Secondary use of health data - let’s go for a joint pilot!

JAANA SINIPURO
Project Director, Sitra
Our project in nutshell

The Isaacus project (2015–2018) at Sitra
• Prepares the basic principles and a business plan for the Digital Health HUB
• Runs pre-production projects as pilots for different technical platforms and develops national research services

The act concerning the secondary use of social and healthcare data in 2018
• New national Permit Authority (THL)
• New legislation (GDPR compliant) enables the founding of a new Digital Health HUB that can combine data from different registries. This provides more opportunities for research and innovation.

The new Digital Health HUB in action in 2018
• A one-stop shop, which offers permits and access to data for research, big pharma and for wide use in the public and private sector
Request for licence or data via an electronic system

- Person/operator needing information

Release of data
- anonymous data can be released as such
- pseudonyms / identifiable data into a secure environment

Licensing authority
- grants the licence to use the material, or accepts the request for information and gives an order to the service operator
- notifies the decision to the person needing information

Service operator
- collects, combines, pseudonymises, anonymises the data and releases it to be used in a secure electronic environment maintained by the service operator or the recipient

Data controllers
- advice service, data resource descriptions and release of data for handling an application for licence or a data request, releases the licensed data to the service operator
What did we do?

Enhancing researcher services and offering better access to national registries

Creating new big data innovation platforms and offering new pools of data

Evaluation of new technology and methods
Digital Health HUB

Recognising the information need and ensuring availability

Data gathering
Pre-processing the data
Data distribution

USE OF THE DATA

Academic research
Development and innovation
Other uses

DATA SOURCE

Social and healthcare registers
Other data concerning individuals

DATA NEED

STEERING AND CONTROL PERMITS TO USE DATA AND ETHICAL EVALUATION

HIMSS 2018 INTERNATIONAL CONFERENCE
What about Me and MyData?

Supported by Government proposal for an Act on Secondary Use of Health and Social Data and related legislation (Ministry of Social Affairs and Health)
Let’s go for a joint pilot – but for what?

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Let’s go for joint pilot, but for what?

Europe
- A single European (or Nordic/Baltic) digital market: one-stop shop for personalised medicine
- Pilot project to deliver service and health data from different countries to a customer
- Research X-Road

Nordic-Baltic
- Proof of concept rare diseases

Secure multiparty computation
- Build a joint training/education program

Training & Education
- Business model

Organisational & legal framework for one-stop shop
- Government (ministry) level coordination and support
- Horizon 2020
- Nord Forsk

Pilot project to test the governance structure

Data
- Metadata catalogue from registers in different countries
- My Data collaboration IHAN
- Decide on common standard
- Patient stories/cases

Sharing best practices e.g. personalised medicine, data linkage, IT infrastructure, GDPR implementation, legislation business planning

Best practices, examples & information
- Patient stories use cases
- Health data donation registry (MyData)
- Common surveys

Citizens engagement trust & communication
- SenseMaker tool
- Shared cybersecurity initiative

Loose network
- Cross-nations live-data-pool

Governance
- Anonymization tools, customised data
- Citizens engagement trust & communication
- Patient stories/cases

Funding
- Business model

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Topics for discussion

- Regulated health data (register data) – who are the Top3 customers and what is the best way to create Nordic data sets?
- How to establish a Nordic one-stop-shop for integrated data for R&D?
- Unregulated lifestyle data sits in silos and is hard to reach for researchers / pharma companies – could the person-driven approach work and what might be right incentives for sharing?
Thank you!

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