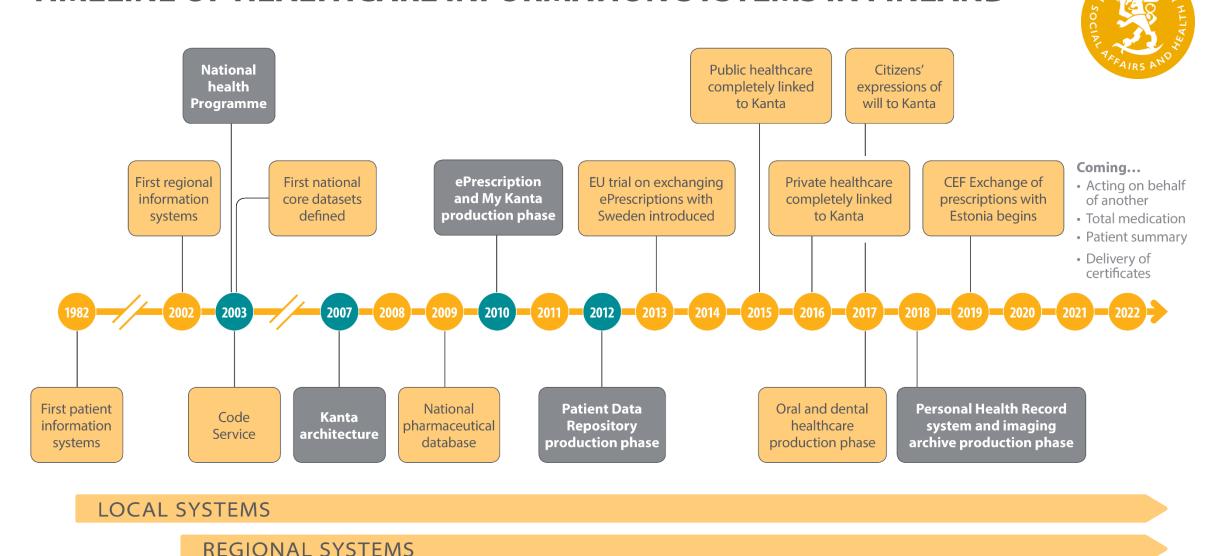


Data in the service of people's health and wellbeing – case Finland

Liisa-Maria Voipio-Pulkki, DG and CMO 11.2.2021

TIMELINE OF HEALTHCARE INFORMATION SYSTEMS IN FINLAND



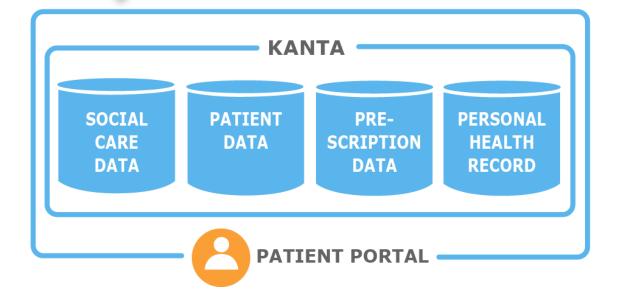
KANTA

NATIONAL PATIENT DATA SERVICES "KANTA"



- Patient, social care and prescription data are gathered in a national databank.
- Healthcare professionals can access the needed data nationwide, store patient records and make prescriptions.
- Citizens can browse their own medical records and prescriptions and order repeat prescriptions in the online service.

KANTA is an entity of digital services, which brings benefits for citizens, pharmacies and the social welfare and healthcare sector

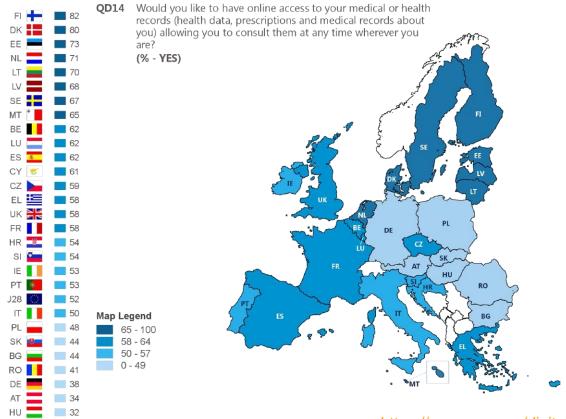


Finland – a leading country in ICT comparisons



In many years, Finland has ranked at the top in international comparisons of healthcare information technology, e.g. in the use of electronic patient records and electronic prescriptions.

