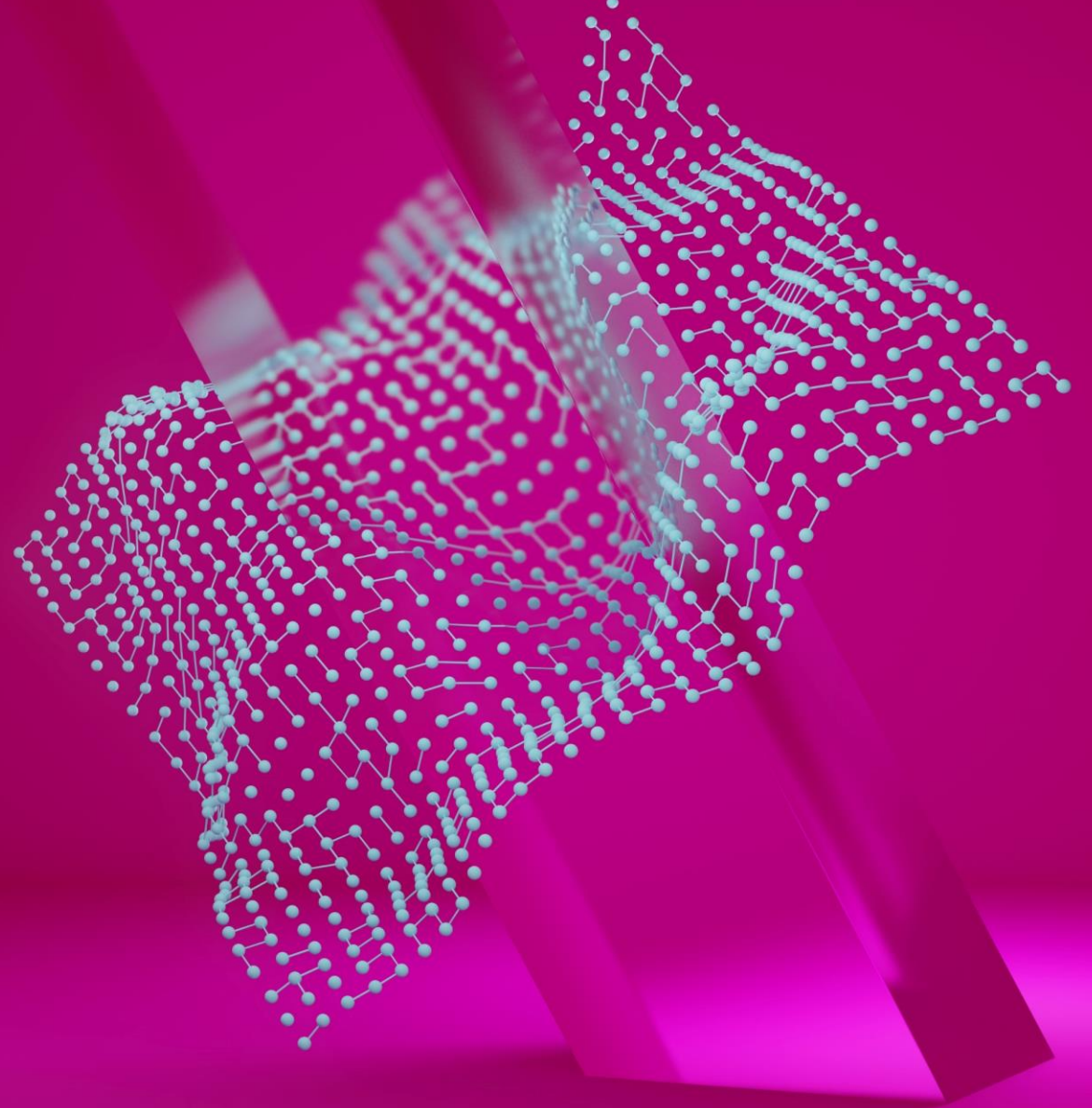# FinHITS Workshop Summary

FinHITS kick-off

April 5, 2024

Content

- Introduction

- Workshop 1: Data Quality
  - Objectives
  - Key Results

- Workshop 2: Development of Kapseli processing environment
  - Objectives
  - Key Results

- Workshop 3: Development of Findata's service portal
  - Objectives
  - Key Results

- Workshop 4: Development of advisory services and an international perspective
  - Objectives
  - Key Results

FinHITS – Strengthening Finnish Health Data ICT for Secondary Use

Introduction

- The FinHITS kick-off event on April 5, 2024, brought together professionals specializing in secondary data use.

