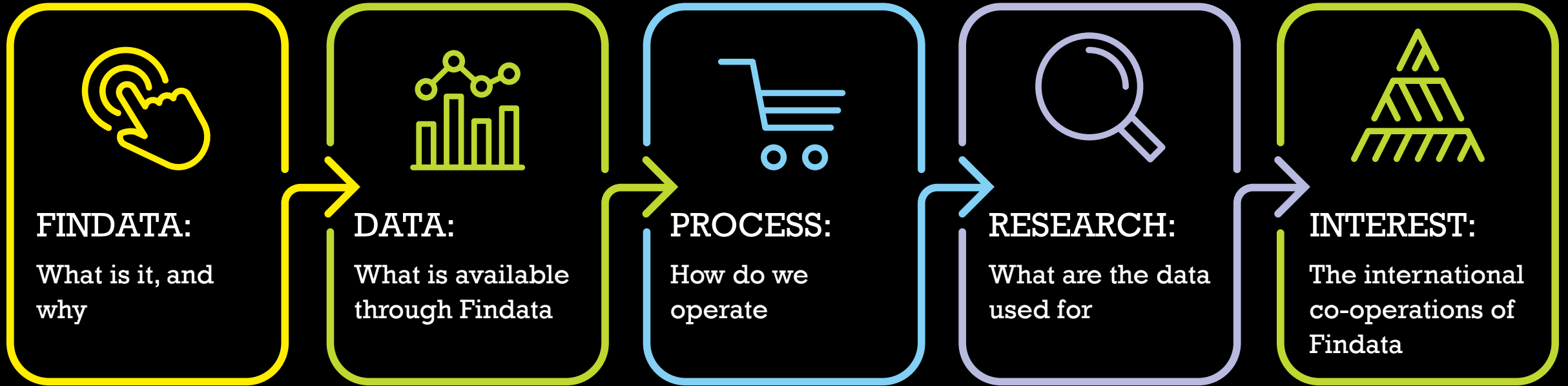# FINDATA HEALTH & WELFARE

A new structure for enabling data for research in Finland:
Social and Health Data Permit Authority

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PhD, Chief Metadata Specialist

FINDATA

Topics covered in the presentation

FINDATA:

What is it, and why

DATA:

What is available through Findata

PROCESS:

How do we operate

RESEARCH:

What are the data used for

INTEREST:

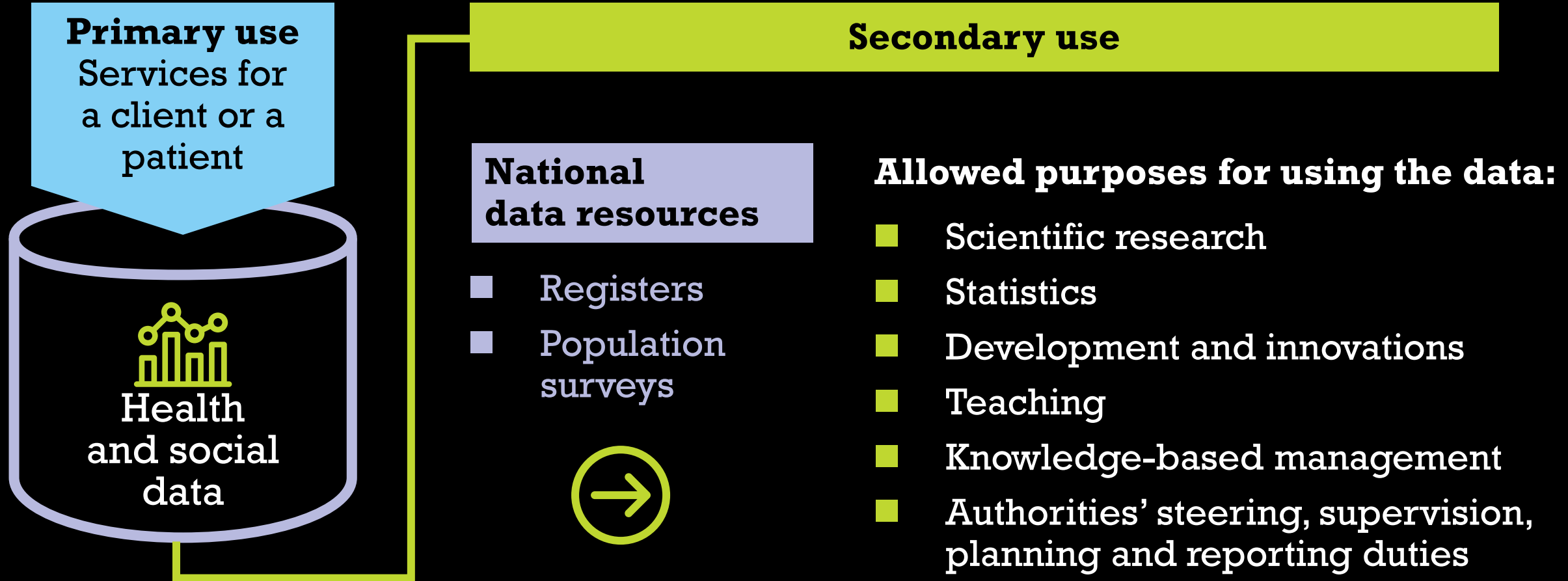The international co-operations of Findata