Finns are active users of their own health information: 1.1 million log ons every month, 0.5 million individuals per month visit My Kanta.



Base: All Respondents (N=27,901)

https://ec.europa.eu/digitalsingle-market/en/news/attitudestowards-impact-digitisation-andautomation-daily-life



Enterprise and innovation department 26.5.2014

Health Sector Growth Strategy for Research and Innovation Activities

MEE reports 16/2014

Health Sector Growth strategy 2014 -

Finland to be

- The source and user of versatile and high quality scientific research, inventions and innovations.
- A preferred global partner in public-private collaboration in research and innovation.
- A dynamic operating environment for new companies.
- •
- A model country of sustainable personalised healthcare.



Updated Roadmap: New innovations in the health sector aim at wellbeing and competitiveness

ry of Economic Affairs and Employment, Ministry of Education and Culture, Ministry of Social Affairs and Health 11.12.2020 8.
RELEASE



Research and innovation activities in the health sector will be developed in a target-oriented way in 2020–2023. People's health and wellbeing will be improved through research and technological development. Steps will also be taken to advance Finland's international position as a forerunner in health sector research and innovation, investment and new business.













Objectives and targets of the National Roadmap for Research, Development and Innovation 2020:

- Increasing the intensity of RDI activities from the current 2,8 per cent to 4 per cent by 2030
- A significant increase in the national level of competence and education
- A new beginning for RDI cooperation between companies and research organisations: New partnership for ecosystems, infrastructures and utilization of research
- Linking RDI activities to support renewal of the public sector and services

Building blocks of the health sector growth strategy

Founding of the Finnish Biobank Cooperative FINBB

eHealth and eSocial Strategy

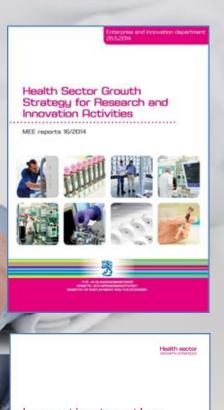
Developing of the research and innovation ecosystems around university hospitals

Legislation on the Secondary of Use of Health and Social Data

Cancer Centre Finland FICAN
Neurocentre Finland
Pharma Centre (TBD)

Preparation of the Genome Law and updating the Biobank Law

Developing of the MyKanta service and its ecosystem









FOUNDING UNIVERSITIES

FOUNDING HOSPITALS

FINNISH HOSPITAL DISTRICTS



STRATEGIC COLLABORATION























BICPANKK













JYVÄSKYLÄN YLIOPISTO



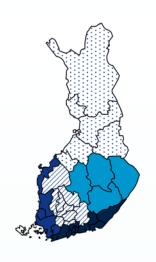


thl Biobank

















Cancer Center





- Patient, data and sample finding
- Study set-up and single point of contact
- Data and sample delivery and analytics

Researchers

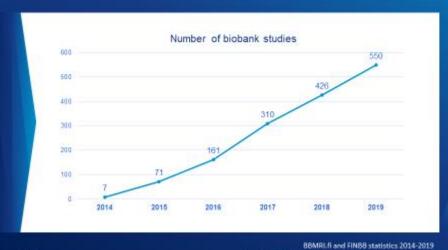


Finnish Biobank Cooperative – FINBB

- Our founding partners are six biggest Hospital Districts, six Universities and Finnish Institute for Health and Welfare (THL)
- FINBB offers a one-access-shop for easy access to Finnish biobank materials, biodata and study participants

Biobank Studies in Finnish Biobanks

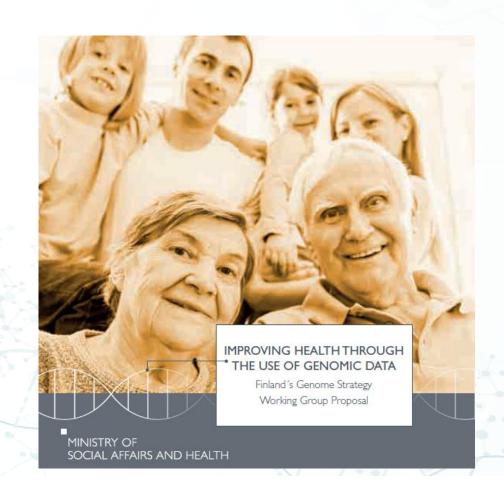






Finland's Genome Strategy: Improving health through the use of genomic data (published in 2015)

- aiming to establish a national Genome
 Centre and a legal framework that will
 enable genomic data to be used effectively in
 healthcare, research and development.
- to make sure that everyone has an equal opportunity to benefit from the use of genomic data with high ethical standard.
- New Genome Act (2021-2022)





