



# The 5<sup>th</sup> Digital Health Society Summit

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# Outline

- Current status and Findata services
- What data are available?
- How to access data?
- Pricing and costs?



# Cornerstones for secondary use in Finland

- Rich national data registers with long time series
  - In practice 100% coverage of Finnish population
  - Long tradition of national health registers and their secondary use
- Opt-out principle in secondary use of social and health data
- Personal identity code: a key to linking personal information from various registers
- High trust on
  - Government and authorities, transparent operation
  - Benefits from research (as better healthcare)
  - Data security and data safety

# Finnish Social and Health Data Permit Authority Findata

Finland has established a centralized health data access point for researchers - Findata

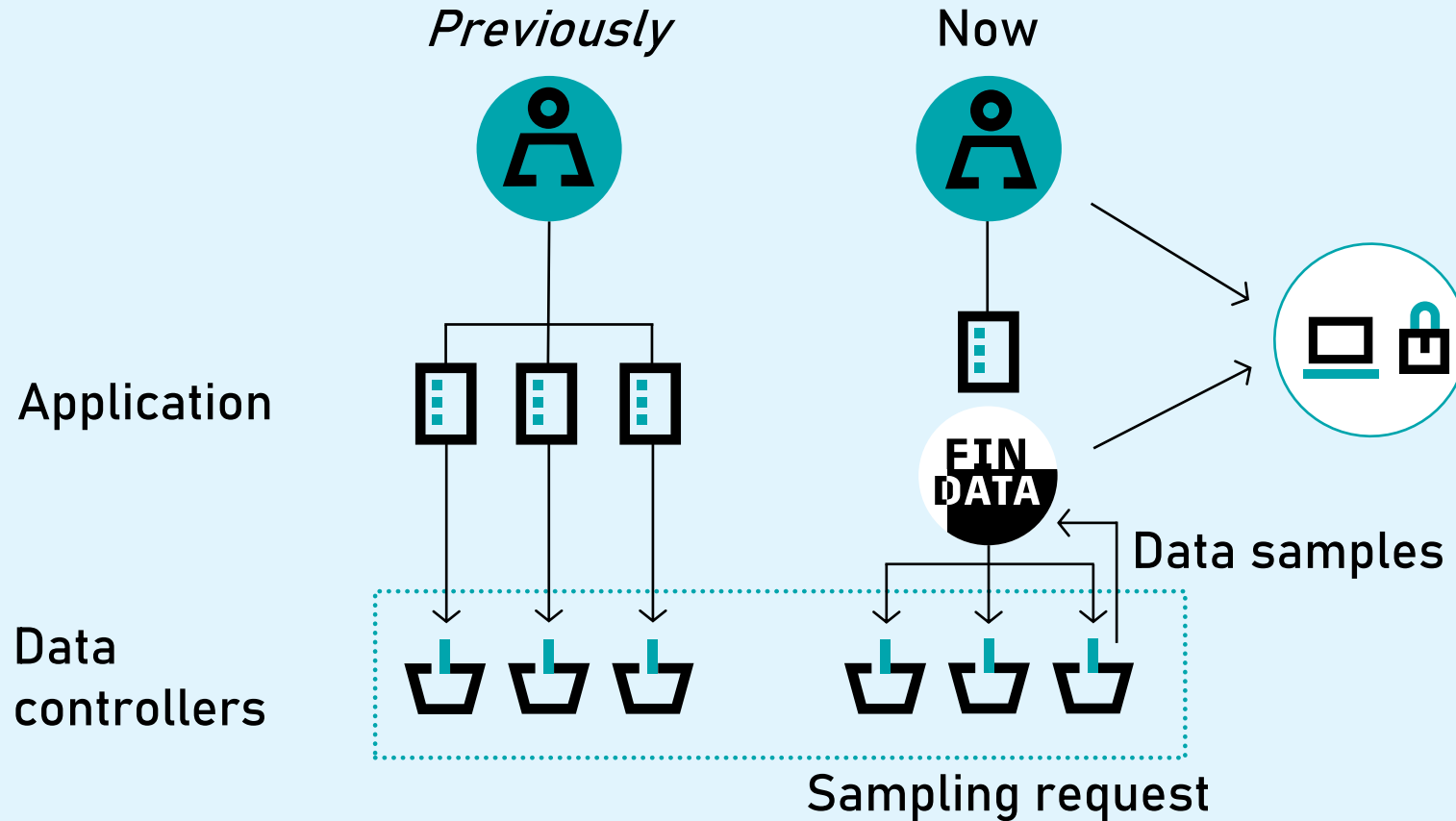
- The aim is to improve access to rich nation-wide datasets
- Operation based on national Act on Secondary Use of Health and Social Data (2019), closely comparable to EHDS
- Findata started to operate in 2020 → Over three years of first-hand experience, about 1 200 applications
- Status: an independent authority positioned in Finnish Institute for Health and Welfare, steering by Ministry of Social affairs and Health
- Non-profit organization, yearly budget ~3 M€, staff ~30 persons

