

FINDATA

The background is a solid blue color. On the right side, there is a 3D geometric structure composed of several blue planes and lines. One of the planes features a grid of small white dots. Another plane has a white square outline. A third plane has a white circle outline. The overall design is modern and tech-oriented.

From Regulation to Practice: Experiences from Finland

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Findata – Finnish Social and Health Data Permit Authority

Introducing Findata



A **centralised** data permit authority for secondary use of Finnish social welfare and health care data.



Our aim is to improve access to rich nation-wide datasets and **enhance** data security and the data protection of individuals.

- Operations based on Finnish Act on the Secondary Use of Health and Social Data (2019)
- An authority in conjunction with Finnish Institute for Health and Welfare

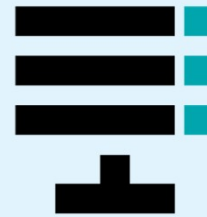
Our core services



Help Desk &
Metadata
Catalogue



Grant
data access
permits



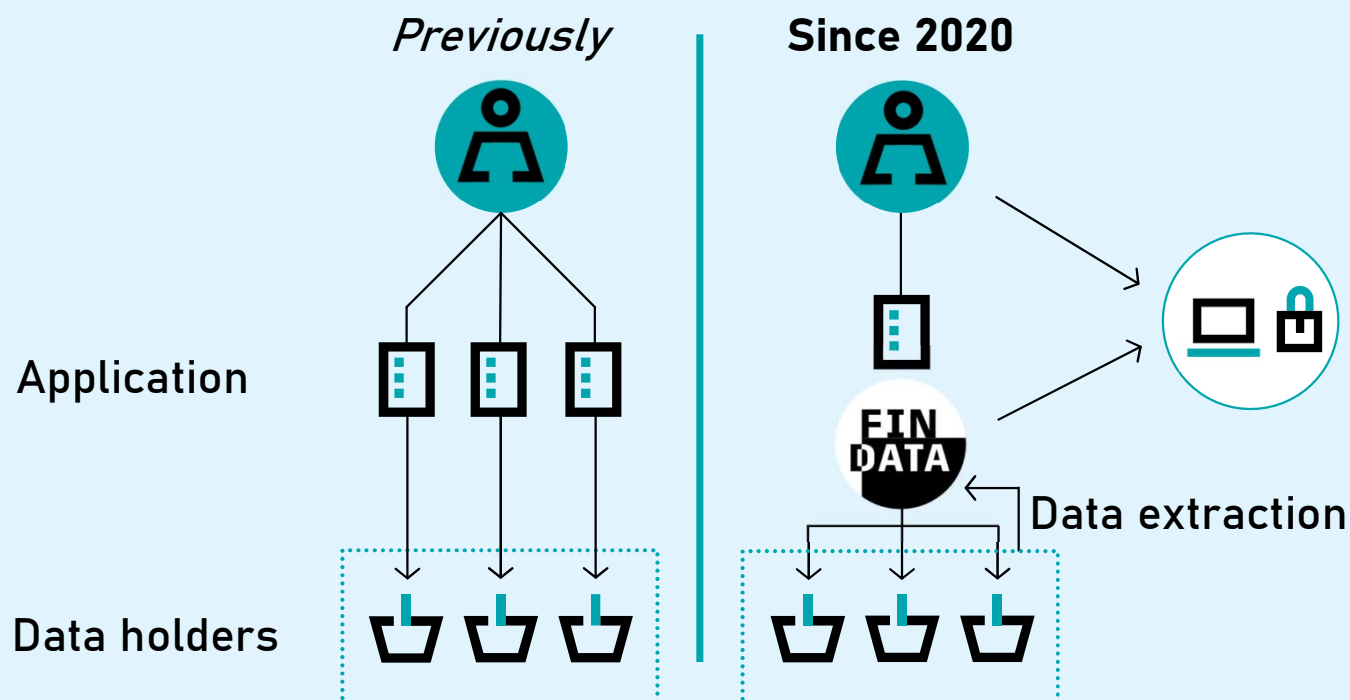
Collect and
pseudonymize
/anonymize
data



Provide
Kapseli®
SPE

How Findata was established

Finnish Act on the Secondary Use of Health and Social Data



What changed:

- Standardised processes
- One application instead of multiple
- Findata links and pseudonymizes the data
- Analysis in SPE (Kapseli or other)

Challenges

An ambitious timetable for setting up the authority and services.

A systemic change in the whole research environment.

Resistance to change and evolving legal framework.

Maintaining the foundation of operation: the trust of the citizens.