- The Genomics Policy Brief is a report produced by the European Observatory on Health Systems and Policies, tailored to the needs of health policy makers for informing them about available evidence and best governance practices.
- The draft genomics policy brief was presented in Brussels during the Finnish EU Presidency event on "Genomics and Personalized Medicine in Public Health" 10th October 2019.
- Published in January 2021

Regulating the unknown

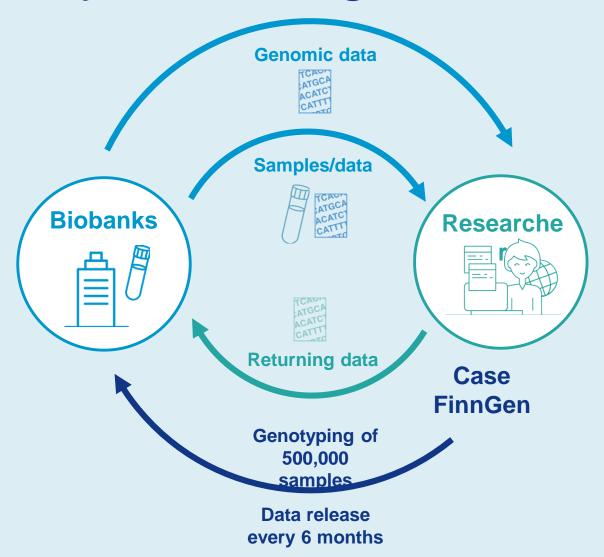
A guide to regulating genomics for health policy-makers







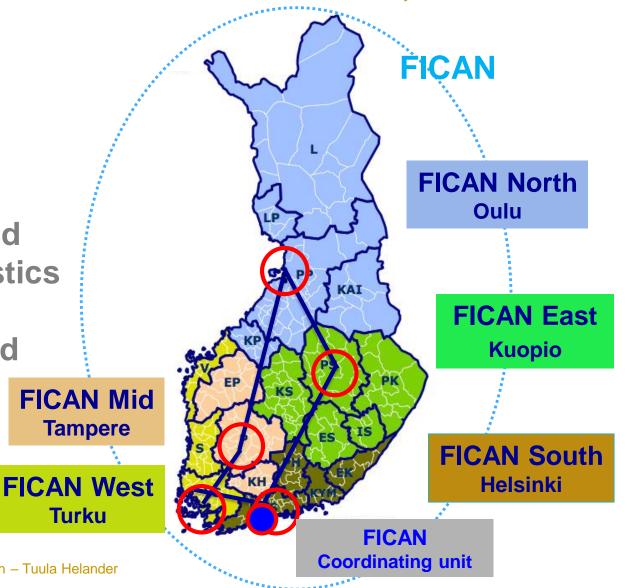
Continuously Enriching Data





CLUSTER OF EXCELLENCE — FINNISH CANCER CENTER, FICAN

- 20 Hospital districts and 5 medical universities
- Five regional cancer centers; a joint coordinating unit.
- Combines high-quality research and education with prevention, diagnostics and treatment.
- Forms a nationwide cooperation and innovation environment.
- Safeguards the equality and high quality of care.
- Decree + cooperation agreement.



