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

Hannu Hämäläinen,
Senior Adviser
Finnish Innovation Fund SITRA

EHTEL 2018 Symposiuim
Brussels 3.12.2018

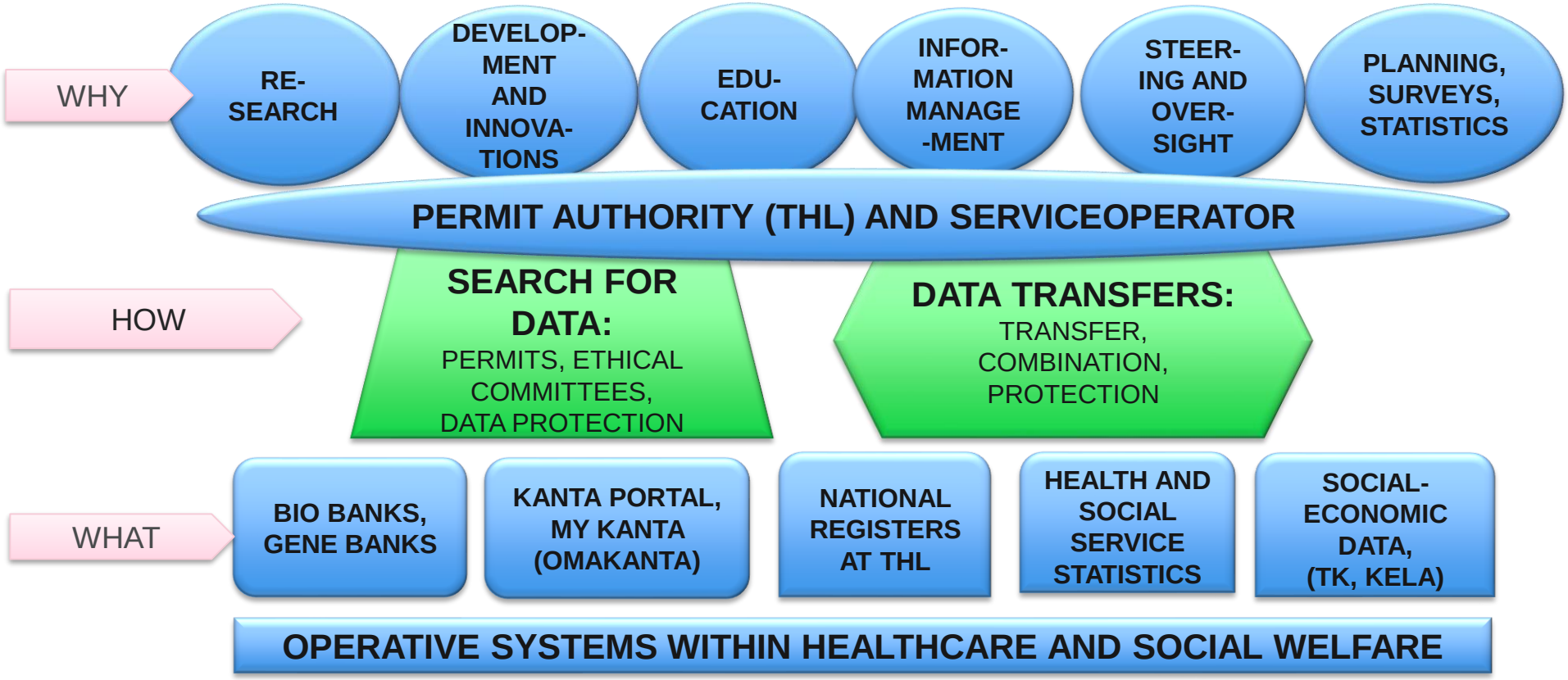
SITRA

Reform: Secondary use of health and social data

