

# KEYNOTE SPEECH by Finnish Presidency



**Tuula Helander**

Senior Advisor, Cabinet and Strategy Group of the Permanent Secretary  
Ministry of Social Affairs and Health,  
Health Secretary General Cancer Institute





**Building World's Best Patients  
Outcomes by Leveraging Health Data  
and Personalised Medicine to  
Accelerate Research & Innovation**



**15.11.2019**

**Dr. Tuula Helander**

**Senior Adviser**

**Permanent Secretary's Cabinet**

**Ministry of Social Affairs and Health**

**Finland**



# HEALTH SECTOR GROWTH STRATEGY - Direction for Developing the Ecosystem

Enterprise and innovation department  
26.5.2014

## 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 reliable partner for the international growth of companies.
- An attractive target country for health sector investment.
- A **model country of sustainable personalized healthcare.**

### Health Sector Growth Strategy for Research and Innovation Activities

MEE reports 16/2014



Health sector  
GROWTH STRATEGY



### Innovating together

Health Sector Growth Strategy  
for Research and Innovation Activities  
Roadmap for 2016–2018

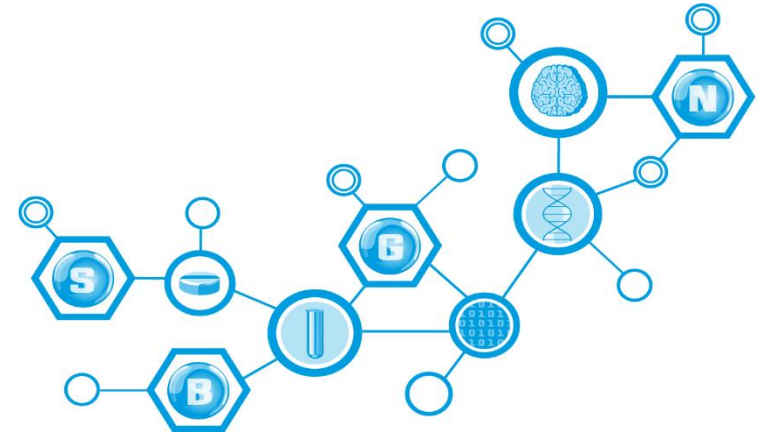




# HIGHEST-CLASS KNOWHOW, RESEARCH AND EDUCATION – CENTERS/CLUSTERS OF EXCELLENCE

Finnish government is investing over 30 million euros for personalized medicine research, innovation, education and data management clusters/centers of excellence.

- Establishing National
  - Cancer Center FICAN
  - Neurocenter
  - Genome Center
  - Drug Development Center
- Enhancing the joint activities of the **biobanks**

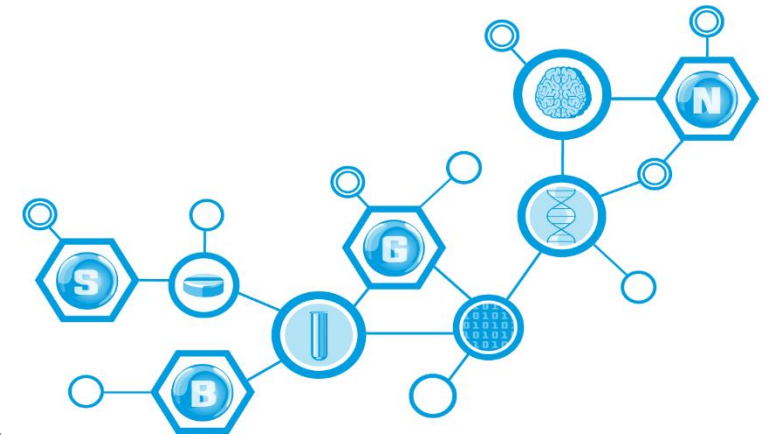




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# **FINLAND, NORWAY, SWEDEN – THE BEST CANCER PATIENTS** **SURVIVAL RATES**

The total number of all-cancer deaths in the first 5 years after diagnosis was about 1.3 million, with an overall relative 5-year survival of 51.9%. If all countries attained the mean survival (57%) of Norway, Sweden, and Finland (countries with high survival and medium-to-high TNEH), about 12% fewer cancer deaths (about 150 000) would occur in the 5 years after diagnosis.

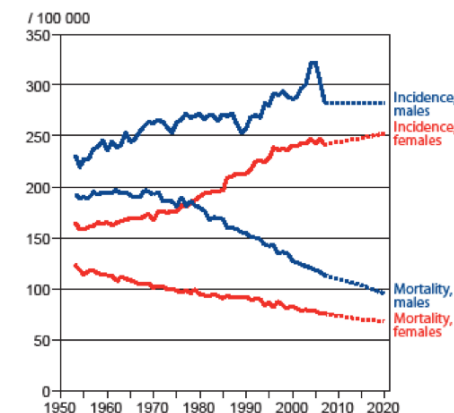
## **Eurocare-4:**

- 2.7 million patients diagnosed 1995-1999, followed up to Dec 2003 (23 countries); Berrino et al. Lancet Oncology, 2007.