Turku

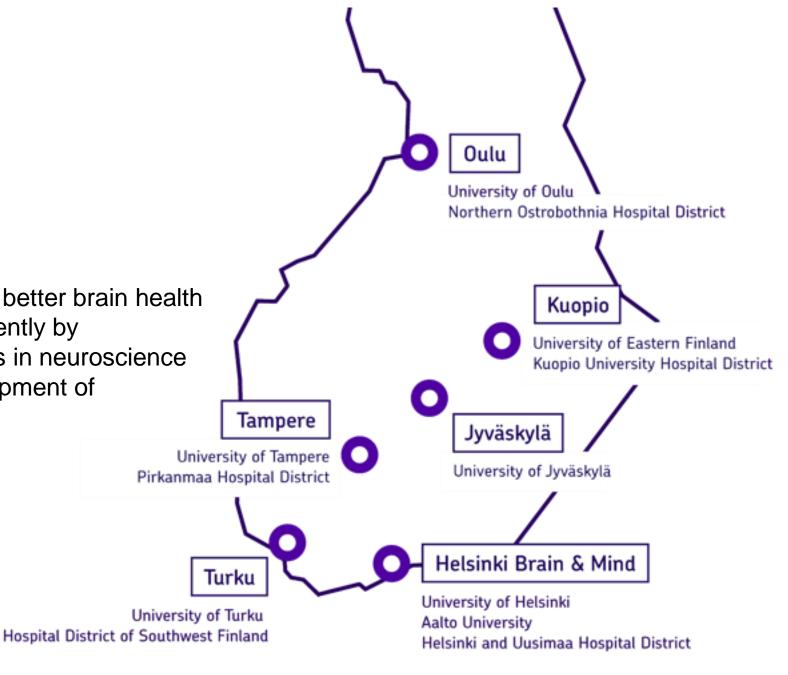
Centres of Excellence in Neurosciences

Neurocenter Finland aims to achieve better brain health and tackle brain diseases more efficiently by strengthening research collaborations in neuroscience and promoting innovation and development of personalised healthcare.





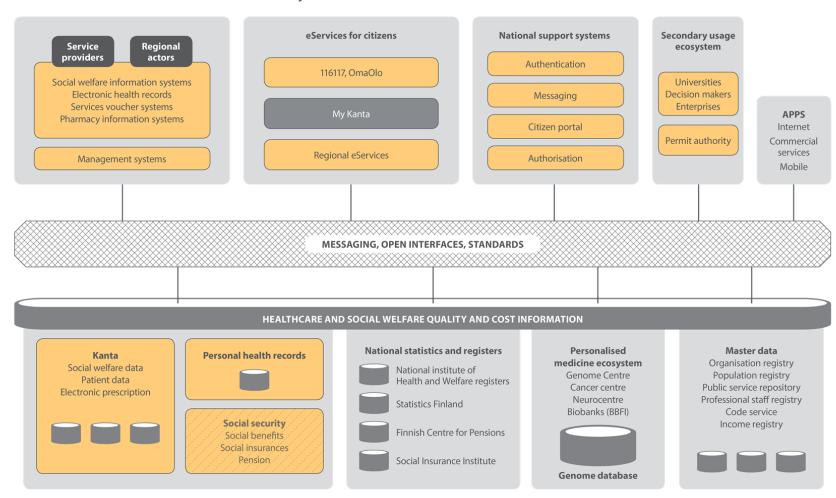
Development of the Kuopio and Helsinki Centres of Excellence is supported by EU funding.





ACCESS TO DATA HAS CHANGED IT ALL - AND WHAT THEN?

National information systems architecture for healthcare and social welfare



FINDATA

Primary and secondary use of personal data

Primary use Services for a client or a patient Health and social data

Secondary use

National

- Registers
- Population studies



Based on the Act on the Secondary Use of Health and Social Data:

- Scientific research
- Statistics
- Development and innovations
- Teaching
- Knowledge based management
- Authorities' steering, supervision, planning and reporting duties

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

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

What we do

- Grant data permits when data are requested from multiple registries
- Collect and process the data
- Provide the data in a secure ITenvironment for data users
- Offer a **Help Desk** for data users



TEHDAS Joint Action Towards the European Health Data Space

Member States interested in participating (22)

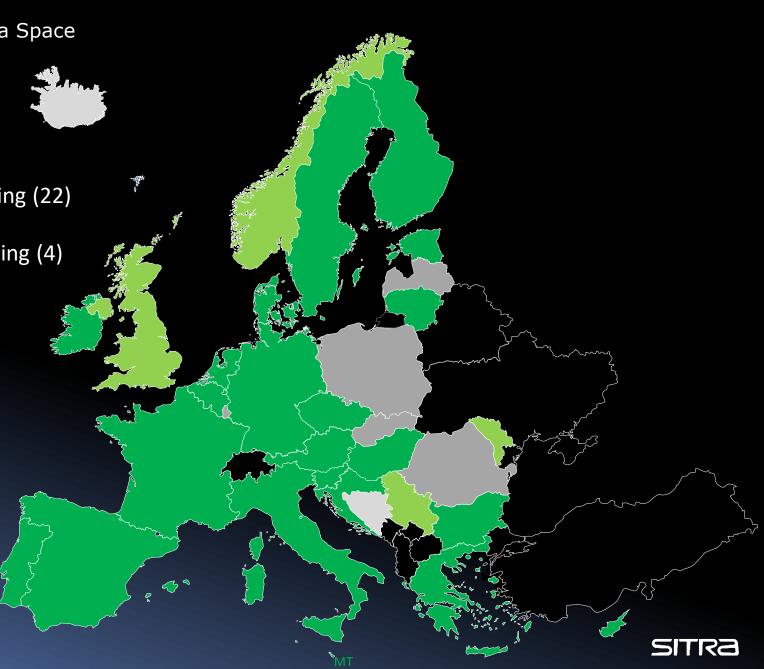
Other countries interested in participating (4)