- Workshops at the event gave participants a chance to shape Findata's service development plans.

- This presentation highlights the objectives and key outcomes of these workshops.

- Insights from the workshops and a satisfaction survey conducted in March 2024 will guide the planning of FinHITS project work packages.

- Some suggested improvements will be implemented outside the project.

Workshop 1

Data Quality

Workshop 1: Objectives

Gain insights into:

- Challenges in the quality of secondary use of health and social data

- Current quality work within data holder organizations

- Measures to improve data quality throughout its lifecycle

- Features for the upcoming EHDS data quality and benefit label

- The impact of standards, data models, data descriptions, data enrichment, and ready-made datasets on data quality

Understand better how Findata can support data quality work in both the short and long term

FinHITS – Strengthening Finnish Health Data ICT for Secondary Use

Workshop 1: Key results

Important factors affecting data quality:

- Iterative data refinement
- Description of missing data
- Data harmonisation

Main challenges:

- Diverse recording practices
- Systems allowing poor data recording

Desired features:

- A feedback channel for users to report data issues, visible to other users
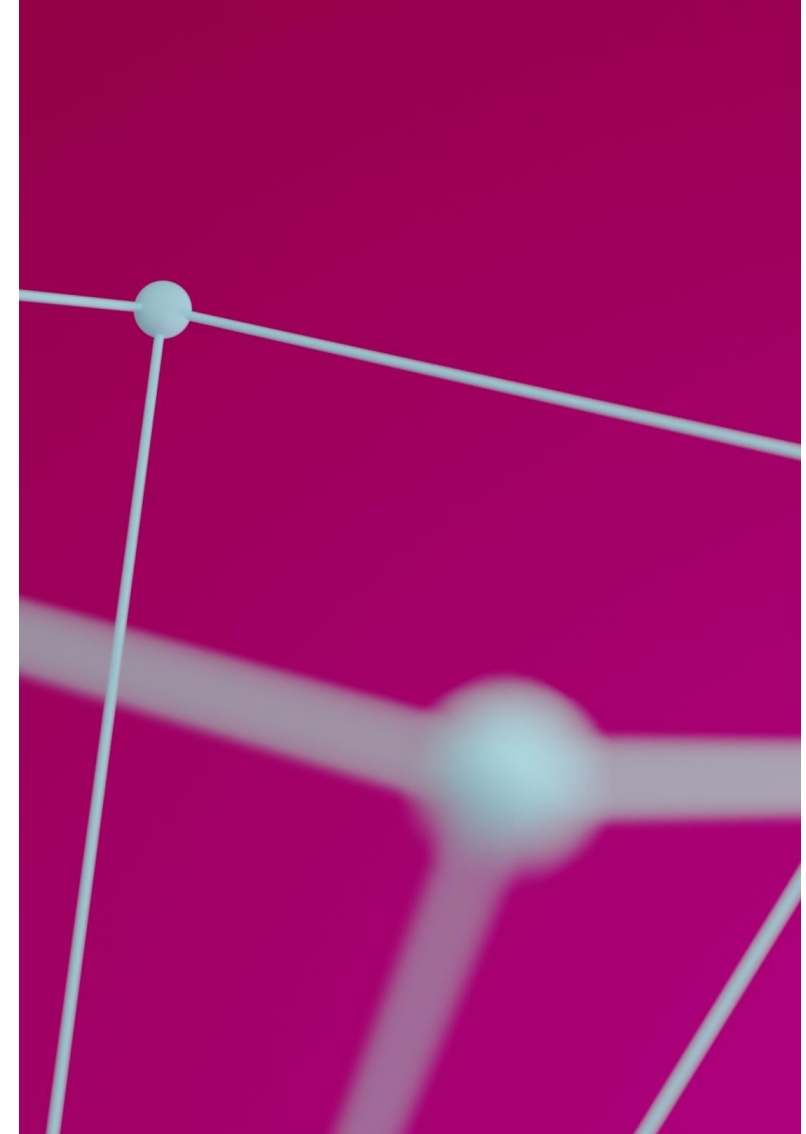
EHDS data quality and utility label:

- Various expectations and ideas exist
- Findata's role is primarily as a messenger on this topic

Workshop 2

Development of Kapseli processing

Workshop 2: Objectives

- Provide information on planned developments

- Gather opinions on development areas and planned solutions

- Create connections among different stakeholders on this theme.