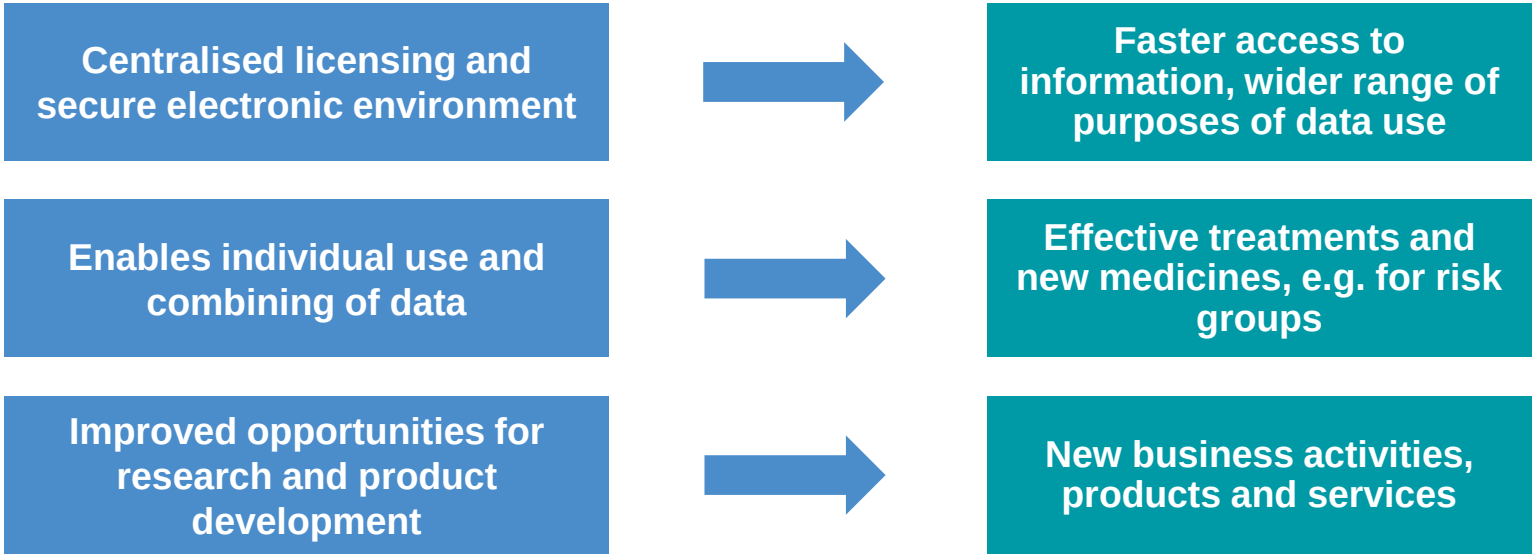
Government proposal of 26 October 2017 to Parliament

MINISTRY OF SOCIAL AFFAIRS AND HEALTH

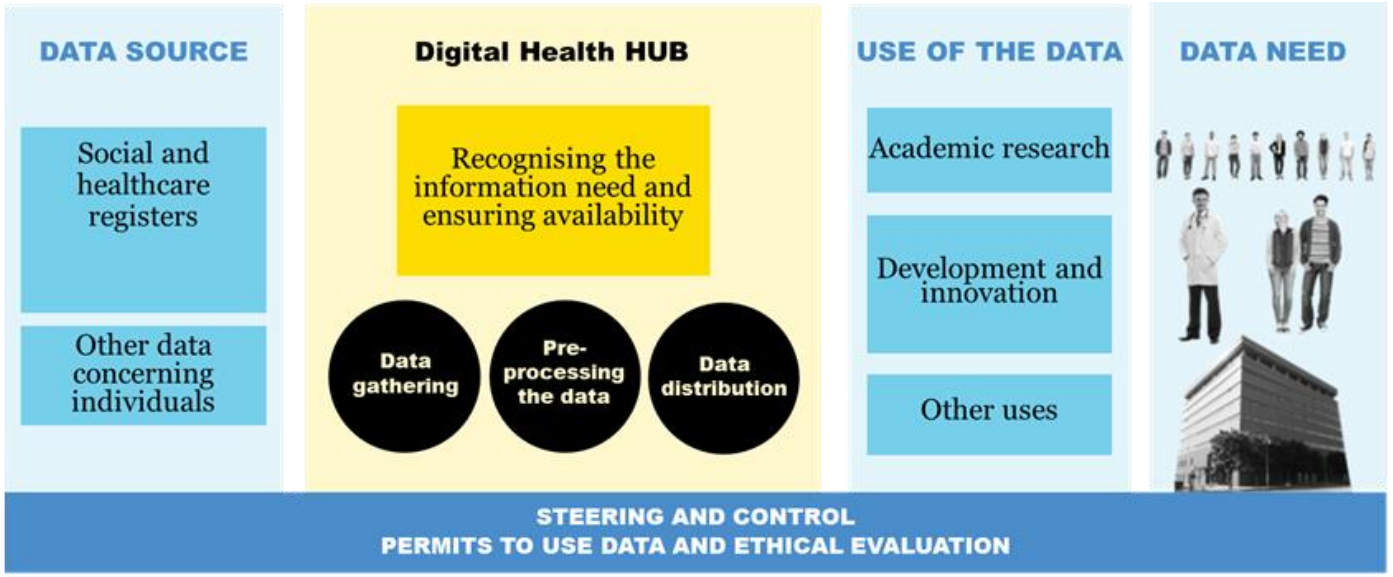
National treasure:
health and social data is tomorrow´s raw material



