Jaana Sinipuro, Project Director

Isaacus - history of the project, outcome and lessons learned

SITRA

5 key facts about Sitra

1. A gift from Parliament to the 50-year-old Finland.
2. An independent foresight agency: futurologist, researcher, visionary, developer, experimentalist, partner, trainer, networker.
3. Funded by returns on endowment capital and capital investments.
4. Envisages Finland as a successful pioneer in sustainable well-being.
5. Its vision is supported by three themes, six focus areas and dozens of projects.

+1

Building our future together

Glossary

The Isaacus project (2015–2018) by Sitra

- Prepared the basic principles and operating plan for “Digital Health Hub” that works together with the new national permit authority ensuring safe and fast access to Finnish data reserves for R&D. Sometimes referred as “Service Operator”.
- Funded pre-production projects as pilots for different technical platforms and developed national research service infrastructure
- Named after Isaacus Rothovius born 1st of November 1572.

The act concerning the secondary use of social and healthcare data

- The new authority Findata, “one-stop shop”
- Planned prepared through national Working Committee led by Ministry, Project Management Office funded by Sitra

Sitra’s IHAN® project for Fair Data Economy (2018-)

- The principles and guidelines as well as the necessary components for the fair data economy
- Focus on personalised services through enriched data and consent-based data sharing

SITRA

Timeline

State's supplementary budget proposes allocating 2.5 million euros for the year 2019 towards launching the operations of the data permit authority and the construction of a data-secure environment.

REGULATION

DATA PERMIT AUTHORITY

Working Committee prepares a new Act on the Secondary Use of Health and Social Data. Working term: April 2015 to December 2017.

Proposal submitted for the first hearing in August 2016.

Government proposes the new act (October 2017).

Parliamentary work, expert hearings and debates, and the social affairs and health committee suggests amendments in April 2018.

Adjusted proposal returned to the committee in October 2018.

The new act is approved by Parliament (March 2019). Act enters into force on 1 May 2019.

Findata – new one-stop shop in operation. Helpdesk opened in November 2019. Information requests to begin January 2020.

2016 - **2017 -** **2018 -** **2019 -** **2020 -**

PROJECT ISAACUS

Project Isaacus starts in November 2015.

Eight pre-pilots begin with Sitra's funding support (of between 30 and 70%).

Isaacus phase 1 completed in September 2017. Pre-production pilots give an insight into future ICT services.

Sitra extends the project to ensure the impact of the work. Sitra funds Project Management Office to support the temporary Steering Group assigned by the Ministry of Social Affairs and Health.

TEMPORARY STEERING GROUP

Temporary Steering Group prepares the launch of Findata operations.

SITRA

Numbers

7 000 000 € / 14 000 000 €

33	Projects (8 pre-production pilots)
25	International meetings and study tours
30	Local events, mostly organized by Sitra
50	International round-table meeting guests
70	End-user interviews

Reflections

Learnings

- Too ambitious goals? Too many reforms?
- Mindset - from production-driven to customer-driven
- More innovative ways for public-private partnerships needed – shortage of technical skills
- Focus on trust

Highlights

- Cross-sector dialogues
- Grassroots level collaboration, individuals
- Hype for datalake solutions and personalised medicine

SITRA

HUS DATA LAKE SYSTEM – SECURE DATA PROCESSING ENVIRONMENT

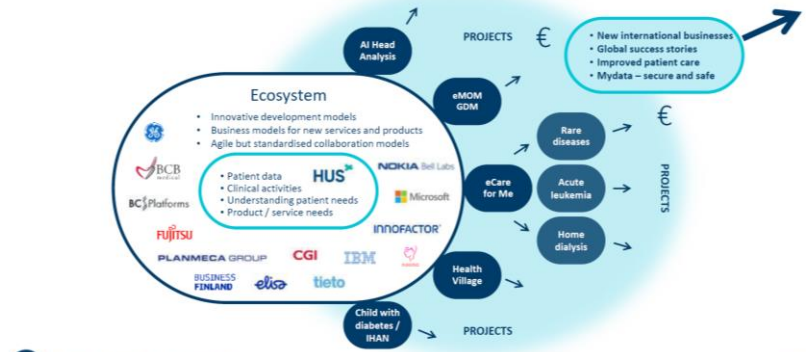
HUS

- Main data lake takes care of data integrations, common data enrichment processes and storage
- Research mini clusters for specific research projects
- HUS-users and external users separated to their own network segments
- Access is role based and limited to data according to research permit
- CE-certified (class 1)