FinHITS – Strengthening Finnish Health Data ICT for Secondary Use

Workshop 2: Key results

User environment:

- Agile development and customization

- Copying customizations

Access and permissions:

- Different access rights and views for different folders and users

Support and guidelines:

- Smooth connection to technical support

- Development of guidelines for producing anonymous results

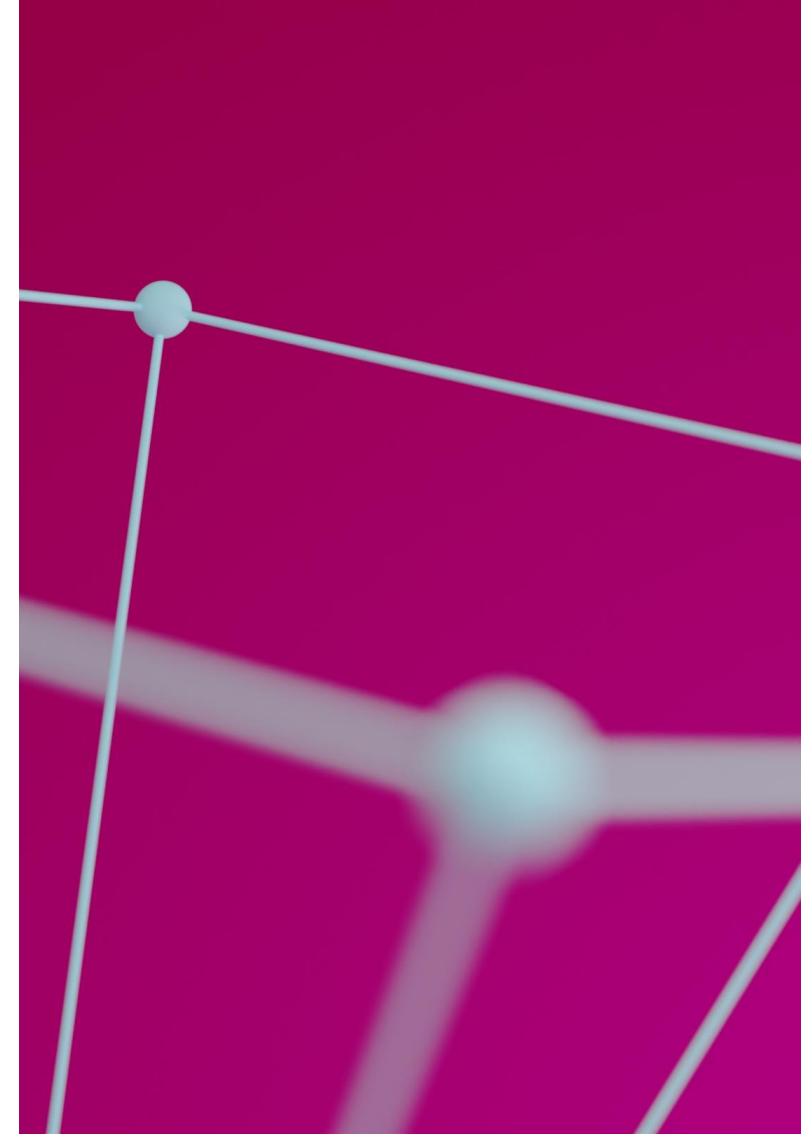- Increasing automation to ensure anonymity

Data usability:

- Software for handling qualitative data

- Creation of a synthetic data sample database to test usability

FinHITS – Strengthening Finnish Health Data ICT for Secondary Use

Workshop 3

Development of Findata's service portal

Workshop 3: Objectives

- Describe the main features of the service portal

- Highlight the most important new development areas

FinHITS – Strengthening Finnish Health Data ICT for Secondary Use

Workshop 3: Key results

Application structure:

