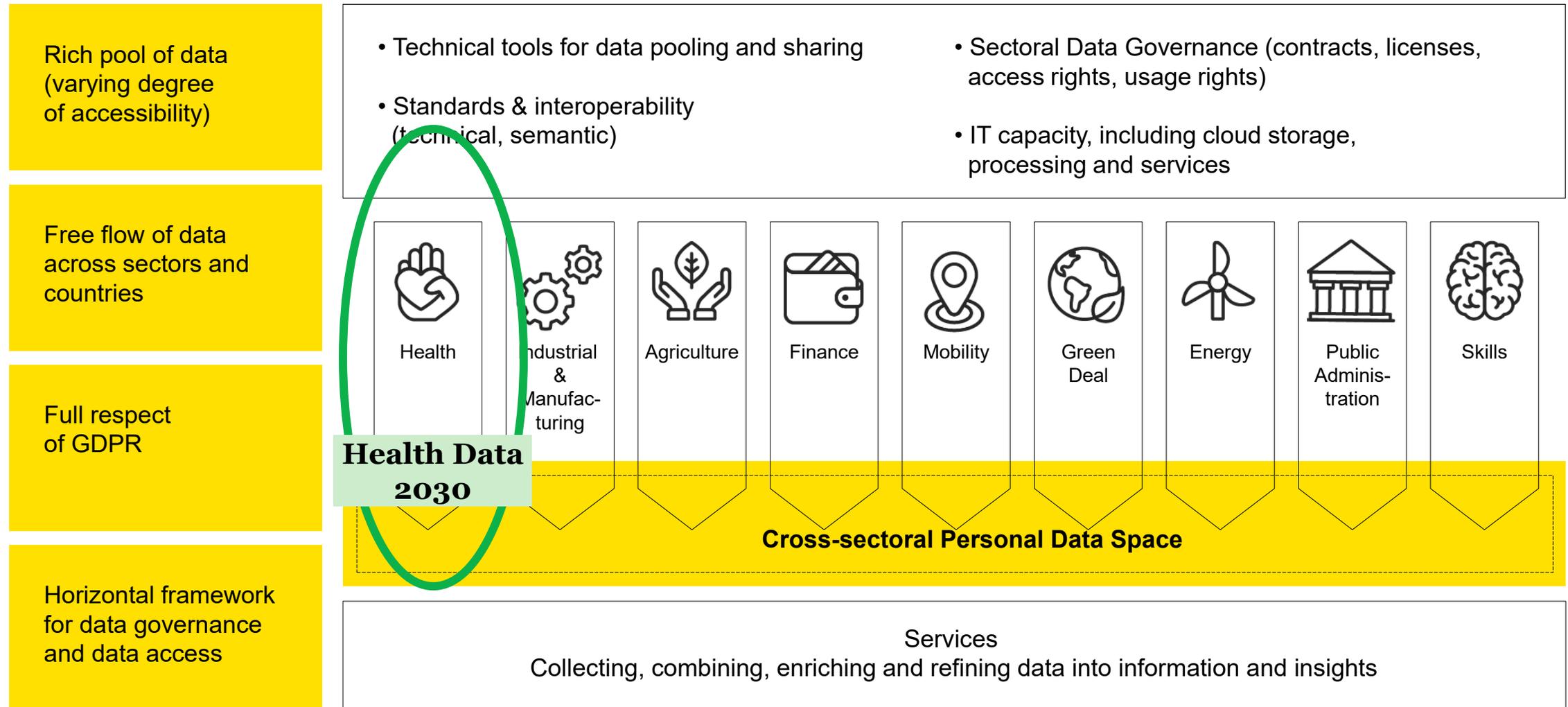
New legislation will speed up the use of Finnish health data

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



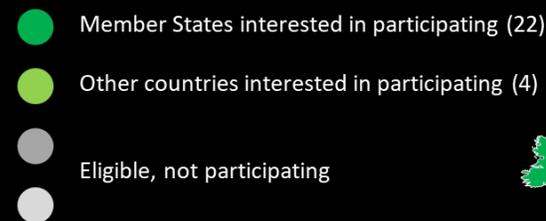
SITRA

Towards European data spaces



Joint Action Towards European Health Data Space

Project Coordinator: Sitra, Finland
Project Acronym: TEHDAS
Starting Date: 1 February 2021 (estimated)
Project Duration: 30 months
Participants: 22 MS + 4 other countries
Co-funding: 3rd EU Health Programme (2014-2020)
Budget: €4.16 mill.
EU €2.5 mill. + MS €1.66 mill.



26 Participant Countries
October 2020

Themes:

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

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