8

Digital health and wellbeing ecosystem

"The world's fastest track for digital health and wellbeing innovations"



Source: "IMPLEMENTING NEW RULES AND TOOLS FOR RESEARCH AT HELSINKI UNIVERSITY HOSPITAL, Secondary use of social and health data in Europe"
Pekka Kahri, HUS – Helsinki University Hospital 11-2019

SITRA

FINDATA

The new authority Findata

One-stop shop for the secondary use of social and health data

- **Grants data permits** when data are requested from multiple registers
- **Collects and links the data**
- **Provides the data** in a secure IT-environment for data users
- **Help Desk** for data users

FINDATA

Goals

- **Enable** effective and safe processing and access to data
- **Enhance** data protection and security
- **Eliminate** overlapping administrative burden
- **Improve** register data quality

FINDATA

Trust is a must.

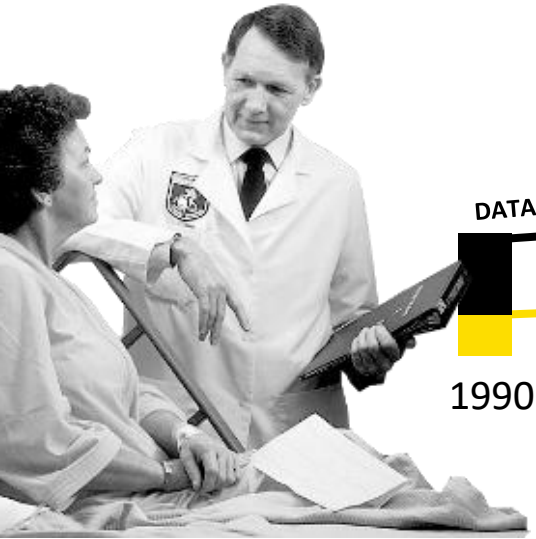
- A secure remote use environment for individual level data sets
- Data sets are only available without individual's direct identifiers
- Compliance with the Act will be supervised by the Data Protection Ombudsman, Valvira and Findata
- Security in the operating environment will be controlled by an information security inspection body and Valvira

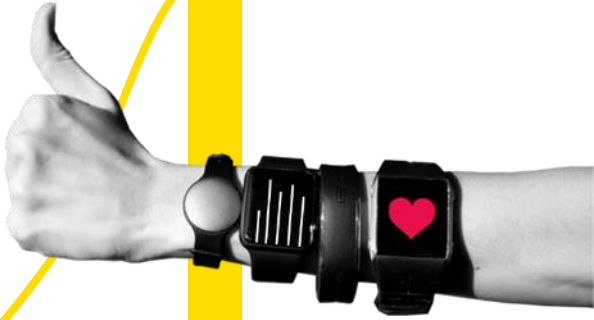
Source: "Implementation of the national Social and Health Data permit authority Findata", Johanna Seppänen 11-2019