What we do

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

- **Grant data permits** when data are requested from
  - multiple registers
  - national electronic health record system
  - private health and social care providers

- **Collect and process** the data

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

- **Help Desk** for data users

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Act on the Secondary Use of Health and Social Data

- May 2019

- Purpose of the Act:
  - Facilitate the effective and safe processing and access to the personal social and health data
  - Guarantee an individual's legitimate expectations as well as their rights and freedoms when processing personal data

4

Primary and secondary use of personal data

Primary use
Services for a client or a patient

Secondary use

Health and social data

National data resources

- Registers
- Population surveys

→

Allowed purposes for using the data:

- Scientific research
- Statistics
- Development and innovations
- Teaching
- Knowledge-based management
- Authorities' steering, supervision, planning and reporting duties

Health and social welfare register data in Finland

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National Institute for Health and Welfare (THL)

- Infectious disease register
- Patient register
- National vaccination register
- Medical birth register
- Register of induced abortions
- Register of congenital malformations
- Cancer register
- 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)

- Presciptions
- 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)

All linked using Personal Identity Codes

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What kind of data are available – and how

Individual level data

↓

Data permit

- Findata started receiving applications **1.4.2020**
- Available in a remote access environment for a set period
- Direct identifying data removed

Statistical level data

↓

Data request

- Findata started receiving data requests **1.1.2020**
- Data delivered to the customer

- Anyone can apply for the data – also from outside Finland
- A data utilisation plan is always required to access data sets
- Data are available for the purposes specified in the Act

Customer path

Help desk
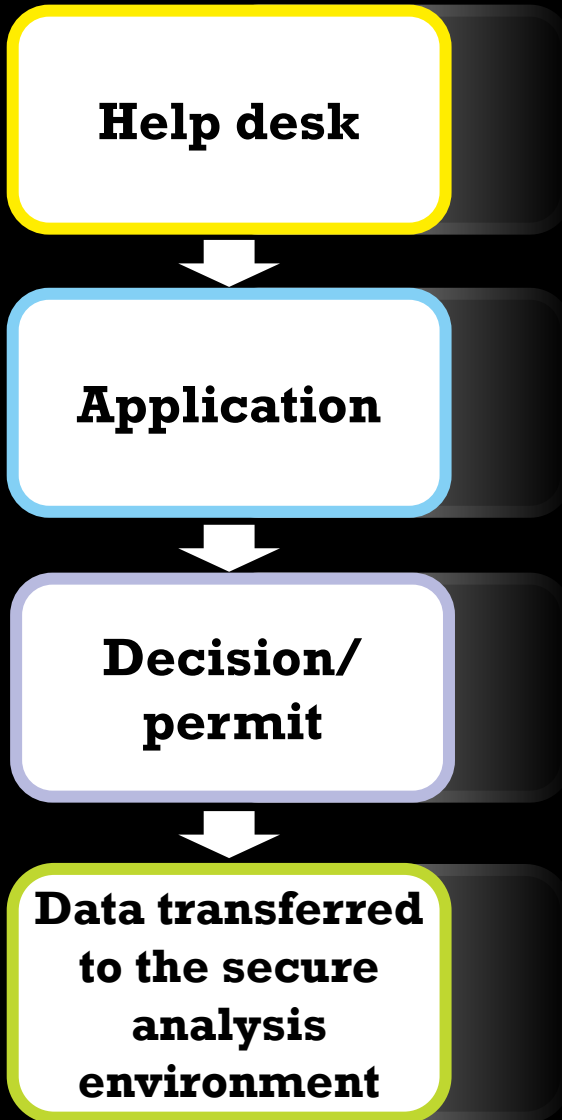
- By phone & email, detailed instructions on website (fin, swe, eng)
- Information on data availability and quality
- National metadata catalogue in development

