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# **Isaacus - history of the project, outcome and lessons learned**

# 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



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# 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 1<sup>st</sup> 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

# 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.

2016 -

2017 -

Government proposes the new act (October 2017).

2018 -

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.

2019 -

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

2020 -

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

# 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

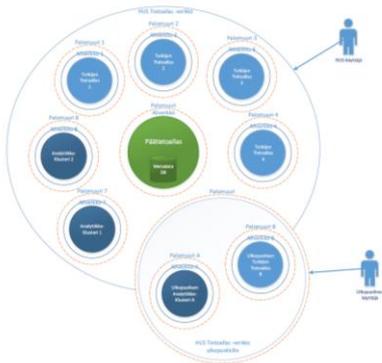
- Too ambitious goals? Too many reforms?
- Mindset - from production-driven to customer-driven
- More innovative ways for public-private partnerships needed – shortage of technical skills
- Focus on trust

## Highlights

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



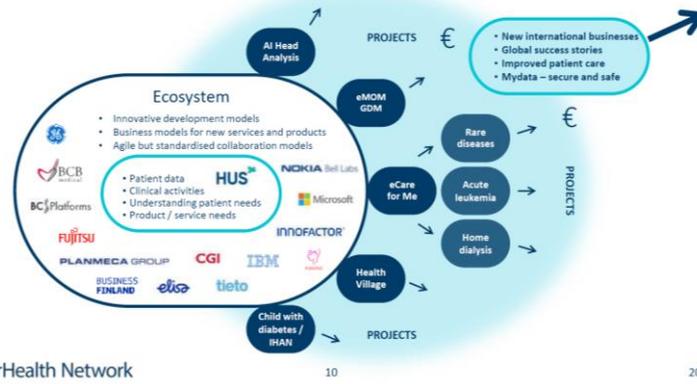
# HUS DATA LAKE SYSTEM – SECURE DATA PROCESSING ENVIRONMENT



- 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)

## 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

## 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

## Goals

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

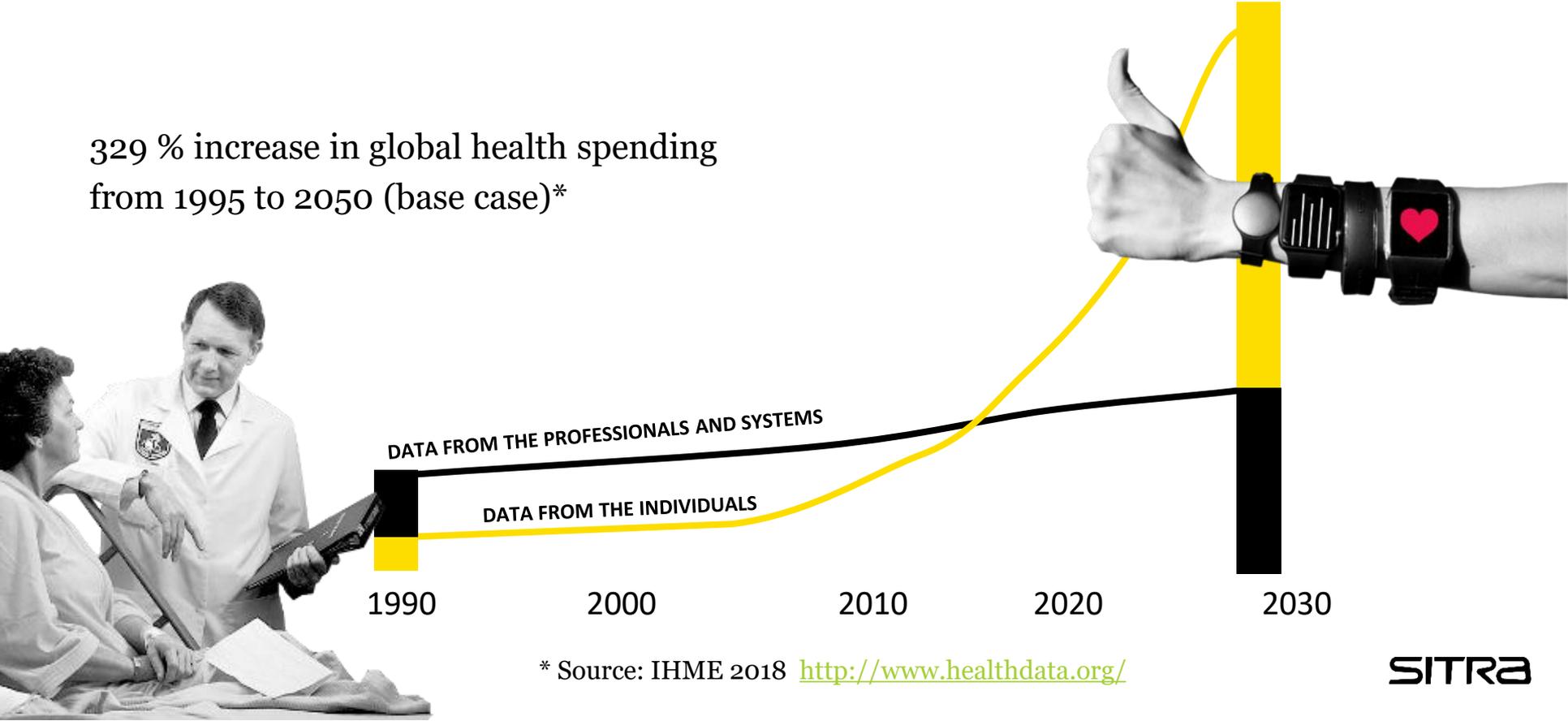
## Trust is a must.