SITRA

It’s Going to Get a Lot More Personal

329 % increase in global health spending
from 1995 to 2050 (base case)*





DATA FROM THE PROFESSIONALS AND SYSTEMS

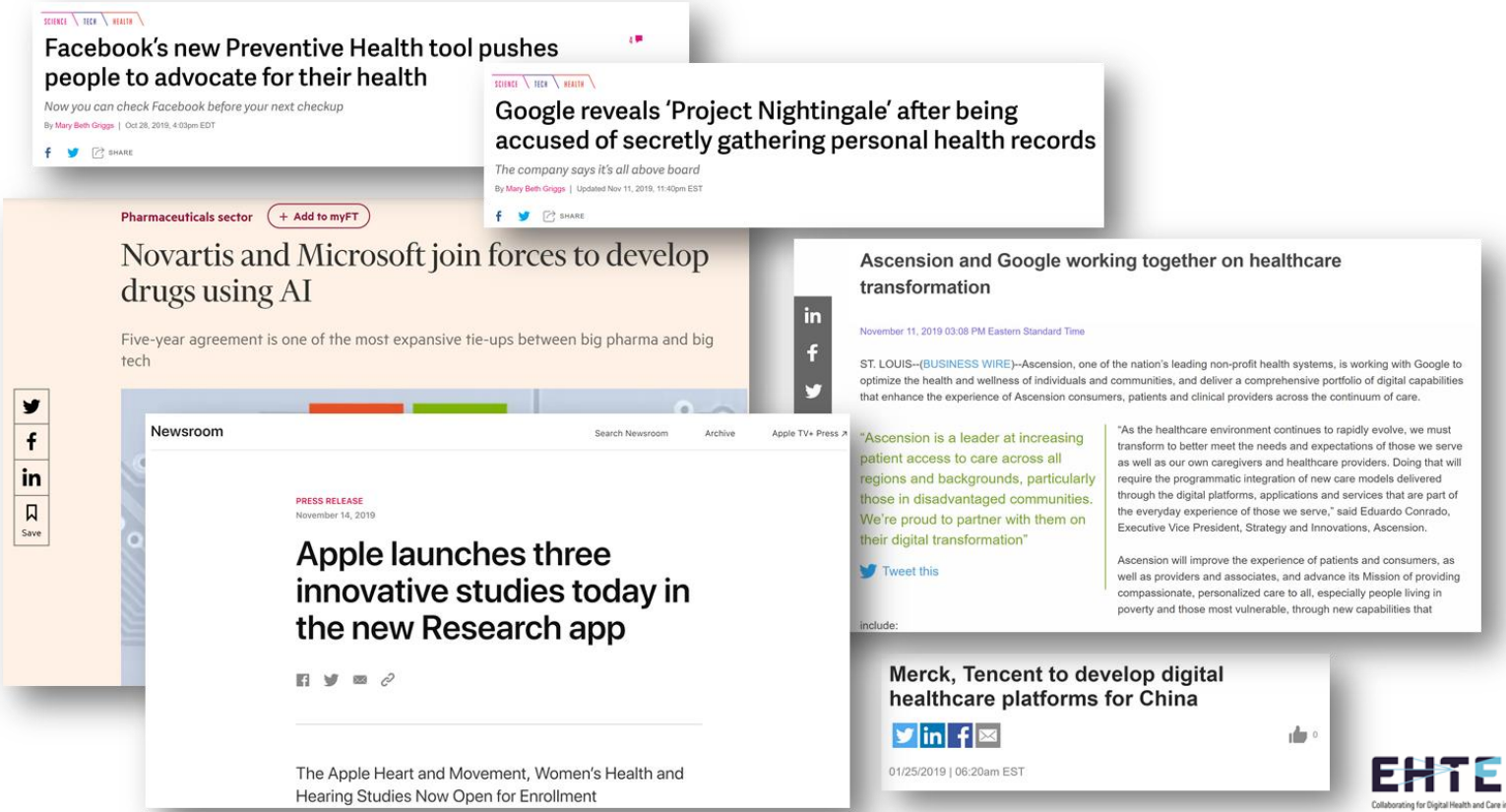
DATA FROM THE INDIVIDUALS

1990 2000 2010 2020 2030

* Source: IHME 2018 http://www.healthdata.org/

SITRA

Our Health is Monetized



EHTEL Collaborating for Digital Health and Care in Europe

SITRA

A recent study of NHS staff

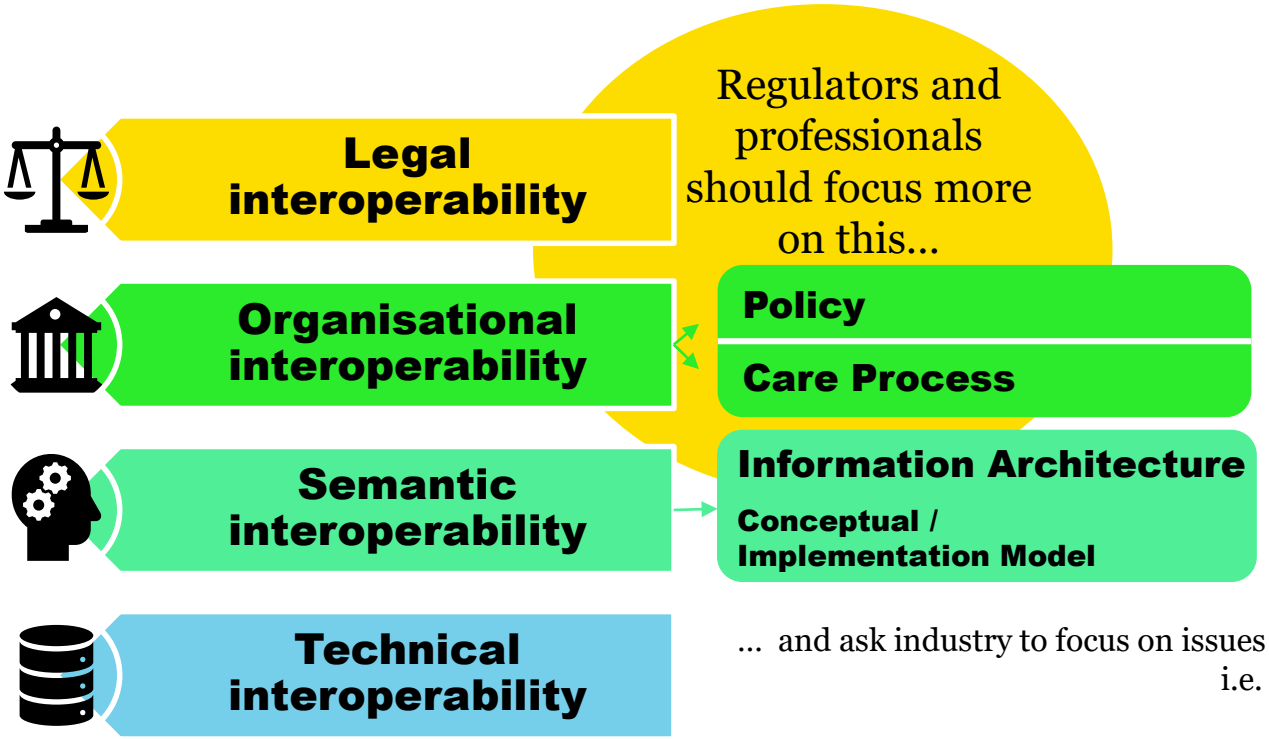
81 %	supported the analysis of anonymised data to enable quicker diagnosis and more effective treatement for patients
12 %	would be comfortable with a multinational big tech company carrying out such analysis
87 %	agreeing that the government should ensure that the NHS and UK taxpayers benefited from gains
73 %	would recommend their patients use data-driven technology
36 %	said their patients made use of existing digital services

Source www.digitalhealth.net 26 November 2019 based on a YouGov poll of 1,027 healthcare professionals

SITRA

WISHLIST?

Multiple levels of interoperability



... and ask industry to focus on issues with technical interoperability, i.e. applications and infrastructure

[Source: “eHealth Network – Refined eHealth European Interoperability Framework”, presented by Priit Tohver, adopted by consensus by the eHealth Network, Brussels, 23 November 2015]

SITRA

Areas for collaboration

Common understanding on different categories of data for Secondary Use

- Aggregated Statistics Data
- Anonymous Data / Pseudonymised Data
- Personal Data

Potential use cases and appropriate ways of handling the data for Secondary Use

- Mostly needed common data sets
- Guidelines for Secure handling

Understanding need for different procedures when handling regulated data compared to MyData

SITRA

Thank you!