

A woman wearing a cycling helmet and gear is standing next to a bicycle in a field of tall grass. The image is split into several sections: a top-left section with tall grass, a top-right section with the woman, a middle section with text, and a bottom section with more tall grass.

# FINDATA

## HEALTH & WELFARE

### Social and Health Data Permit Authority

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PhD, Director

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# **Cornerstones for secondary use in Finland**

- **Rich national data registers**
  - in practice 100% coverage of Finnish population
- **Opt-out principle in secondary use of social and health data => consent not required for registry based research**
- **Personal identity code: a key to linking personal information from various registers**
- **Data security and data safety => trust**

## **Legal basis: Act on Secondary Use of Health and Social Data**

- To streamline and secure the secondary use of social and health data

### **Findata:**

- Prescribes the establishment, tasks, services, steering and supervision of Findata
- Gives Findata authority to grant permissions for secondary use of Finnish health and social data
- Status: Findata is an independent authority located in the Finnish Institute for Health and Welfare

## **Legal basis: Act on Secondary Use of Health and Social Data**

- According to the Act, data can be granted to following secondary use purposes:
  - Scientific research
  - Statistics
  - Development and innovations
  - Teaching
  - Knowledge based management
  - Authorities' steering, supervision, planning and reporting duties

## **Secondary Use of Health and Social Data**

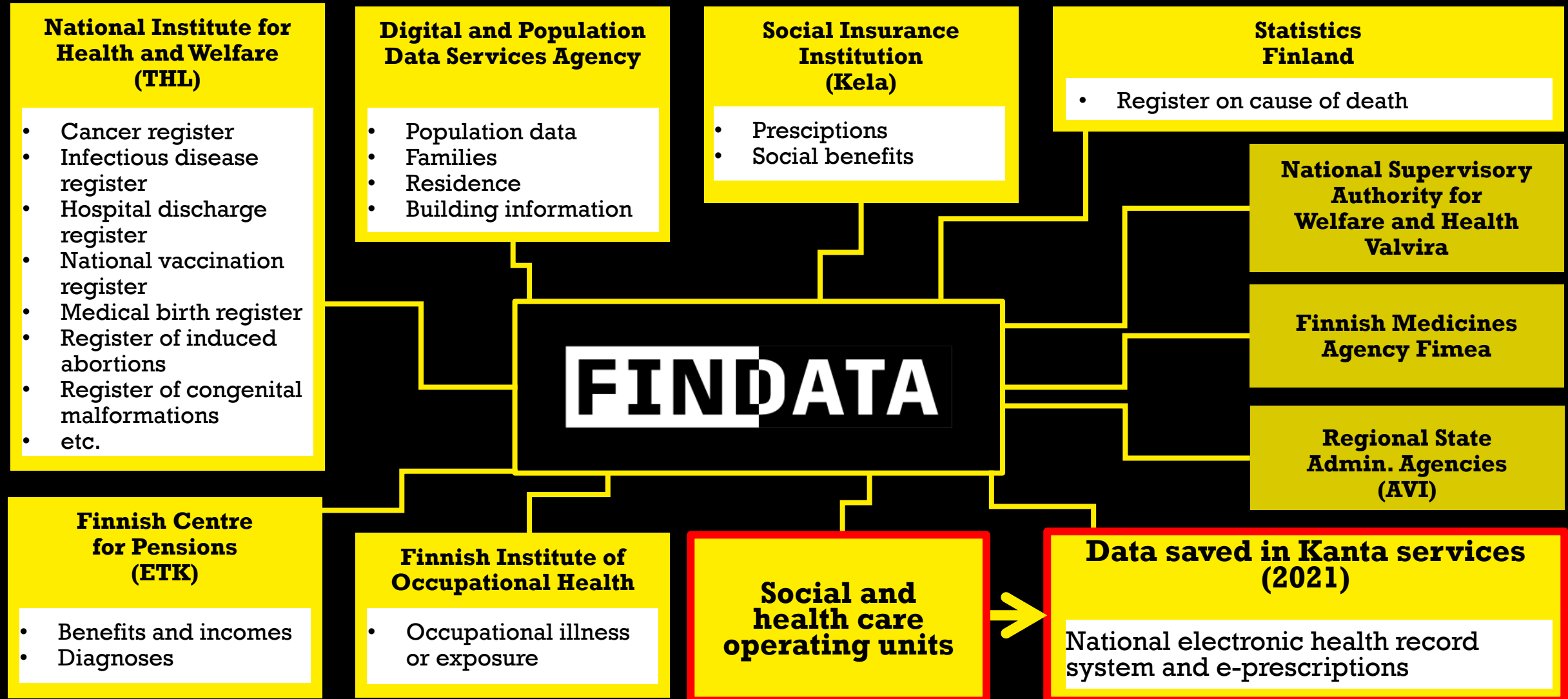
**Data collected in connection of social and health services in Finland (both public and private sector)**