Impacts of the new Act on the Secondary Use of Health Data



The Digital Health HUB



Supported by Government proposal for an Act on Secondary Use of Health and Social Data and related legislation (Ministry of Social Affairs and Health)

SITRA

EXAMPLES OF THE SECONDARY USE OF FINNISH HEALTH DATA

SITRA

CASE 1

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

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

Case 2

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

Case 3

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

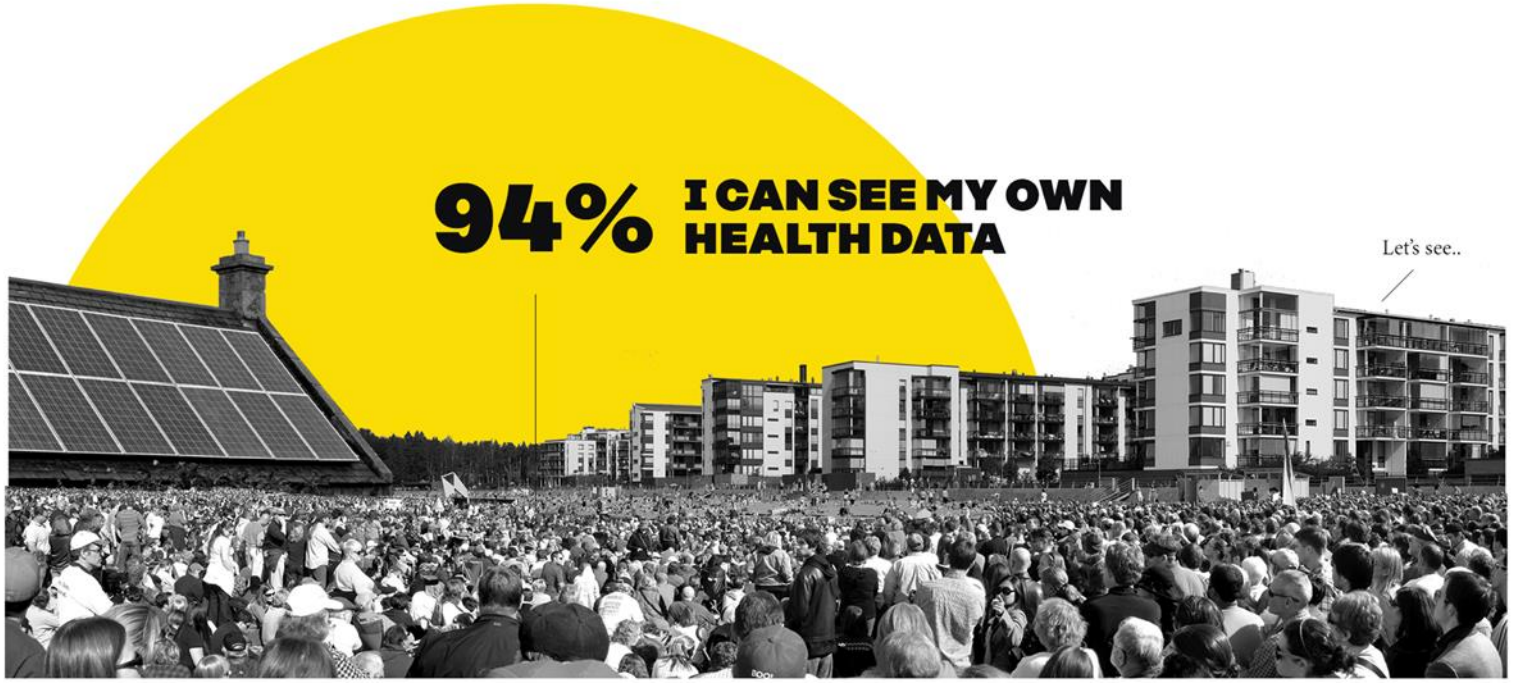
FINNISH E-HEALTH ENGAGES CITIZENS

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

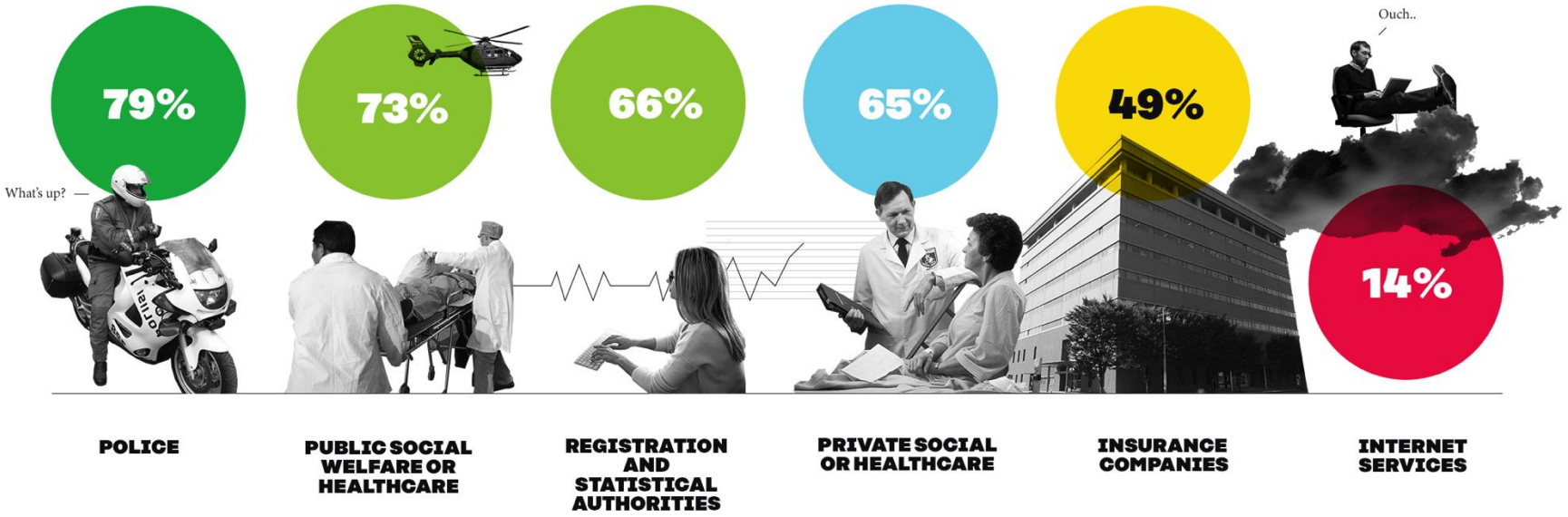
Basic principles on the use of data



Percentage of respondents who considered it to be important or very important
[Source: Survey made by TNS Gallup / Sitra 2016, link to Research outcomes]