- |  |   |
|--|---|
| <ul style="list-style-type: none"> <li>■ A secure remote use environment for individual level data sets</li> <li>■ Data sets are only available without individual's direct identifiers</li> </ul> | <ul style="list-style-type: none"> <li>■ Compliance with the Act will be supervised by the Data Protection Ombudsman, Valvira and Findata</li> <li>■ Security in the operating environment will be controlled by an information security inspection body and Valvira</li> </ul> |
|--|---|

# It's Going to Get a Lot More Personal

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



\* Source: IHME 2018 <http://www.healthdata.org/>

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# Our Health is Monetized

## Facebook's new Preventive Health tool pushes people to advocate for their health

Now you can check Facebook before your next checkup

By Mary Beth Griggs | Oct 28, 2019, 4:03pm EDT

f t SHARE

## Google reveals 'Project Nightingale' after being accused of secretly gathering personal health records

The company says it's all above board

By Mary Beth Griggs | Updated Nov 11, 2019, 11:40pm EST

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Pharmaceuticals sector [+ Add to myFT](#)

## Novartis and Microsoft join forces to develop drugs using AI

Five-year agreement is one of the most expensive tie-ups between big pharma and big tech

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PRESS RELEASE  
November 14, 2019

## Apple launches three innovative studies today in the new Research app

f t

The Apple Heart and Movement, Women's Health and Hearing Studies Now Open for Enrollment

## Ascension and Google working together on healthcare transformation

November 11, 2019 03:08 PM Eastern Standard Time

ST. LOUIS--(BUSINESS WIRE)--Ascension, one of the nation's leading non-profit health systems, is working with Google to optimize the health and wellness of individuals and communities, and deliver a comprehensive portfolio of digital capabilities that enhance the experience of Ascension consumers, patients and clinical providers across the continuum of care.

"Ascension is a leader at increasing patient access to care across all regions and backgrounds, particularly those in disadvantaged communities. We're proud to partner with them on their digital transformation"

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"As the healthcare environment continues to rapidly evolve, we must transform to better meet the needs and expectations of those we serve as well as our own caregivers and healthcare providers. Doing that will require the programmatic integration of new care models delivered through the digital platforms, applications and services that are part of the everyday experience of those we serve," said Eduardo Conrado, Executive Vice President, Strategy and Innovations, Ascension.