### **National registers**

- **Both health and social data registers**
- **Also population studies**

**Biobanks  
2023?**

**Genome  
data?**



## Role of Findata

- Grants data permits when data are requested
  - from multiple controllers
  - private health care units
  - Kanta-services (electronic health records)
- Collects and links the data
- Maintains a secure IT-environment for data users
- Help Desk for data users [info@findata.fi](mailto:info@findata.fi)
- Anonymization services

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

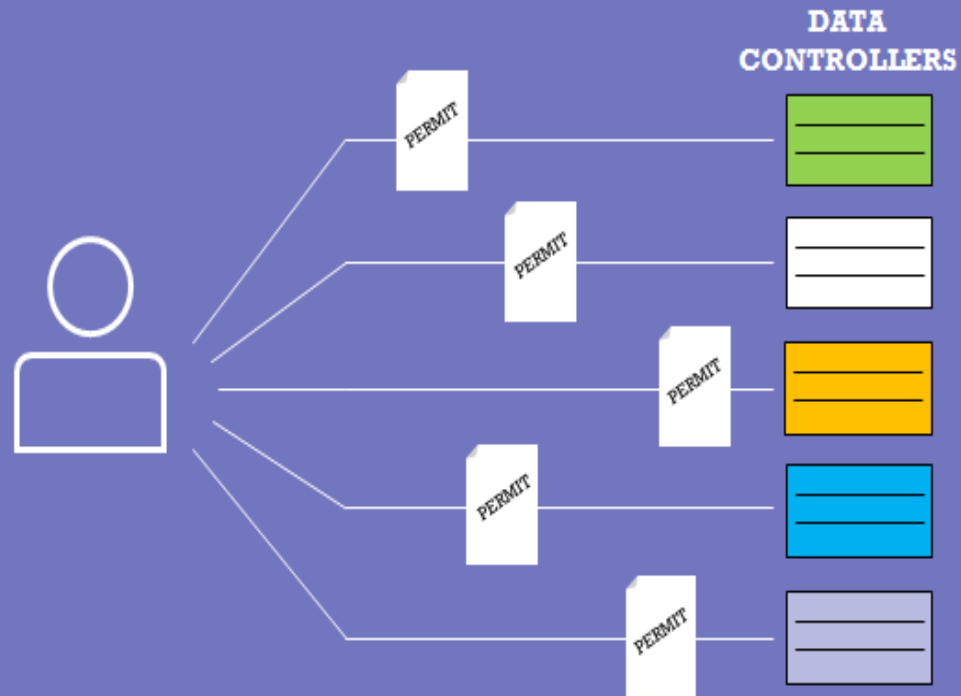
## Goals

To streamline and secure the secondary use of health and social care data

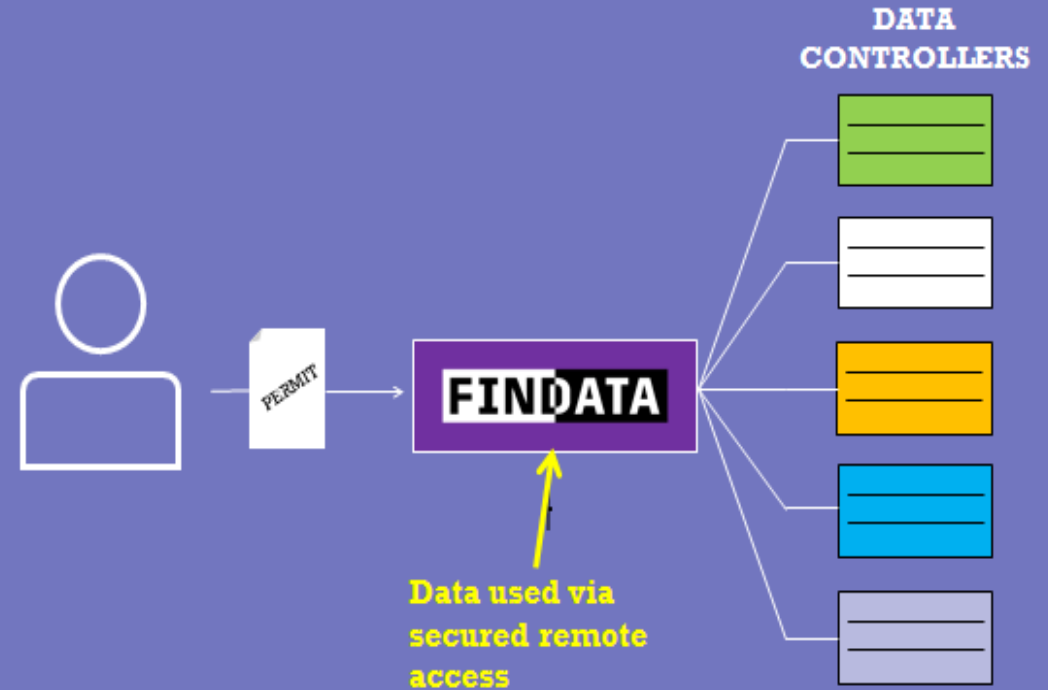
- **Enable** effective and safe processing and access to data
- **Enhance** data protection and security
- **Eliminate** overlapping administrative burden
- **Improve** register data quality



# Previously



# From 2020: One-stop-shop



## Steering

### Steering group

Appointed by Ministry of Social Affairs and Health (STM)