SITRA

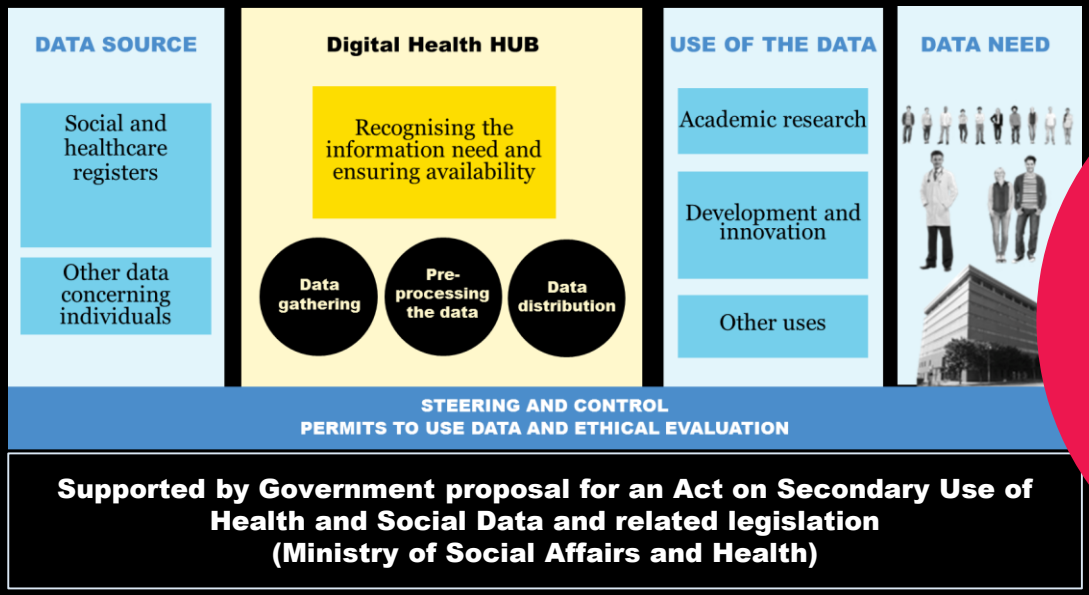
Trust in those who use my data

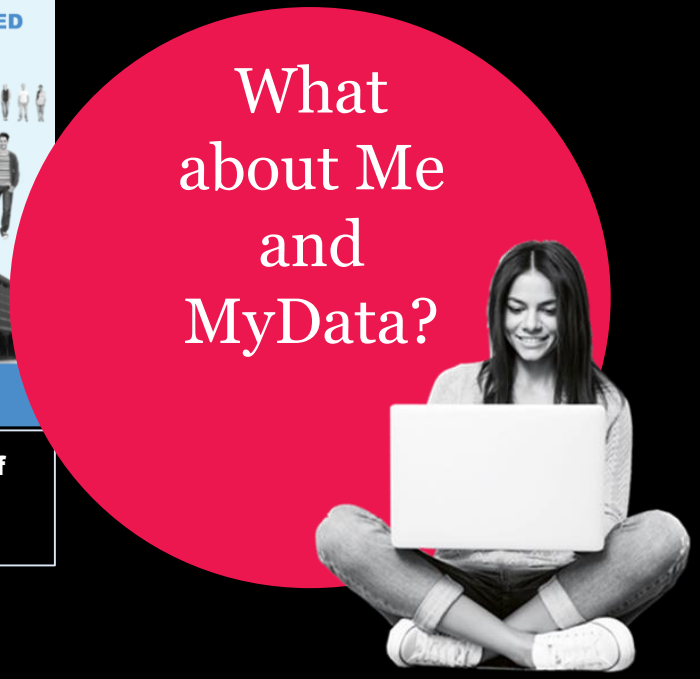


Percentages of those considered to be trustworthy or quite trustworthy
[Source: Survey made by TNS Gallup / Sitra 2016, link to Research outcomes]

SITRA

The Isaacus project at Sitra was focused on public sector registers





SITRA

Enabling regulation?

#GDPR

General Data Protection Regulation

#PSD2

Payment Services Directive

#EIDAS

EU regulation on electronic identification and trust services for electronic transactions

SITRA

IHAN® AS AN ENABLER OF PARADIGM SHIFT

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.