Application

Findata:
- Corresponds with the applicant if additional information is needed → Defining the final data request
- Contacts the data controllers → Cost estimate for the applicant

Decision/ permit

Customer: orders the remote access environment for the analyses
Data controllers: sample the data, transfer them to Findata
Findata: manages and pseudonymises the data

Data transferred to the secure analysis environment

Findata:
- Provides the analysis tools in the remote access environment
- Controls the anonymity of the final results
- Removes/deletes the data when the permit expires (if not extended)

Received applications
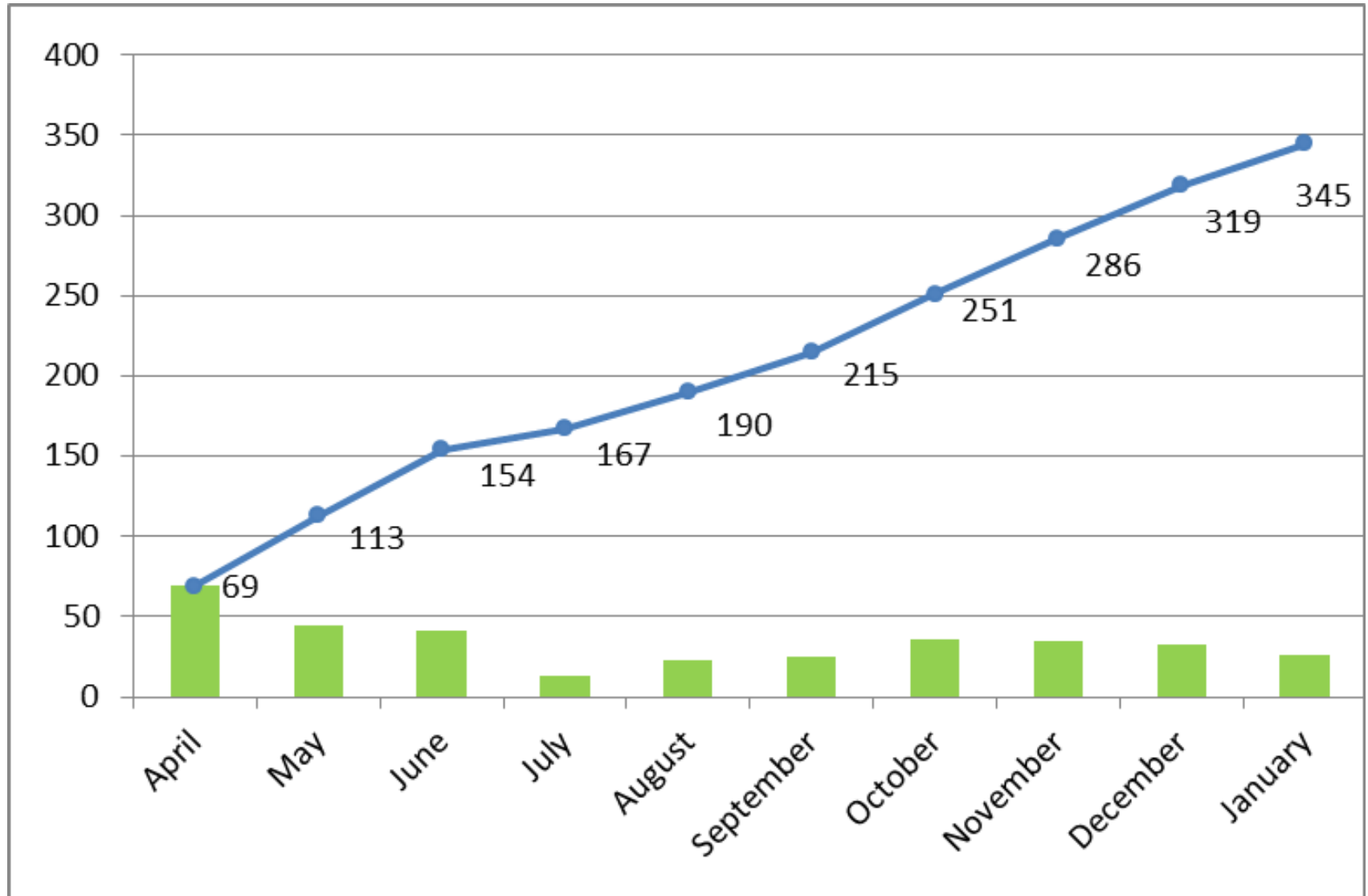
- Total of 203 decisions by the end of January
- Data needs for Covid-19 prioritized