Eligible, not participating

Project coordinator Finnish Innovation Fund Sitra, Finland

Participant Countries

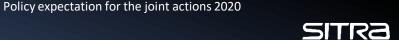
October 2020



Joint Action is expected to produce as its outputs options for

- Data Governance for the European Health Data Space (EHDS), complementing the horizontal European Data Spaces framework, including functions and responsibilities of the relevant actors.
- Guidelines on using health data for research and policy making
- Guidelines on Ethical, Legal and Social issues in the European Health Data Space
- Data Quality framework encompassing semantic interoperability and FAIR principles, as well as anonymization and pseudomisation techniques.
- Infrastructure architecture and technical interoperability guidelines to enable European Health Data Space services
- Economics models focused on the sustainability of European Health Data Space





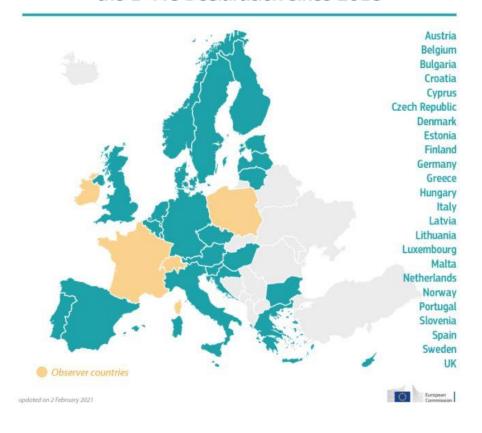
Adapted from CHAFEA Ares(2020)1379455 - 05/03/2020:



"Towards access to at least 1 million sequenced genomes in the European Union by 2022"



Countries that have signed the 1+MG Declaration since 2018



Declaration for delivering cross-border access to **genomic database**



1 million **genomes accessible** in the EU by 2022



Linking access to existing and future genomic database across the EU



Providing a sufficient scale for new clinically impactful associations in research







Lessons of the COVID 19 crisis

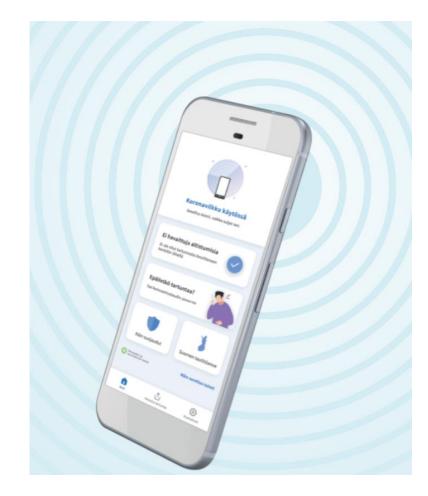


Corona contact tracking app (Koronavilkku.fi) was launched 31st of August 2020. About 40 % of the Finnish population has downloaded the app.

The crisis has highlighted the need for improvement in national level data interoperability \Leftrightarrow real-time monitoring of HS performance.

Customer-oriented and reliable online services promote patient satisfaction, access to care and effectiveness of services - a win-win.

Demand for cross-border interoperability is increasing.

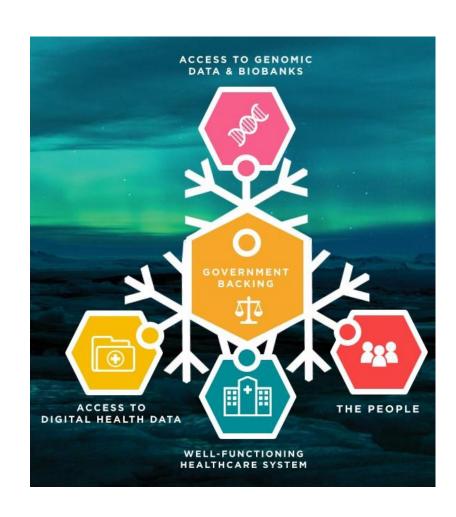




DATA (AND PM) WILL TRANSFORM HEALTH SYSTEMS

Building a sustainable ecosystem that delivers is a joint venture of citizens, companies, authorities and health care providers:

- Legislation and ethical principles => established procedures
- An open, innovative environment for PPP
- Professional excellence (medical, legal, ICT)
- Dialogue with the health system and public health experts / opinion leaders
- Trust





THANK YOU!

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Twitter: @MSAH_News

