Enabling Secondary Use of Health Data in Europe-
Lessons learned from Finland

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Reform: Secondary use of health and social data

Government proposal of 26 October 2017 to Parliament
National treasure: health and social data is tomorrow’s raw material
Impacts of the new Act on the Secondary Use of Health Data

- Centralised licensing and secure electronic environment
- Enables individual use and combining of data
- Improved opportunities for research and product development

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- Faster access to information, wider range of purposes of data use
- Effective treatments and new medicines, e.g. for risk groups
- New business activities, products and services
The Digital Health HUB

**DATA SOURCE**
- Social and healthcare registers
- Other data concerning individuals

**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 NEED**

**STEERING AND CONTROL**
Permits to use data and ethical evaluation

**Supported by Government proposal for an Act on Secondary Use of Health and Social Data and related legislation**
(Ministry of Social Affairs and Health)
EXAMPLES OF THE SECONDARY USE OF FINNISH HEALTH DATA
FINNGEN - A GLOBAL RESEARCH PROJECT FOCUSING ON GENOME DATA OF 500,000 FINNS

A unique study that combines genome information with digital health care data has been launched in Finland.

FinnGen taps into a unique gene pool to find the next breakthroughs in disease prevention, diagnosis and treatment.

The project is expected to continue for six years, with a current budget of €59M.

Abbvie, AstraZeneca, Biogen, Celgene, Genentech, a member of the Roche Group, Merck & Co., Inc., Kenilworth, NJ, USA and Pfizer are taking part of the study.

Read more: https://www.finngen.fi/en
ARTIFICIAL INTELLIGENCE ANTICIPATES DANGER

- HUS uses the Watson artificial intelligence system from IBM to predict the risk of sepsis in small premature infants.

Watson is what is known as a learning AI system. It draws conclusions by combining data and ruling out options, until only the most probable options remain.

This enables it to take into account factors such as that the same word may mean different things depending on its context.

Based on data collected at the Children’s Hospital over the years, AI has a 70 per cent chance of predicting the possibility of sepsis 24 hours before the attending physician
CORONARY HEART DISEASE RISK — CARDIOCOMPASS
a digital tool to communicate and interpret personal risk information

(GRS computed from ~49,000 common variants)

Genetic risk factors explain 50% of the disease risk variation between individuals

Source: FIMM, Sitra
FINNISH E-HEALTH ENGAGES CITIZENS

Holistic approach integrating genomic and traditional health information for clinical practice can support lifestyle changes reducing the risk for CVD

The preliminary results of the GeneRISK study (over 7000 participants), 2018:
- 88.4% of participants said that their personal risk information had inspired them to take better care of their health. (clinical check-up 1,5 years after).
- 13.7% had achieved sustained weight loss (-3 kg) and 17% of smokers had quit smoking.

Case: using CardioCompass as a tool to communicate and interpret personal risk information
Basic principles on the use of data

Percentage of respondents who considered it to be important or very important

94% I CAN SEE MY OWN HEALTH DATA
93% I CAN SEE WHO IS USING MY DATA
91% I CAN PREVENT THE USE OF MY DATA
93% THE USE OF MY DATA IS OVERSEEN BY AN AUTHORITY

[Source: Survey made by TNS Gallup / Sitra 2016, link to Research outcomes]
Trust in those who use my data

Percentages of those considered to be trustworthy or quite trustworthy

[Source: Survey made by TNS Gallup / Sitra 2016, link to Research outcomes]
The Isaacus project at Sitra was focused on public sector registers supported by the Government proposal for an Act on Secondary Use of Health and Social Data and related legislation (Ministry of Social Affairs and Health).
Enabling regulation?

#GDPR
General Data Protection Regulation

#PSD2
Payment Services Directive

#EIDAS
EU regulation on electronic identification and trust services for electronic transactions
Our project aims to build the foundation for a fair and functioning data economy.

The main objectives are to create a method for data exchange and to set up European level rules and guidelines for fair use of data.
Establish key principles and guidelines for human-driven data exchange

Develop standard for consent-based data portability. Test standard in multiple industries and countries. Ensure interoperability and readiness for scaling through technical Proof-of-Concepts [IHAN® APPROVED]

Develop common roadmap for fair and sustainable data economy. Build common governance model
Service Data Authorization to use my data

Service provider

Requests for data

Service

Data providers
NEW CEN Workshop on Human-driven data economy IHAN

IHAN aims to make people aware of their rights and give them practical tools to easily manage their own information and privacy. With IHAN, businesses and public actors can provide services faster and more cost-efficiently to make people’s lives easier. These services will be based on the people’s consent to collect their data regardless of where they are located.

The CEN WS ‘IHAN’ will develop a protocol that will address the following topics:

- Data identifiers: a unified identifier connecting my identifier and personal data;
- Consent management: a structure which will include one or more authorization to access my data in various systems in either one time or on continuous basis;
- Log system: an immutable system which contains information about consents and data transfer & usage.

This Workshop builds upon the activities facilitated by The Finnish Innovation Fund Sitra, which notably aims at developing common roadmap for fair data exchange. You can find a presentation on the activities and objectives of Sitra here:

- IHAN project page
- IHAN presentation
- IHAN blueprint

Download the meeting documents:

- Project plan
- Draft agenda

The kick-off meeting and first plenary will be held on Tuesday 22.1.2019 at 10.00 in Sitra office (Helsinki, Finland).

All interested parties are welcome to register for participation and submit comments on the draft Project Plan to the Workshop Secretary, Elmah Huttunen (mailto:elmah.huttunen@sitra.fi).
Consumer/Patient

Consent to My Personal Data

To whom
For what purpose
Collect & use my personal data
Actions after usage

Transparency IHAN® approved

IHAN® The Big Picture
SAVE THE DATE
11–13 JUNE 2019
Helsinki, Finland
HIMSS & HEALTH 2.0 EUROPE CONFERENCE

CHAMPIONS OF HEALTH UNITE
THANK YOU!

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Sitra is the future-oriented organisation of the Finnish people.