## One-stop shop for secondary use of health data

### Findata services

- Grants data permits when data are requested
  - from multiple controllers
  - private health care units
  - Kanta-services (electronic health records)
- Collects, links and pseudonymises the data
- Produces aggregated data on request
- Maintains a secure IT-environment for applying, transferring and managing data
- Provides secure remote access system Kapseli® for data analysis
- Help Desk for data users [info@findata.fi](mailto:info@findata.fi)
- Anonymization services
- Issues R&D&I infrastructure regulations

# Previously and at present



- One application regardless number of registers
- Findata links and pseudonymizes data
- Data analysed in a secure remote access system Kapseli®

# Data access and discovery

# Data accessed via Findata

Social and health care service providers, both public and private sector

- Patient records in primary and special health care
- e-prescriptions
- Social welfare services

Cover 100% of Finnish population

National registers

Biobanks?  
Genome data?



# Data accessed via Findata

## Social and health care service providers

- Public and private sector
- Patient records in primary and special health care
- Social services



## Kanta services

Key health data, COVID-19, e-prescriptions + more

## Finnish 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.

## Social Insurance Institution of Finland (Kela)

- Prescriptions
- Social benefits

## The Finnish Digital Agency (DVV)

- Population data
- Families
- Residence
- Building information

## Finnish Centre for Pensions (ETK)

- Benefits and incomes
- Diagnoses

## Finnish Medicines Agency Fimea

- Special permit register
- Adverse reaction register
- Incident report register

## Finnish Institute of Occupational Health (TTL)

- Occupational illness
- Exposure measurements
- Patient register

## Statistics Finland

- Register on cause of death

## National Supervisory Authority for Welfare and Health Valvira

- Social and healthcare professional person registers
- Register of private service providers

## Regional state administrative agencies (AVI)

- Matters related to social and health care



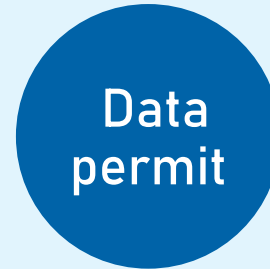
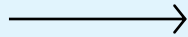
# Data discovery: National Metadata Catalogue

- Task mandated to Findata by the Act on the Secondary Use of Health and Social Data
- Regulation on the data contents, concepts and data structures for data descriptions issued by Findata in 2/2021: [findata.fi/en/data/regulation-on-data-descriptions/](https://findata.fi/en/data/regulation-on-data-descriptions/)
- Metadata catalogue: [www.aineistokatalogi.fi](http://www.aineistokatalogi.fi)
- Currently includes data descriptions of health and social data from 39 data controllers, both national and regional
- Data descriptions extending from data resource/dataset level to variable and code level
- Includes information on data quality

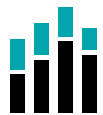
# How to access data



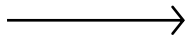
Individual level  
data



- Direct identifiers removed
- Available in an audited environment for a set period
- For the purposes specified in the Act