Subgroup  
Data controllers and  
clients

Chair: Findata



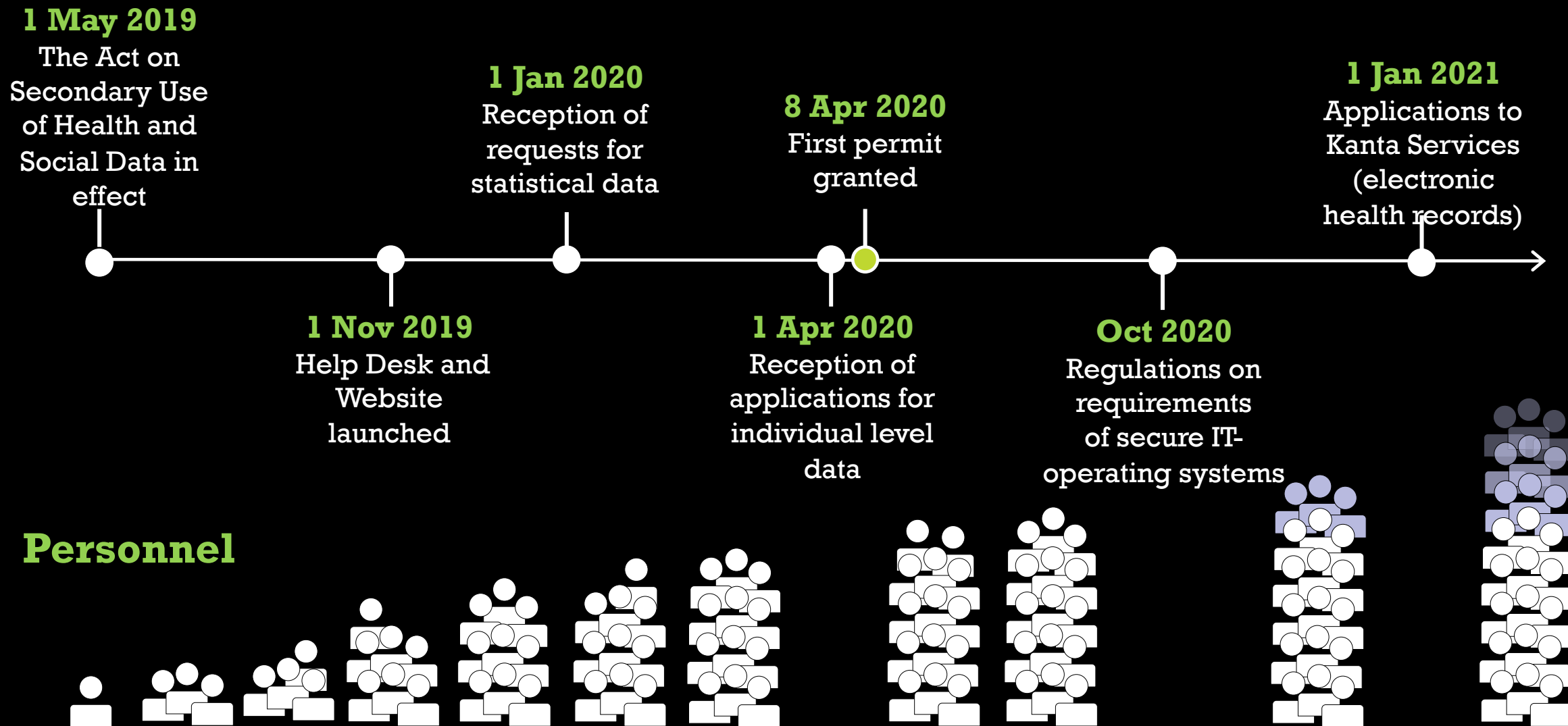
Subgroup  
Secondary use  
Ecosystem

Chair: STM

High-level expert  
group  
Chair: STM

Creates guidelines on  
anonymisation, data  
protection and data  
security for Findata's  
operations.

## First year milestones - Up and running!



## Two types of data

Individual  
level  
data



- Available in a remote access environment for a set period
- Direct identifying data removed
- For the purposes specified in the Act

Statistical  
level  
data



- Delivered to the customer
- Free use for the purposes specified in the Act

→ **A data utilisation plan is always required to access data sets**

# FINDATA

## Help Desk

[info@findata.fi](mailto:info@findata.fi)  
tel. +358 29 524 6500

Data descriptions [Data catalogue]  
Availability  
Quality

## Application

[www.findata.fi](http://www.findata.fi)

### Findata:

- Requests client for additional information (if needed)
- Contacts data controllers → Define sampling  
→ Cost estimate (applicant's approval)

## Decision

**Client:** order remote access environment

**Controllers:** data sampling and transfer to Findata

**Findata:** data management

**Data transfer to  
remote access  
environment**

### Findata:

- Provides tools for analysis
- Controls anonymity of results
- Removes the data after the permit expires

## Findata issues R&D&I infrastructure regulations

### **Regulation on the requirements of secure operating environments (October 2020)**

- Regulation concerns the secondary use of social and health data
- Analysis of data at individual level is permitted only in environments that meet the requirements of the regulation