Solutions

→ Lea(r)ning processes to meet the expectations and high demand.

→ Improving guidance for data users and data holders.

→ Collaborating closely with ecosystem stakeholders.

→ Transparent communication, increased data protection and security with standardised processes.

Finnish model in practice

Findata provides access to multiple data sources for data combination

Social and health care service providers

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



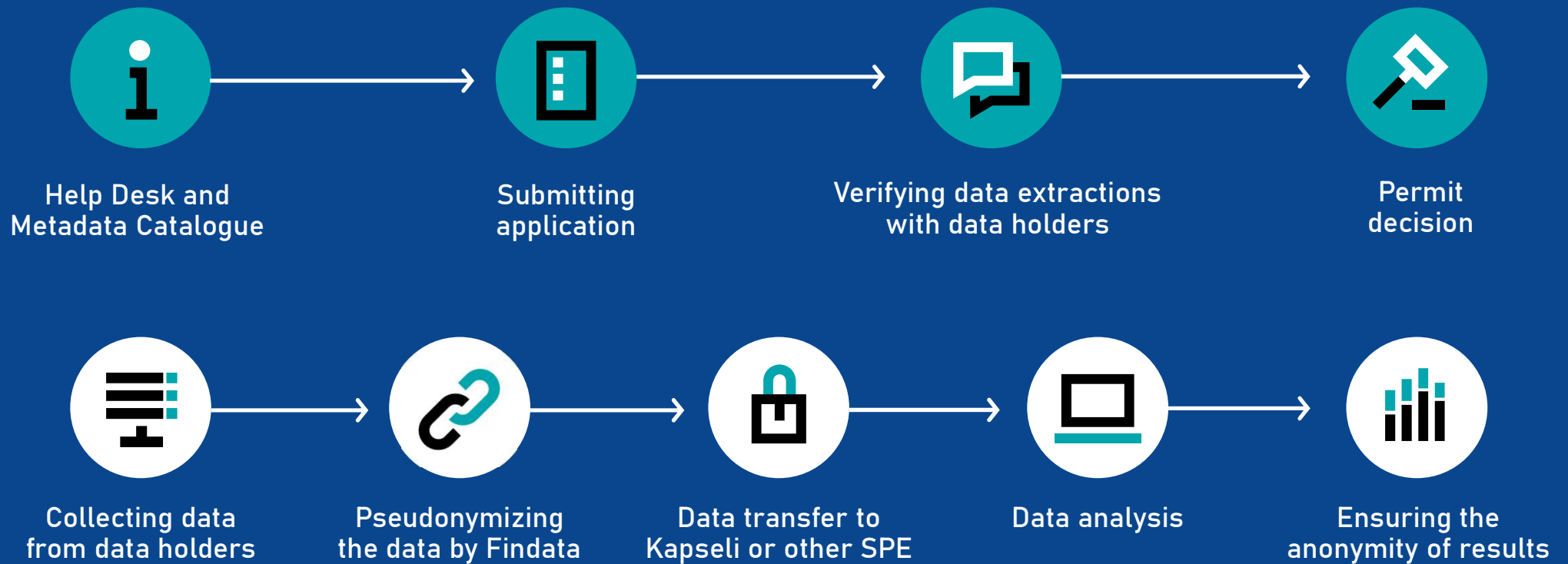
Kanta Services

Key health data, EMS, e-prescriptions + more

National data holders

- Digital and Population Data Services Agency
- Finnish Centre for Pensions
- Social Insurance Institution of Finland
- Statistics Finland
- Finnish Institute of Occupational Health
- Finnish Medicines Agency Fimea
- Finnish Supervisory Agency
- Finnish Institute for Health and Welfare (THL)