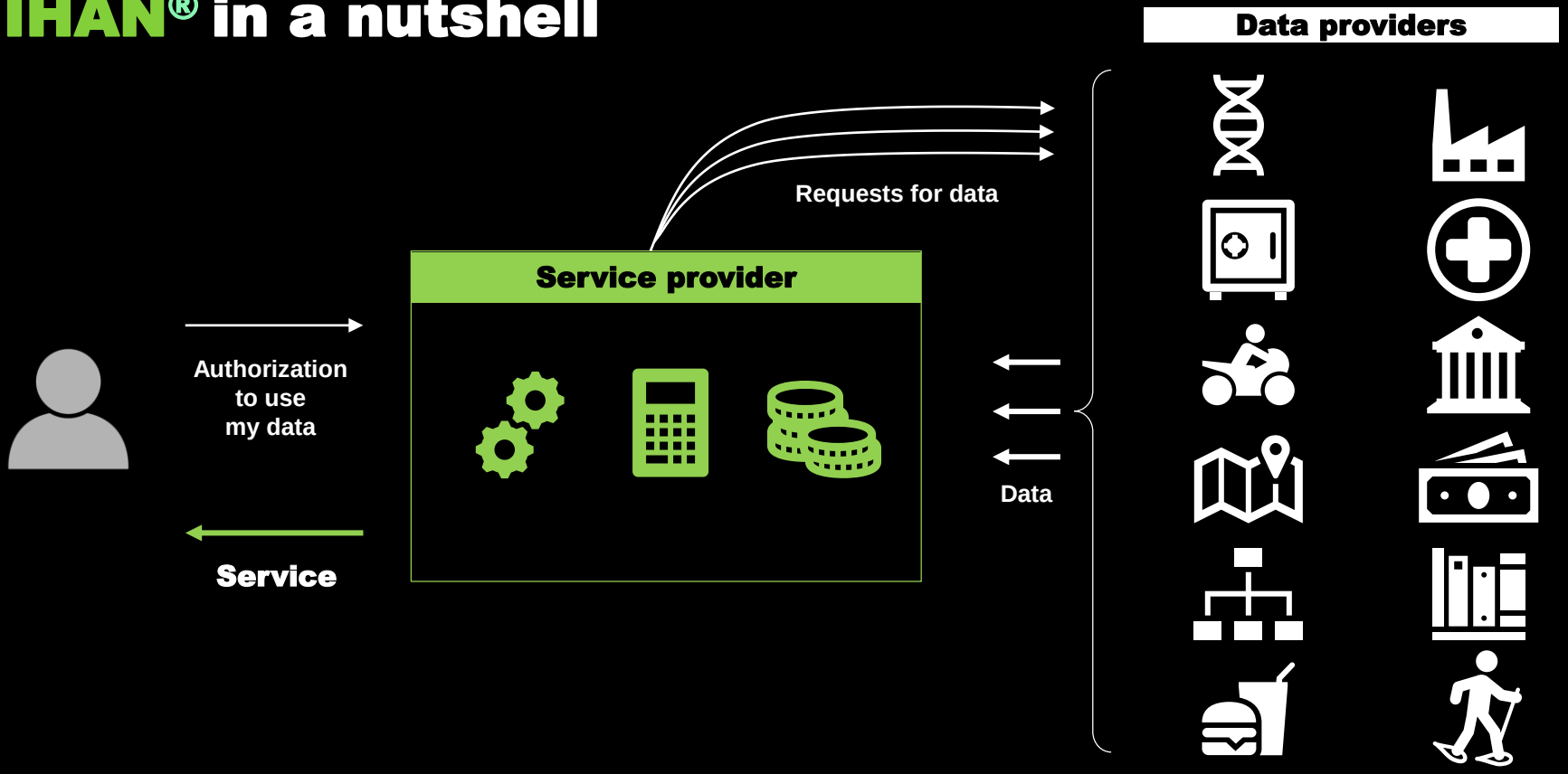
SITRA

IHAN® project in nutshell

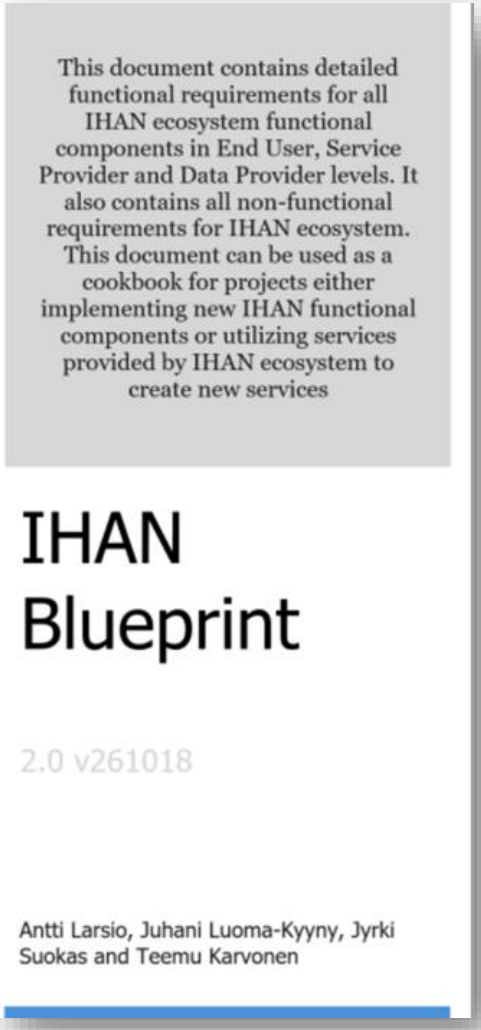
- Establish key principles and guidelines for human-driven data exchange
- Develop standard for consent-based data portability. Test standard in multiple industries and countries. Ensure interoperability and readiness for scaling through technical Proof-of-Concepts [IHAN® APPROVED]
- Develop common roadmap for fair and sustainable data economy. Build common governance model