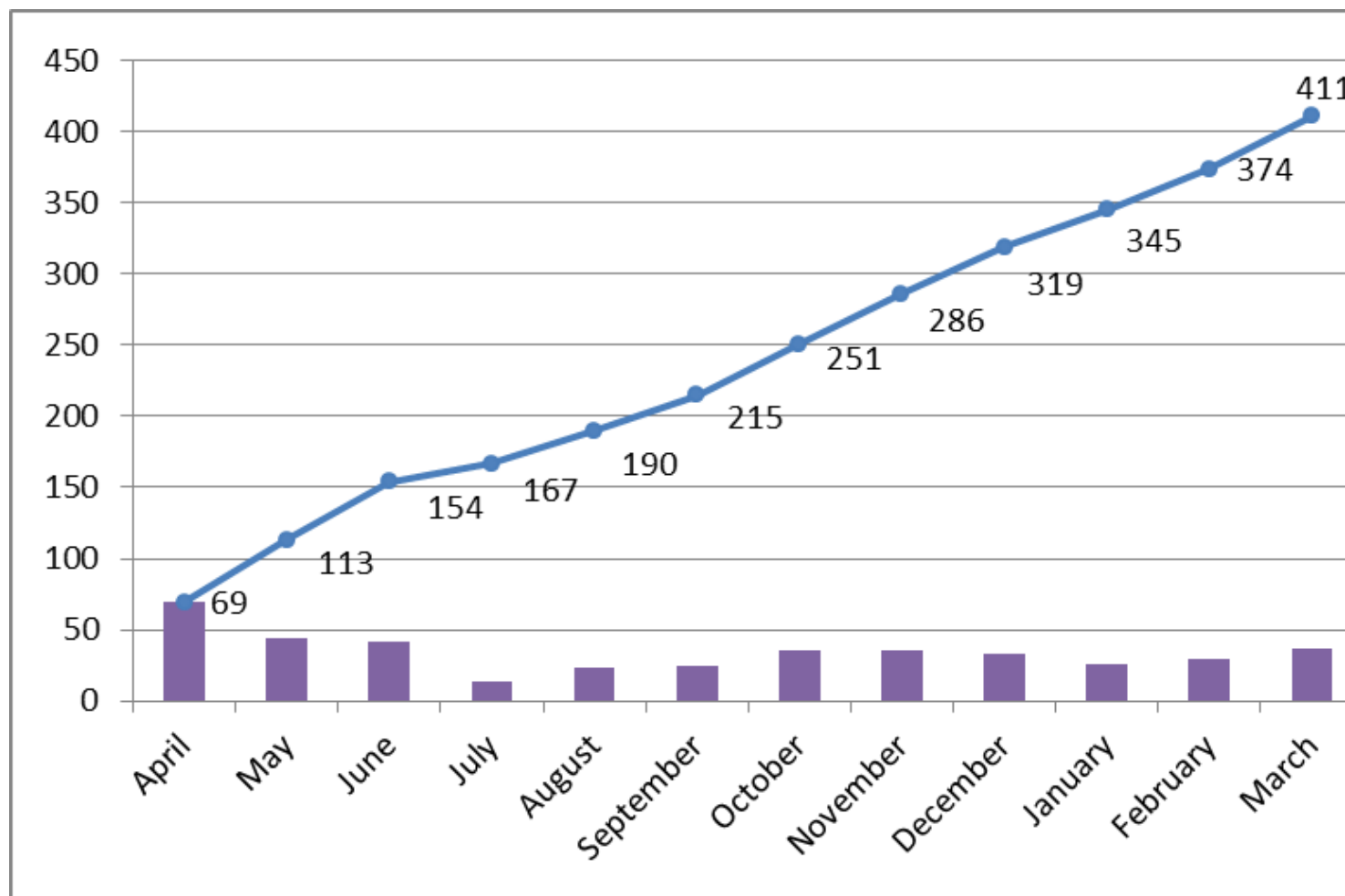
<https://www.findata.fi/uploads/2020/10/048ba8a0-findata-regulation-1-2020-requirements-for-other-service-providers-secure-operating-environments.pdf>

### **Regulation on data description contents, concepts and datastructures (Feb 2021)**

- Aims to national data catalogue
- Interoperatibility of different register data

<https://www.findata.fi/sv/nyheter/findata-har-utfardat-en-foreskrift-om-materialbeskrivningar-for-sekundar-anvandning-av-social-och-halsovarsdata/>