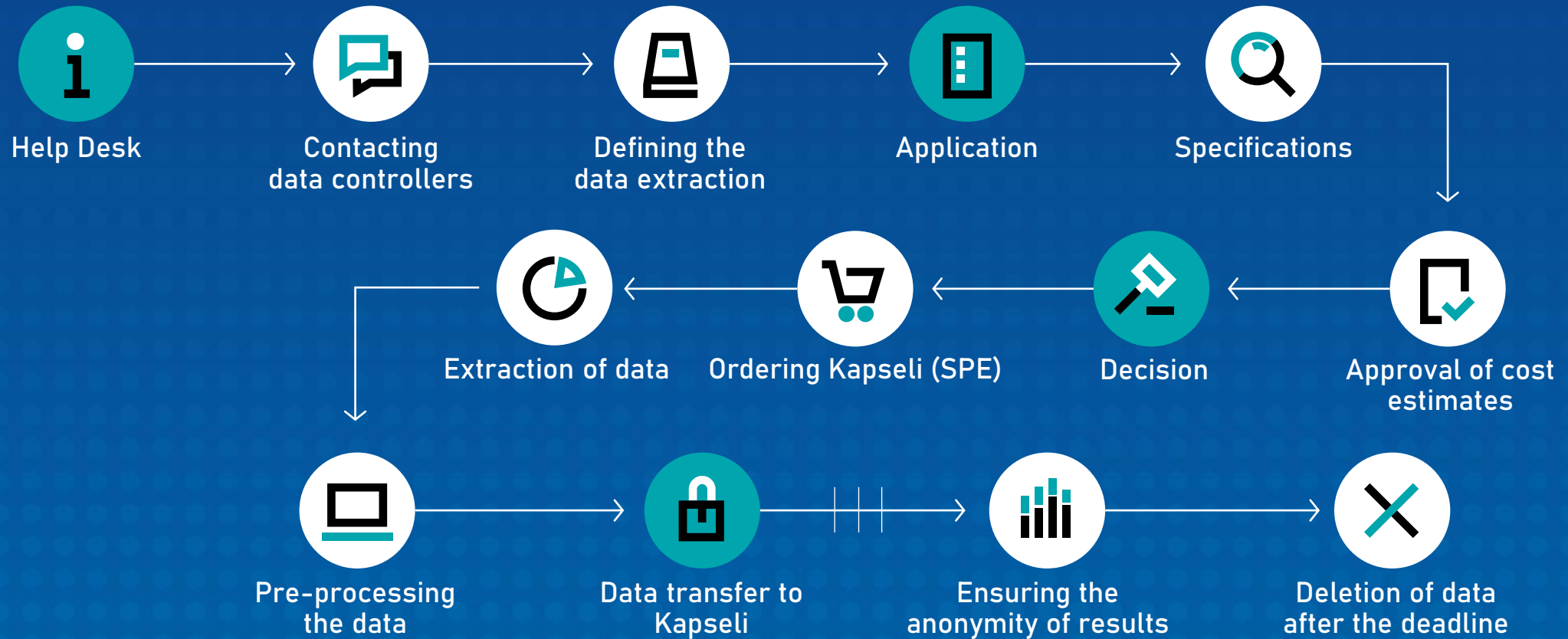
Aggregated  
data



- Anonymous statistical level data
- Sent to the client
- For the purposes specified in the Act

- A data utilisation plan is always required to access data sets
- Individual level data permits are always for specific purpose, time period and persons

# Customer path



# Duration of the permit process

First check	Queue	Processing of application	Extracting and compiling of data
<ul style="list-style-type: none"><li>• Done within one week of submitting an application</li><li>• If information is missing, Findata provides guidance on filling it in</li></ul>	<ul style="list-style-type: none"><li>• At the moment approximately 4 months</li><li>• Queues have shortened significantly over the years (Aug 2023: 47 vs. Aug 2022: 104 applications in queue)</li></ul>	<ul style="list-style-type: none"><li>• Approximately 3 months</li><li>• Systemic process, in which every party can slow or speed up the process (applicant, controllers, Findata)</li></ul>	<ul style="list-style-type: none"><li>• Goal: 60 days from the permit decision</li><li>• Factors that affect the process: extraction carried out in several stages, delays from controllers, particularly complex data etc.</li></ul>
<p>Estimated total time for applying and accessing individual level data: <b>9 months</b></p> <p>Estimated total time for amendments to existing permit: <b>~1-6 weeks</b></p>			