Ascension will improve the experience of patients and consumers, as well as providers and associates, and advance its Mission of providing compassionate, personalized care to all, especially people living in poverty and those most vulnerable, through new capabilities that

include:

## Merck, Tencent to develop digital healthcare platforms for China

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01/25/2019 | 06:20am EST

**EHTEL**  
Collaborating for Digital Health and Care in Europe

**SITRA**

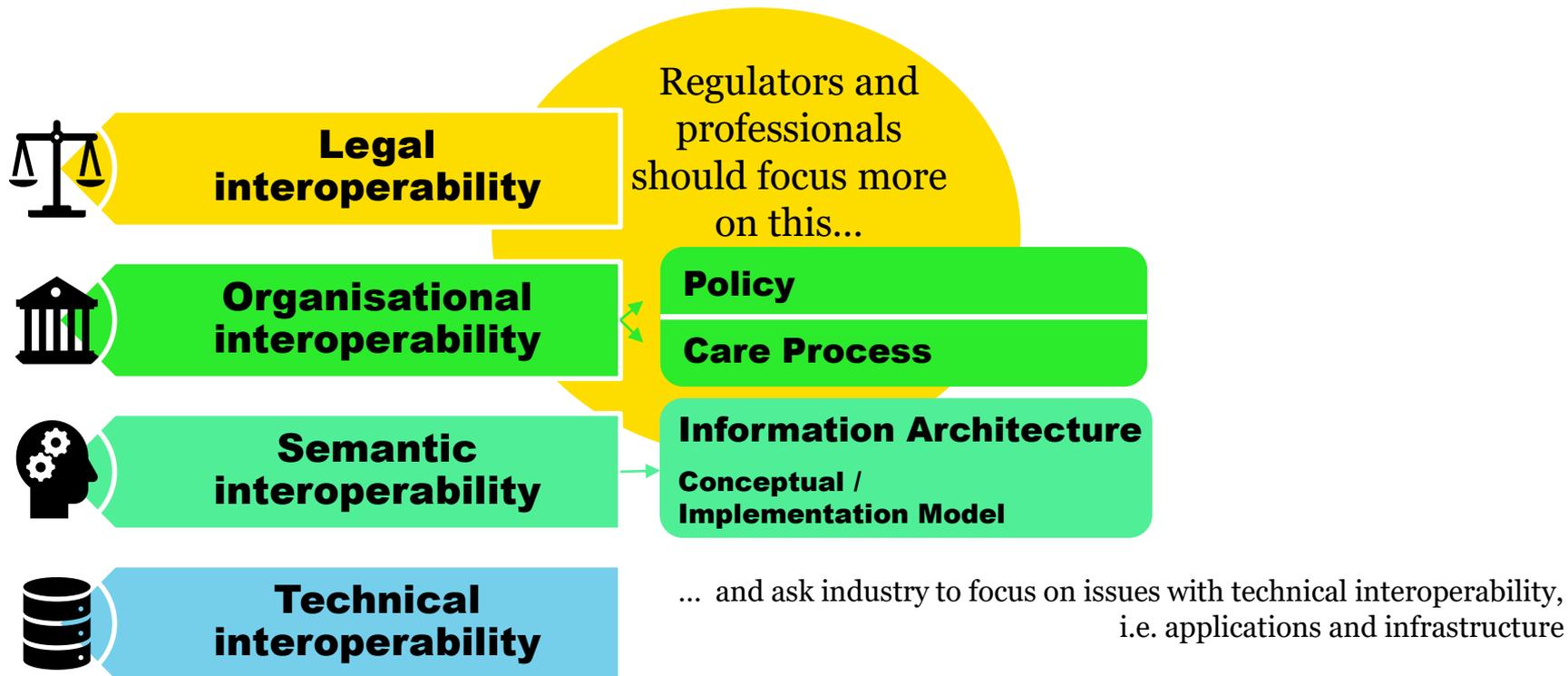
# A recent study of NHS staff

- 81 % supported the analysis of anonymised data to enable quicker diagnosis and more effective treatment 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](http://www.digitalhealth.net) 26 November 2019 based on a YouGov poll of 1,027 healthcare professionals

**WISHLIST?**

# Multiple levels of interoperability



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

# 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

**Thank you!**