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Granting the permits

- **Applications:**
  - Very few completely rejected
  - Findata does *not* act as a scientific gatekeeper & evaluate the research plans per se – if they abide by the law/Act and fall within the use purposes listed there, we will grant the permit

- **Handling times:**
  - Act: 3 months from application to decision (+ another 3 if needed in special cases)
  - From decision to delivering the data: on average maybe 1-2 months
  - Applications piled up at the moment: learning process for all involved

- **Overview of the studies:**
  - Granted permits are listed on our website (mainly in Finnish): https://www.findata.fi/tietoa-meista/paatokset/

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A sample of studies receiving permit in 2020

11

- Real world evidence study on the burden of atopic dermatitis in Finland: Treatment practices, healthcare resource utilization, treatment costs, and prevalence
- Risk factors for tumors of the brain in children (RiFaTuB)
- Five-year outcome after coronary surgery from the European Coronary Artery Bypass Grafting (E-CABG) Registry
- The interrelated effects of sociodemographic factors and polygenic risk for health and social outcomes
- Cellular mechanisms of hypercholesterolemia and statin induced new-onset diabetes
- A real-world analysis of patients treated with [-] in Finland
- A retrospective cohort study to assess the safety of baricitinib compared with other therapies used in the treatment of rheumatoid arthritis in Nordic countries
- Finnish retirement and aging study
- European research database on dialysis and kidney transplantation patients' COVID-19 infections (ERACODA)
- Clinical registry study on diffuse large B-cell lymphoma and mantle cell lymphoma
- Treatment practices, healthcare resource utilization, and treatment costs of psoriasis in Finland – A population-based register study
- Finnish Diabetes Control study – FinDiCon
- Nordic EpiLung Study
- VOLT: Nordics (Venous Thromboembolism Treatment)
- The nature of nurture: the interplay between genetic and the social environment in impacting health
- Type 2 diabetes and renal outcomes in the Hospital District of Southwest Finland
- FinnGen
- FinWeight

Possibilities for the Nordic / international community

As customers wanting to use the Finnish data:

- Warmly welcome to do so, our systems and information (including Help desk) are provided in Finnish, Swedish, and English

Interested in building similar one-stop-shops:

- Happy to consult and tell about our experiences

- Taking part in international initiatives

Our metadata work:

- National regulation on data contents, concepts and data structures of data descriptions issued in February

- Actively taking part in Nordic co-operation, sharing knowledge

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