## Number of applications First year total = 411



Total of  
265 decisions

Data needs for  
Covid  
prioritized

# FINDATA

First year of  
operation

## Received applications

**249**

**Data permit applications**

Approx 21/month,  
since 1 April 2020

**110**

**Amendment applications**

Approx 9/month,  
since 1 April 2020

**52**

**Data requests**

Approx 4/month,  
since 1 January 2020

**Data applied  
from**

**85+**

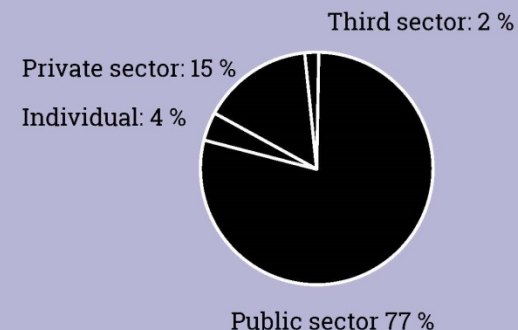
data  
controllers

Total **411** applications

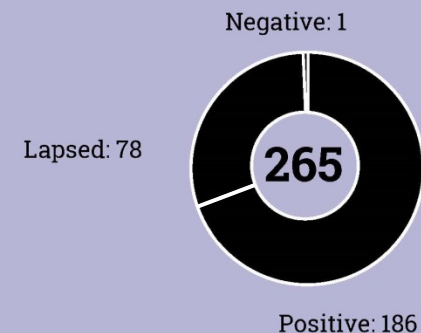
## Purposes

■ Scientific research	386
■ Statistics	11
■ Steering and supervision of authorities	6
■ Development and innovation operations	7
■ Education	1

## Applicants



## Decisions



## Regulations

**5.10.2020:** Regulation on the requirements of secure operating environments

**1.2.2021:** Regulation on data contents, concepts and structures of data descriptions



# FINDATA

Comms 2020

Help Desk



Received telephone  
calls

**717**



New e-mail threads  
[info@findata.fi](mailto:info@findata.fi)

**2 445**

## Website



Visitors

**18 000**

1 500 / month

Visits

**35 000**

2 900 / month

Pageviews

**101 000**

3 pages / visit

## Social media



Followers

**782**

(+ 392)



Followers

**1 430**

(+ 1 304)

## Events and presentations



Presentations  
in total

**80+**



Countries/  
continents

**14/4**

## Newsletter



Subscribers

**430**

Since June

## Media



Articles

**35**

Web/print/  
TV/radio

# **TOP 10 Applied data**

## **TOP 10 Data Controllers**

Finnish Institute for Health and Welfare

Social Insurance Institution

Statistics Finland

Digital and Population Data Services Agency

Helsinki University Hospital (district)

Finnish Cancer Registry

Other University Hospital districts

Finnish Centre for Pensions

Helsinki City, Espoo City, Vantaa City

Terveystalo, Mehiläinen (private sector service providers)

## **Pricing of services**

- Based on
  - Act on Secondary Use of Health and Social Data (50§)
  - Decree issued by Ministry of Social Affairs and Health
  
- Prices consist of four elements:
  - Findata permit fee
  - Findata data management work
  - Reimburses for data controllers' sample costs
  - Payment for remote access

Additional  
computing  
resources  
available on  
request

## REMOTE ACCESS ENVIRONMENT PACKAGES

- S (small):
  - 8 GB RAM
  - 4 cores
- M (medium):
  - 16 GB RAM
  - 6 cores
- L (large):
  - 32 GB RAM
  - 8 cores
- XL (MaxPower):
  - 90 GB RAM
  - 20 cores



Including tools for data analysis:  
SAS, SPSS, Stata, R,...

## Trust is a must!



- Compliance with the Act supervised by

- Ministry of Social Affairs and Health
- Data Protection Ombudsman
- National Supervisory Authority for Welfare and Health (Valvira)

- Data sets made available without individual's direct identifiers
- A secure remote access environment for individual level data sets
- Security in Findata operating environment will be controlled by an information security inspection body and Valvira

**FINDATA**

More information:

**findata.fi**

info@findata.fi | @FindataFi



**Streamlining and securing the secondary use of social and health data.**