- The application must be structured
- Descriptions should be provided once
- Minimize free text fields

Stakeholder access:

- All stakeholders should have access to the same portal
- Visually distinguishable views for different stakeholders

Data descriptions:

- Data descriptions must be obtained from data holders: comprehensive and include quality metadata
- Standardise descriptions
- Consider how to include "tacit knowledge"
- Direct integration of data descriptions into the portal (National Data Resource Catalogue)
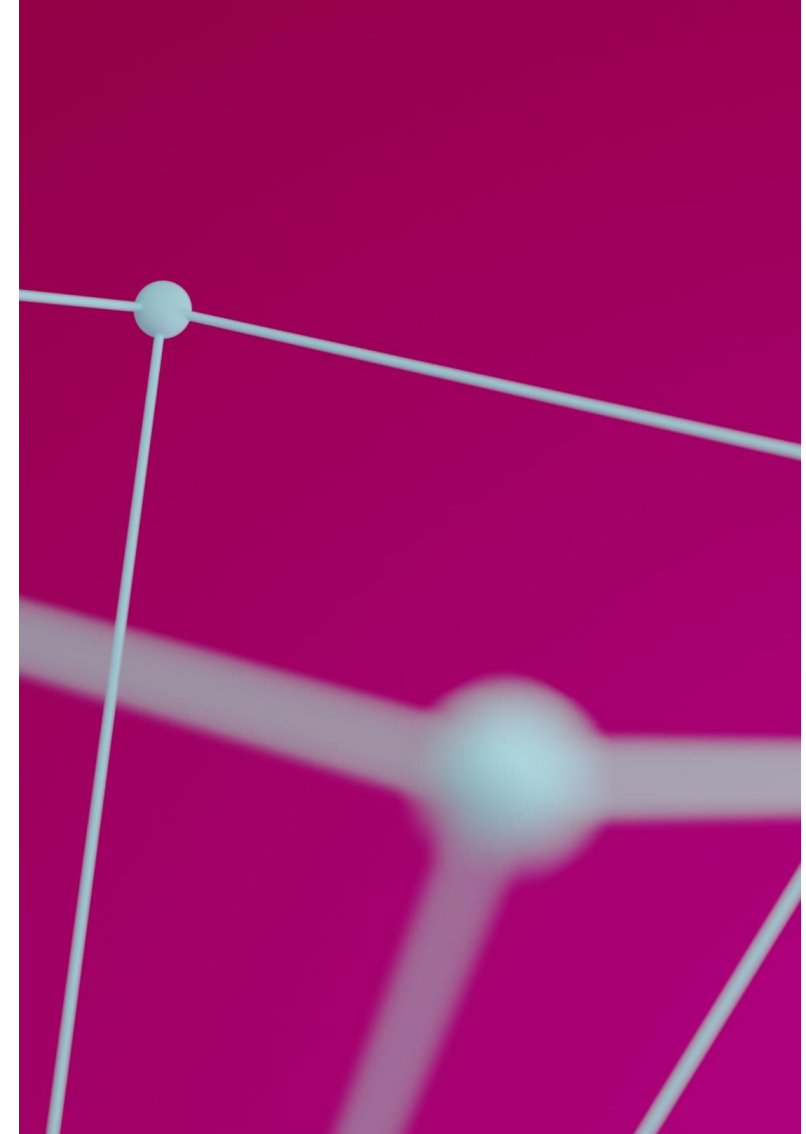
Design and integration:

- Implement a shopping cart-type solution with pricing possibilities
- Include a solution to identify impossibilities (co-pilot)
- Build a solution that works for a very heterogeneous user base
- Involve all stakeholders (data holders and users) in the design process

FinHITS – Strengthening Finnish Health Data ICT for Secondary Use

Workshop 4

Development of advisory services and an international perspective

Workshop 4: Objectives

- Identify barriers to secondary use advisory service

- Generate ideas for developing secondary use advisory services and defining their roles

FinHITS – Strengthening Finnish Health Data ICT for Secondary Use

Workshop 4: Key results

Mega-Catalogue:

- Broadly described datasets with a functional search feature
- Available in multiple languages (English, Swedish)
- Include datasets beyond the scope of the Secondary Use Act and related legislation

Automation and AI:

- Automate and structure the initial advisory service path to clarify customer needs before accessing the service
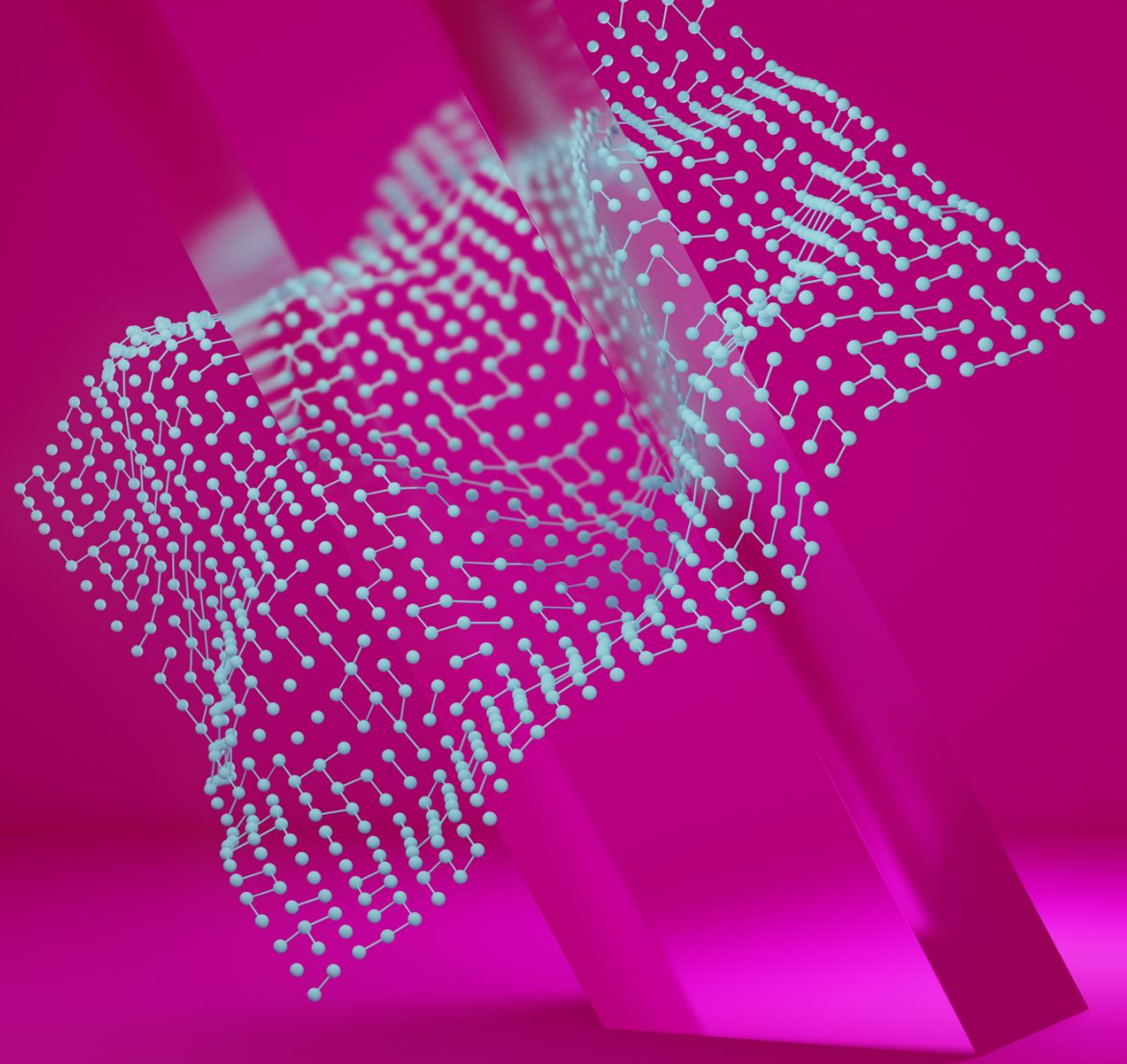- Utilising AI for efficiency

Roles and processes:

- Clarify the roles of Findata, data holders, and users
- Standardise processes

Additional service:

- "Find a Researcher" service to locate collaboration partners

Thank you!

findata.fi/finhits
info@findata.fi | @FindataFi

FINDATA