FINDATA

The 5th 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?

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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

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Finnish Social and Health Data Permit Authority Findata

Finland has established a centralized health data access point for researchers – Findata
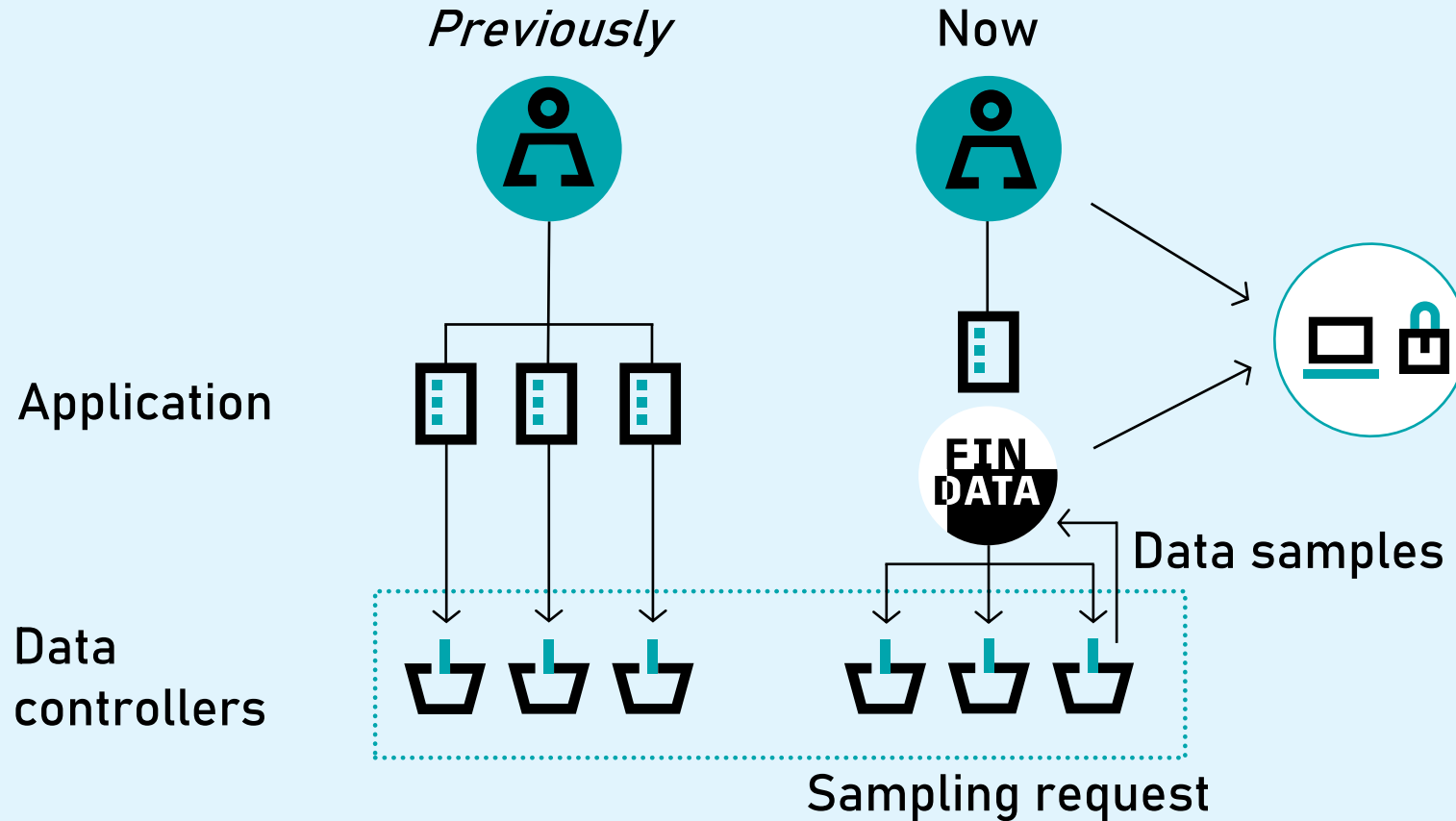
- The aim is to improve access to rich nation-wide datasets

- 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

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Findata services

One-stop shop for secondary use of health data

- 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
- Anonymization services
- Issues R&D&I infrastructure regulations

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Previously and at present

Previously

Now

Application

Data
controllers

FIN
DATA

Data samples

Sampling request

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

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Data access and discovery

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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?

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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)

- Presciptions
- 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
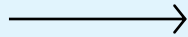
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Data discovery: National Metadata Catalogue

- 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/

- Metadata catalogue: 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
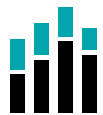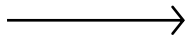
- Includes information on data quality