Customer path



Timelines for data permit applications in 2026



**Application
processing**

47 days median

90% within 3 month DL



**Data
processing**

27 days median

89% within 30 day DL

Volumes in 2025

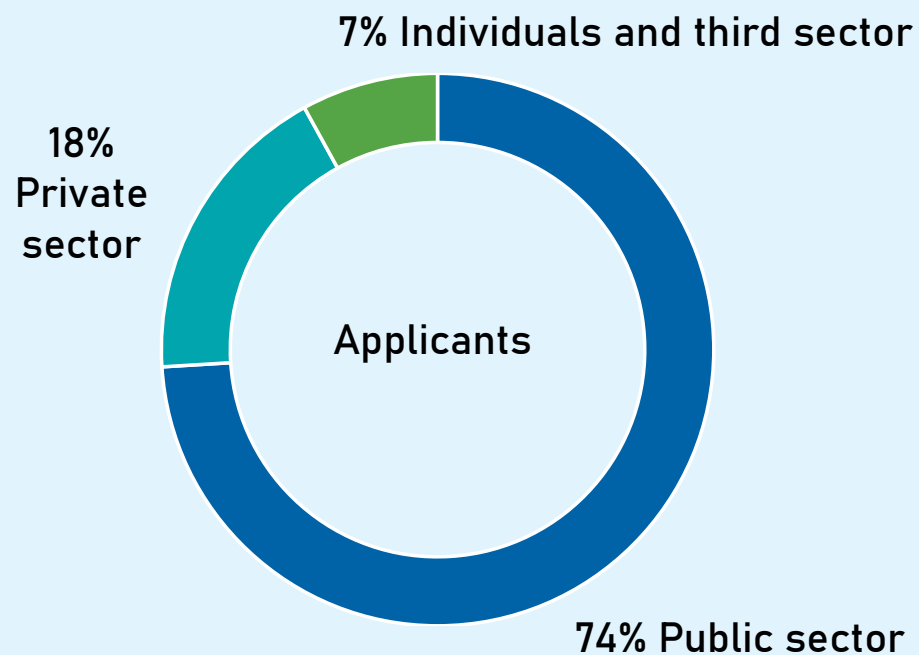
370 Applications

367 Permits decisions

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

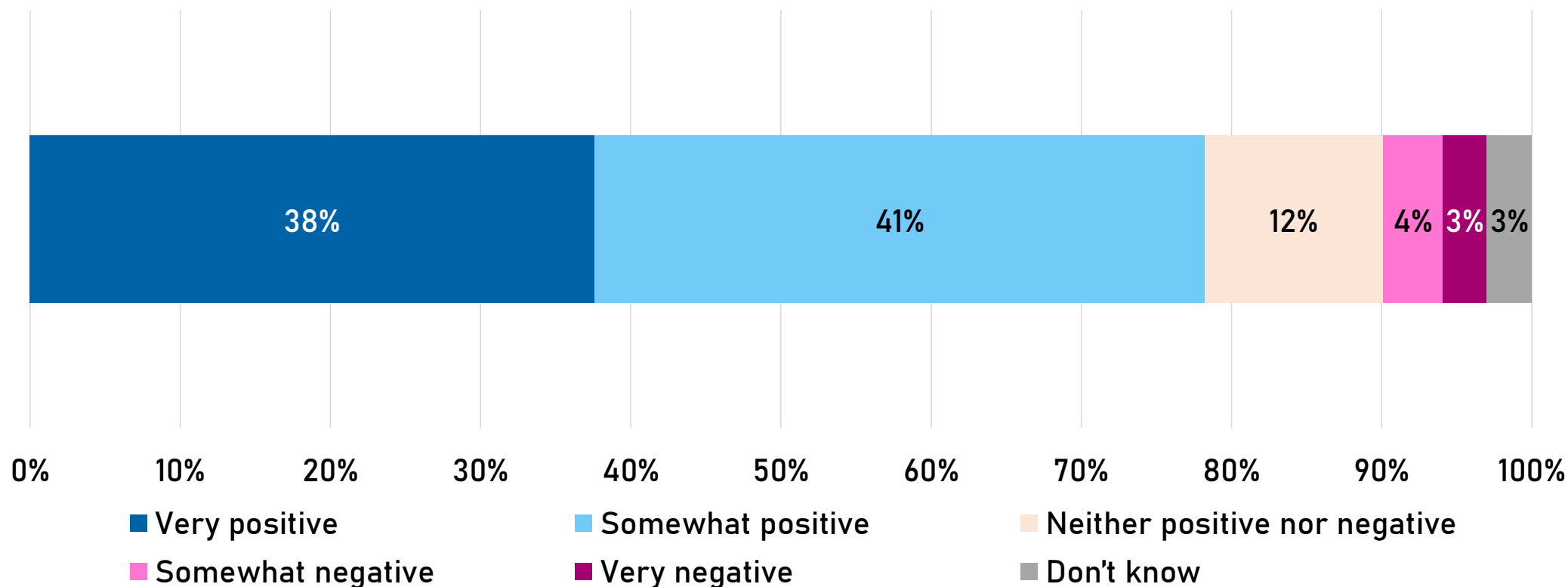
Issued permits: findata.fi/issued-permits