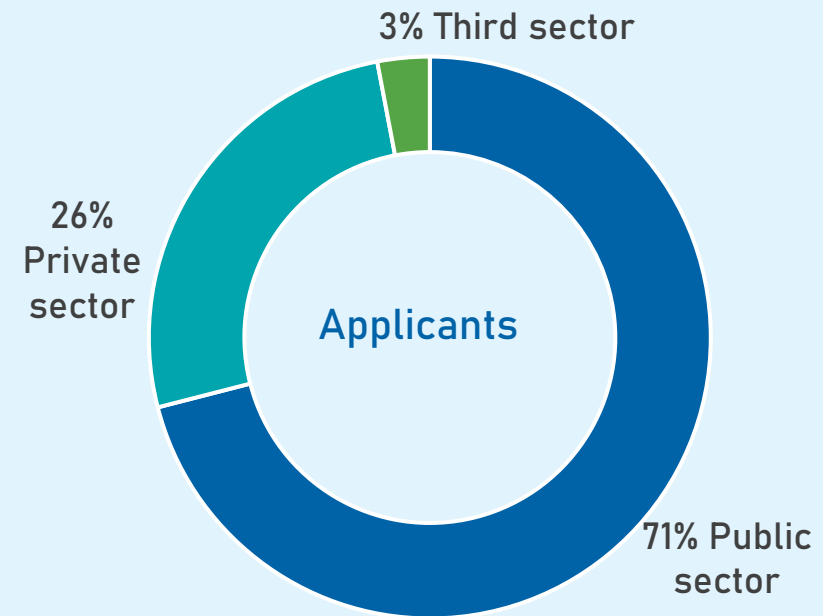
## Year 2022

270 Applications

284 Decisions

From which

- 94% individual level data
- 95% for scientific research



Issued permits openly available: [findata.fi/issued-permits](https://findata.fi/issued-permits)

# Pricing and costs

# Pricing of services

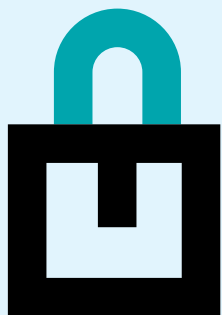
- Based on decree issued by Ministry of Social Affairs and Health
- Prices consist of four elements:

Element		Price	Additional information
1. Permit fee	Data permit	600-3 000 €	250 € for students
	Data request	2 500 €	250 € for students
2. Reimburses for data controllers' sample costs		2 000 € median price per data controller	0-60 000 € range
3. Findata's data management work		135 €/hour	Maximum estimate given in advance
4. Payment/subscription for Kapseli SPE		160-460 €/month	Depending on the size of the computing package

For up-to-date information, please see: [findata.fi/pricing](https://findata.fi/pricing)



# Kapseli® remote access users (Oct 2023)



Projects

139

Users

1 035

Machine packages	Number
Small	42
Medium	45
Large	43
Extra large	9
Total	139

Overview: [findata.fi/en/kapseli](https://findata.fi/en/kapseli) [Findata Regulation on secure operating environments](#)

# Challenges

- A systemic change in the whole R&D environment
  - Not just a new player on the field, the rules have changed for all
- An ambitious timetable for setting up the services
  - Agile process
- Legal frame still developing
  - Compatibility with other regulation
- Data controllers' resources and capabilities
  - Data availability and interoperability
- Need for public discussion about the price and costs of health data

# Trust is a must!

- Data sets made available without individual's direct identifiers
- A secure remote access environment for individual level data sets
- Security in Findata operating environment is controlled by an information security inspection body and Valvira
- Compliance with the Act supervised by
  - Ministry of Social Affairs and Health
  - Data Protection Ombudsman
  - National Supervisory Authority for Welfare and Health (Valvira)



# Summary of the presentation

1. Findata's activities are based on the Act on the Secondary Use of Health and Social Data, issued in 2019.
2. Findata has received more than 1 000 applications and made around 900 decisions.
3. Findata takes care of the whole process: aiding data discovery → providing a help desk for clients → handling applications → issuing permits → requesting & managing the data → providing the pseudonymised data in a SPE.
4. Findata has faced challenges but also overcome difficulties & streamlined its processes during the first few years, relying in active co-operation with the stakeholders.
5. Findata is actively taking part in the EHDS preparations.

Thank you!

**FIND DATA**

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