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How to access data

Individual level data → **Data permit**

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

Aggregated data → **Data request**
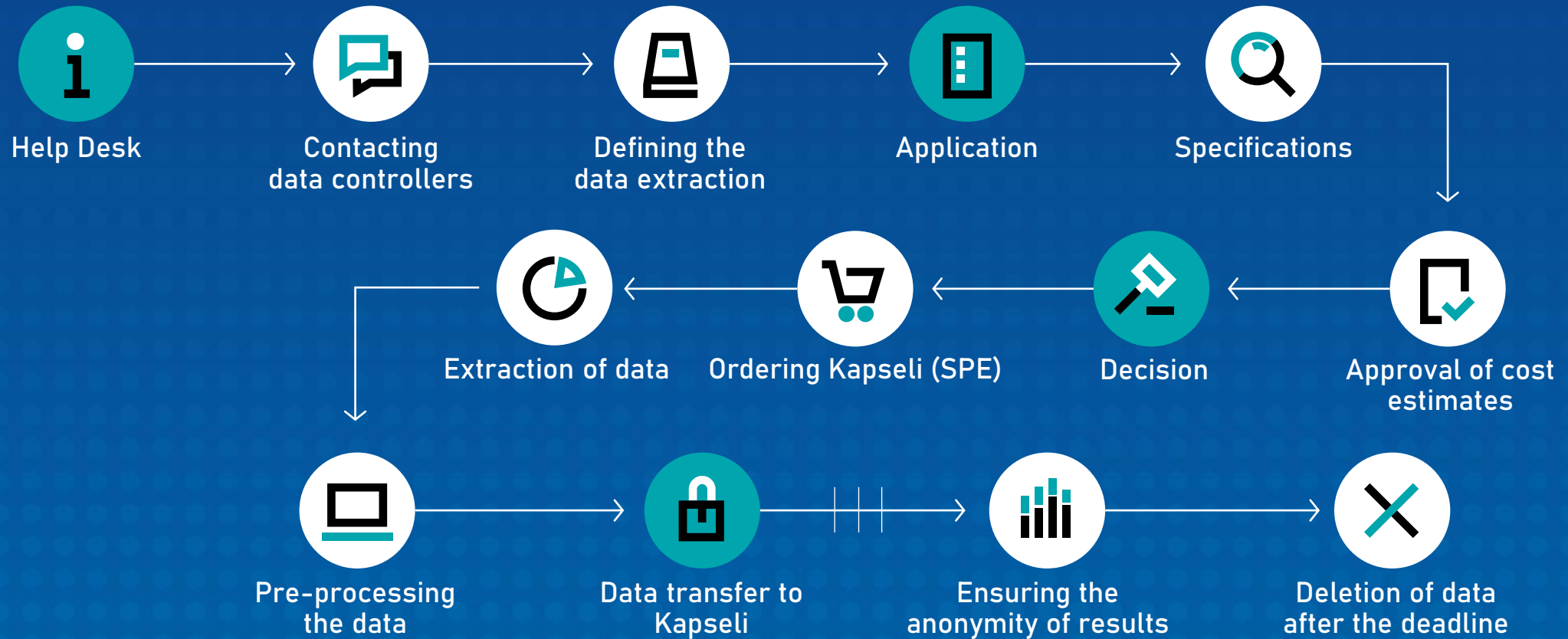
- Anonymous statistical level data
- Sent to the client
- For the purposes specified in the Act

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

FIN**DATA**

Customer path

Help Desk → Contacting data controllers → Defining the data extraction → Application → Specifications → Approval of cost estimates → Decision → Ordering Kapseli (SPE) → Extraction of data → Pre-processing the data → Data transfer to Kapseli → Ensuring the anonymity of results → Deletion of data after the deadline

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Duration of the permit process

First check	Queue	Processing of application	Extracting and compiling of data
• Done within one week of submitting an application • If information is missing, Findata provides guidance on filling it in	• At the moment approximately 4 months • Queues have shortened significantly over the years (Aug 2023: 47 vs. Aug 2022: 104 applications in queue)	• Approximately 3 months • Systemic process, in which every party can slow or speed up the process (applicant, controllers, Findata)	• Goal: 60 days from the permit decision • Factors that affect the process: extraction carried out in several stages, delays from controllers, particularly complex data etc.

Estimated total time for applying and accessing individual level data: **9 months**

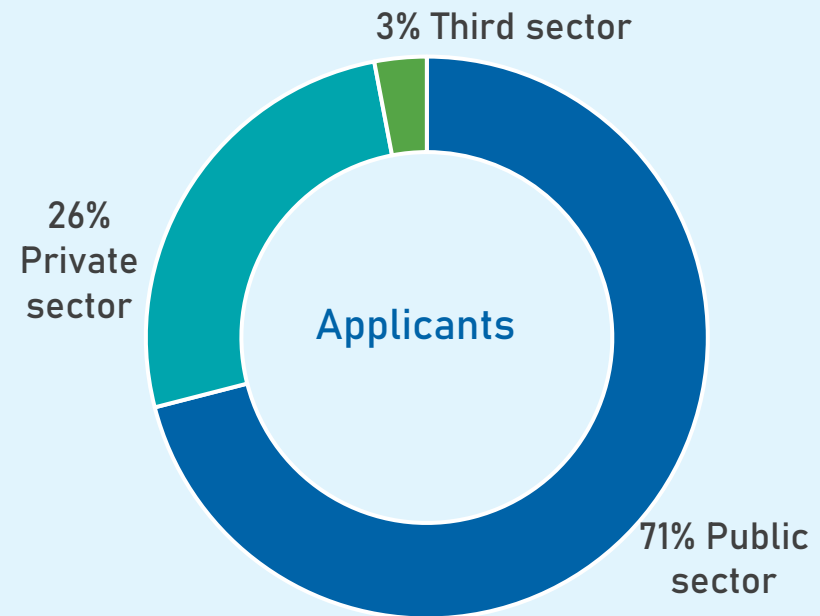Estimated total time for amendments to existing permit: **~1–6 weeks**

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Year 2022

270 Applications
284 Decisions

From which

- 94% individual level data

- 95% for scientific research

3% Third sector

26% Private sector

Applicants

71% Public sector

Issued permits openly available: findata.fi/issued-permits

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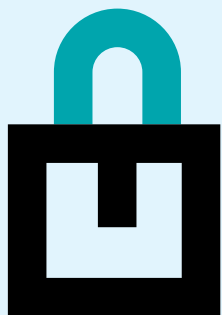
Pricing and costs

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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

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Kapseli® remote access users (Oct 2023)

Projects	Users
139	**1 035**

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

Overview: findata.fi/en/kapseli   Findata Regulation on secure operating environments

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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**

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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)

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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.

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Thank you!

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