Published results: findata.fi/published-results

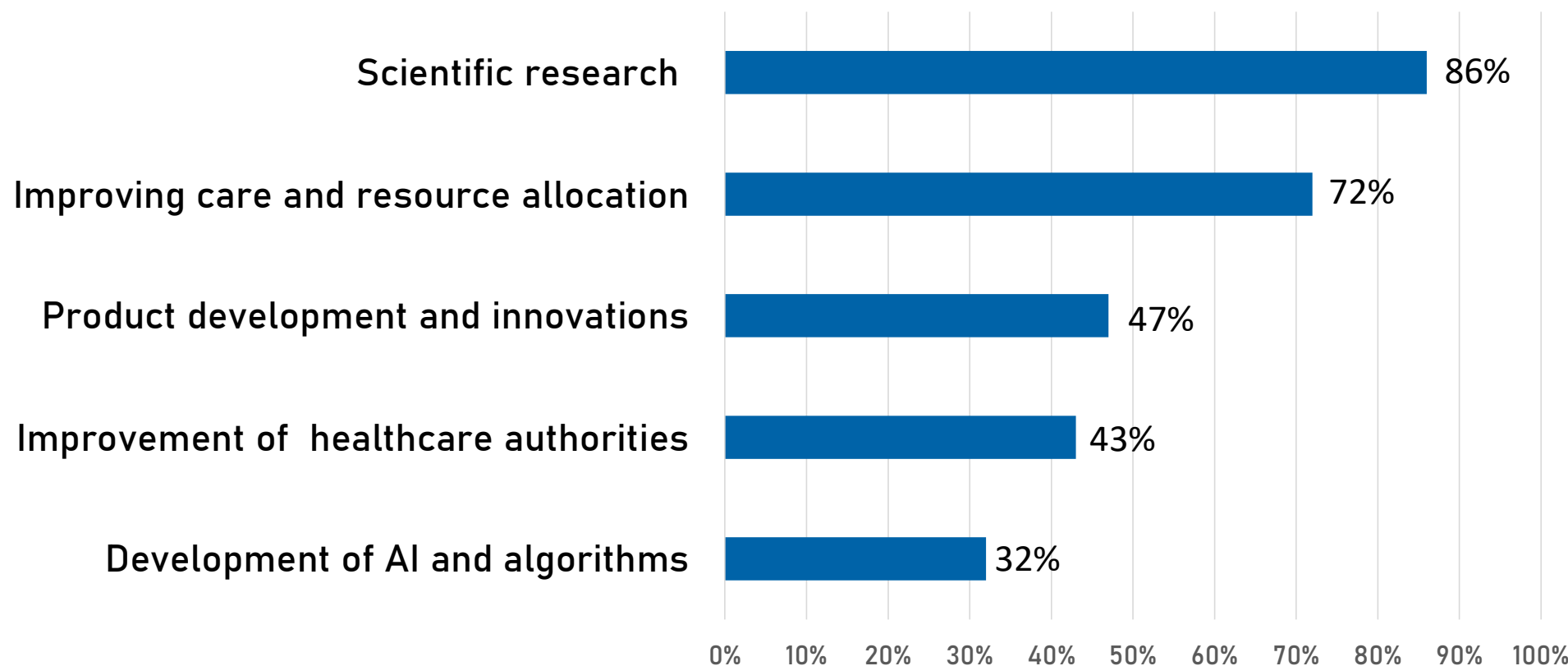


Citizens' perspectives

Attitudes toward the secondary use of health data



Purposes for which health data could be used



Individual control comes first

- **86%** want to decide themselves which entities can use their health data
 - Control is a baseline expectation
 - Acceptance seems conditional, not automatic