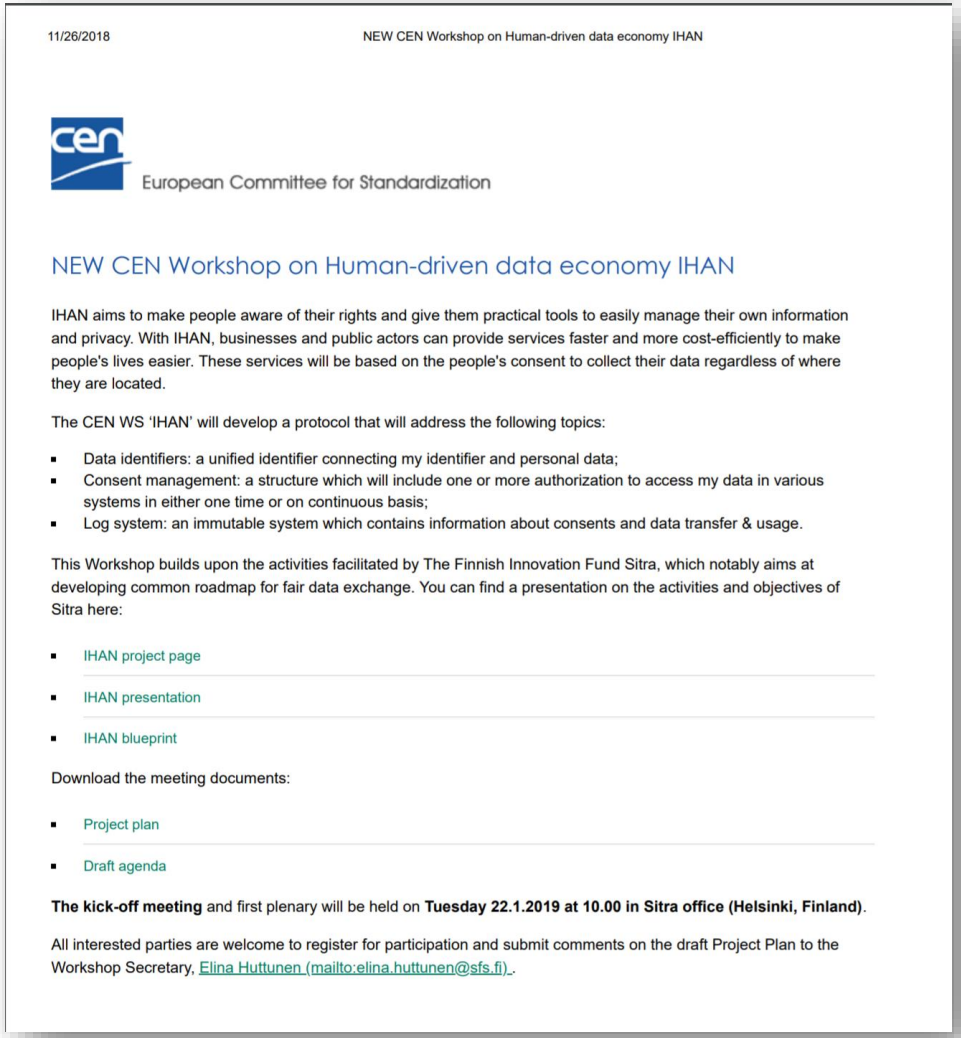
SITRA

IHAN® in a nutshell



SITRA





11/26/2018 NEW CEN Workshop on Human-driven data economy IHAN

European Committee for Standardization

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, Elina Huttunen (mailto:elina.huttunen@sfs.fi) .

SITRA

IHAN® The Big Picture

Consumer/Patient

Consent to My Personal Data

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

Transparency IHAN® approved

SITRA

HIMSS Europe

Health 2.0

SAVE THE DATE
11–13 JUNE 2019

Helsinki, Finland

HIMSS & HEALTH 2.0 EUROPE CONFERENCE

HIMSS | Health 2.0

CHAMPIONS OF HEALTH UNITE

THANK YOU!

Hannu Hämäläinen
Senior Adviser
Capacity for renewal
+358 50 513 5375, +358 294 618 481
hannu.hamalainen@sitra.fi

The Finnish Innovation Fund Sitra
PO Box 160 (Itämerenkatu 11–13)
FI-00181 Helsinki, Finland
http://www.sitra.fi/en

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