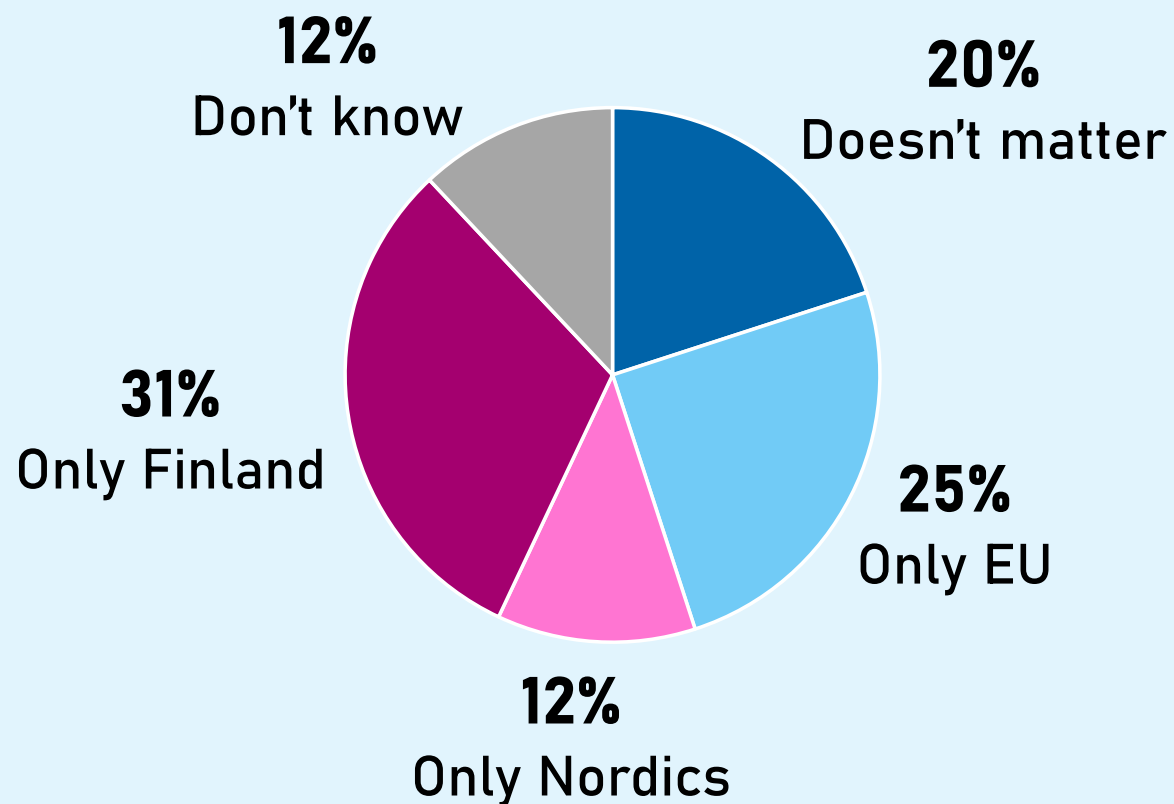
However,...

- **82%** think that all data collected about individuals should be used as extensively as possible for disease prevention and development
- **59%** see that people have a responsibility to share their health data if it enables treatments that benefit everyone

Where organisations using health data can be based

A majority expressed preferences that stop at national, Nordic, or EU borders.

EHDS is legally European, but trust has local aspects.

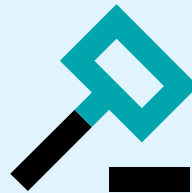


Preparing for EHDS

Current situation in Finland

- **National implementing acts under parliamentary review**
- **Proposed HDAB structure (1+5):**
 - Findata: coordinating HDAB, national HDAB and NCP
 - Five university hospital regions: regional HDABs
- **Stakeholder engagement**
 - Steering group led by the Ministry of Social Affairs and Health
 - Primary and secondary use working groups
 - National communications group
 - EHDS architecture group

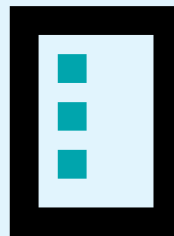
Critical factors to have in place



Official decisions on national implementation



Sufficient funding secured



EHDS implementing acts provided in

- timely manner, and
- a level that will enable the actual implementation

Comparing the Finnish secondary use model and DGA

	Finnish Secondary Use Act	DGA data altruism framework
Primary objective	Securely enable secondary use of social welfare and healthcare data	Voluntary data sharing for the common good
Legal basis	National legislation	EU legislation, consent / permission
Role of the citizen	Data subjects with specific rights, no case-by-case consent	Active data donors
How data are made available	Data generated in health and social care, national registries, data catalogue	Data voluntarily shared by individuals or organisations
Authorisation	Findata + data holders as authorities	Data altruism organisations
Mechanism	Permit process + SPE	Voluntary data sharing

From data access to data contribution?

- **Lessons from Finland**

- Permit process is important, but only part of the journey
- Metadata and data extraction processes are increasingly important
- Data availability does not automatically mean data usability

- **Looking ahead through the lens of altruism**

- EHDS recognises that citizens are not only subjects of health data, but can also contribute information themselves
- How to make such data discoverable, usable and governable in practice?

Five key takeaways for EHDS



1. Public trust must be maintained
2. Roles and responsibilities must be clear
3. Processes matter as much as technology
4. Data holder engagement is essential
5. Implementation is a continuous journey

Thank you! Any questions?

FINDATA

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Ikonit