## **Eurocare-5:**

- cancer registry coverage 100% in Nordic countries
- 10 million patients diagnosed 1999-2007, followed up to 2008 (29 countries); De Angelis et al., Lancet Oncology, 2014.

The improvement of diagnostics and treatments clearly evidenced by the continually decreasing mortality from cancer diseases



Age-adjusted incidence and mortality of cancer per 100,000 person/years in 1953–2007, and predicted in 2020 (Finnish Cancer Registry 2009).



# LEVEL OF RESEARCH



*Publication  
Analysis 1998-2009*

## Cancer Research

(Lab Times 1:40, 2012)

Country	Citations/Article	Rank
Finland	26.4	1
USA	22.4	2
Switzerland	21.7	3
Australia	21.5	4
Netherlands	21.4	5
Sweden	21.2	6
Belgium	20.8	7
Canada	20.8	7
Norway	20.6	9
Denmark	20.2	10
Scotland	19.4	11
France	19.0	12
Israel	17.8	13
England	17.5	14
Germany	16.8	17
Spain	16.2	18
Italy	14.3	19
Turkey	5.5	26
Europe	14.9	

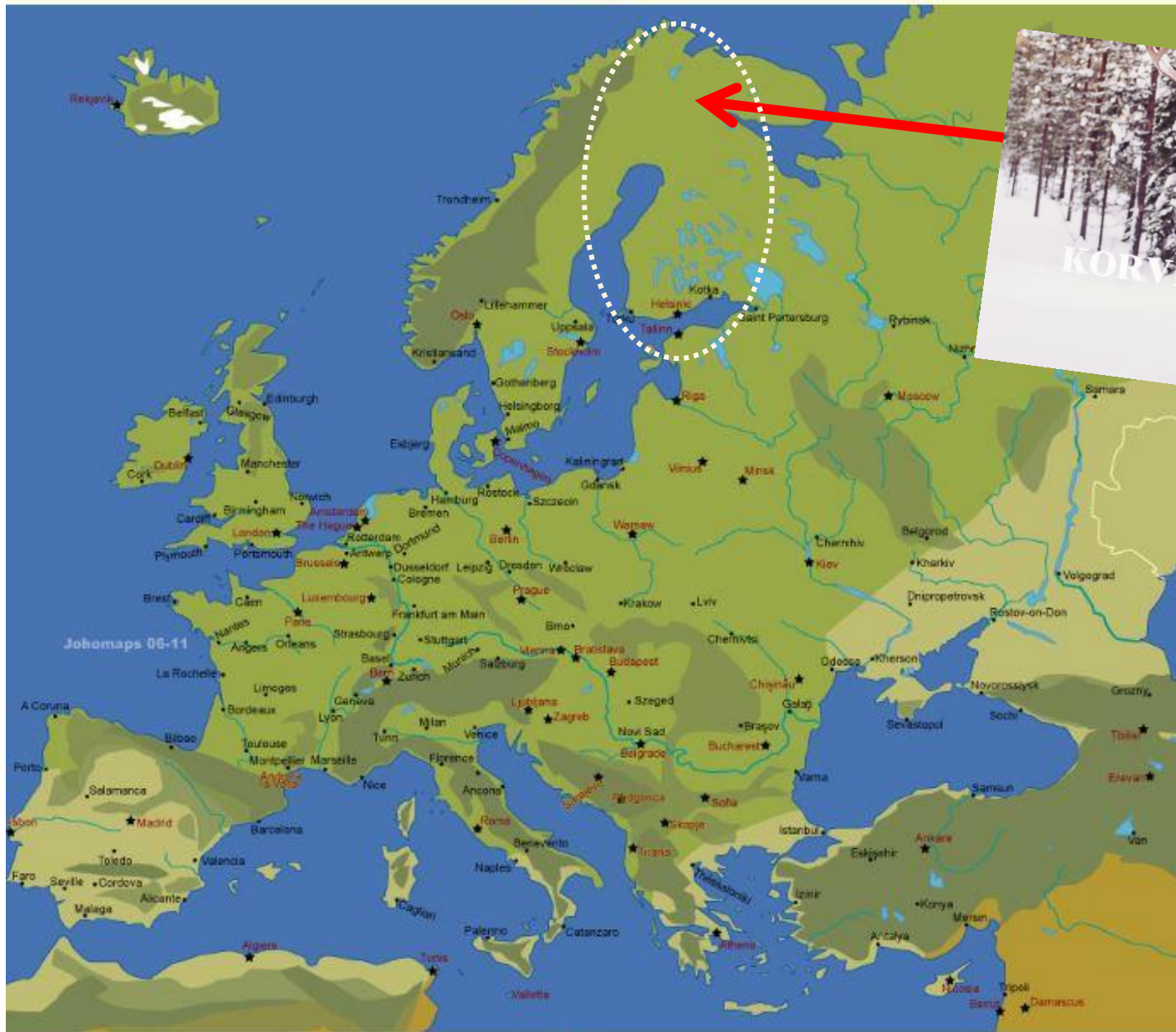


## Top nations in clinical medicine

January 2000–April 2010

Data provided by Thomson Reuters from its Essential Science Indicators,

	Country	Papers	Citations	Citations per paper	Rank 2008
1	Finland	21,085	386,878	18.35	1.
2	Denmark	23,608	430,836	18.25	3.
3	The Netherlands	66,735	1,192,435	17.87	2.
4	Belgium	31,448	560,346	17.82	8.
5	Scotland	22,563	397,701	17.63	5.
6	Switzerland	40,586	707,057	17.42	7.
7	United States	692,884	11,927,811	17.21	4.
8	Sweden	44,741	759,746	16.98	9.
9	Canada	88,373	1,499,059	16.96	6.
10	England	163,755	2,573,872	15.72	11.

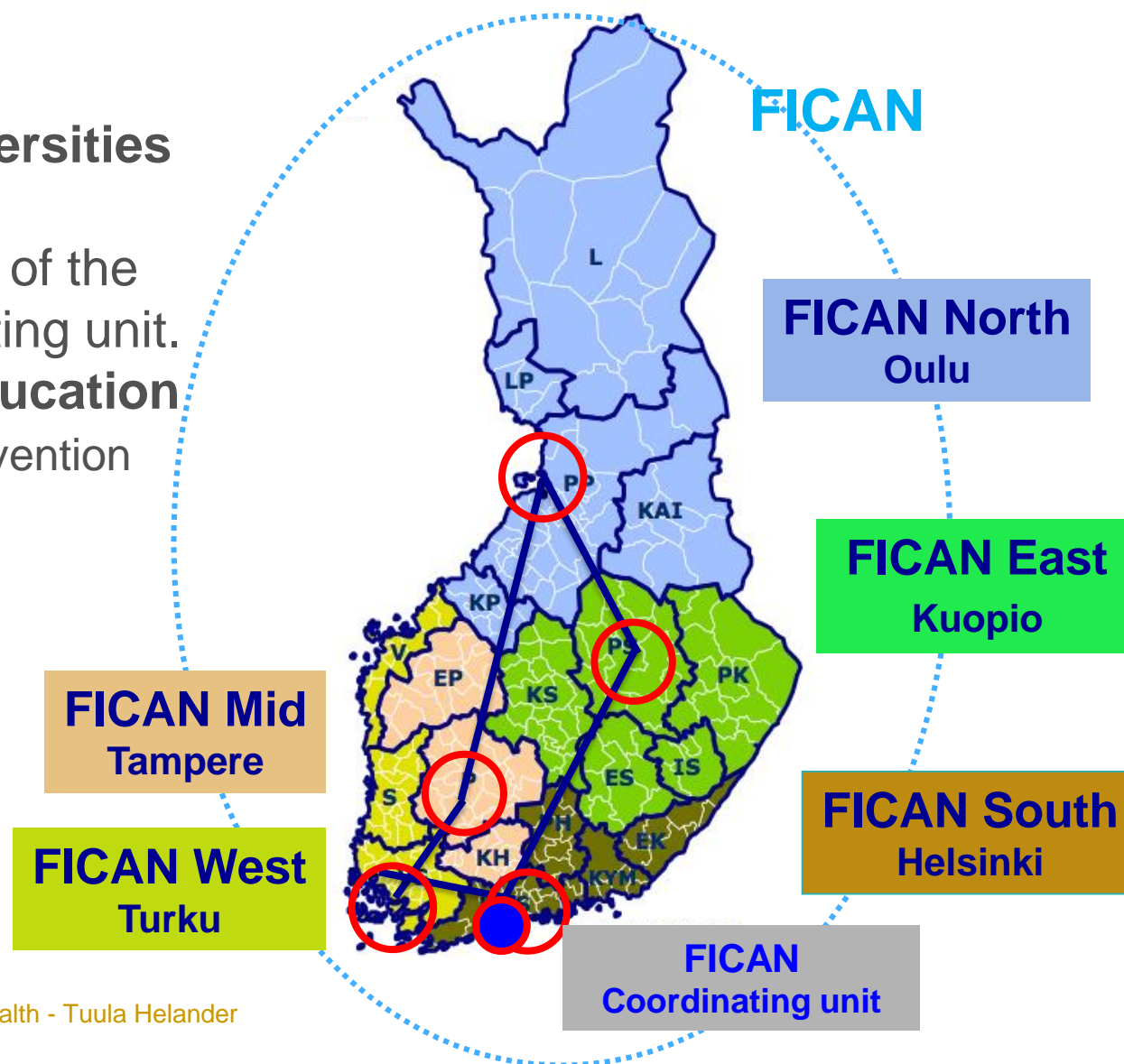






# FINNISH CANCER CENTER - FICAN

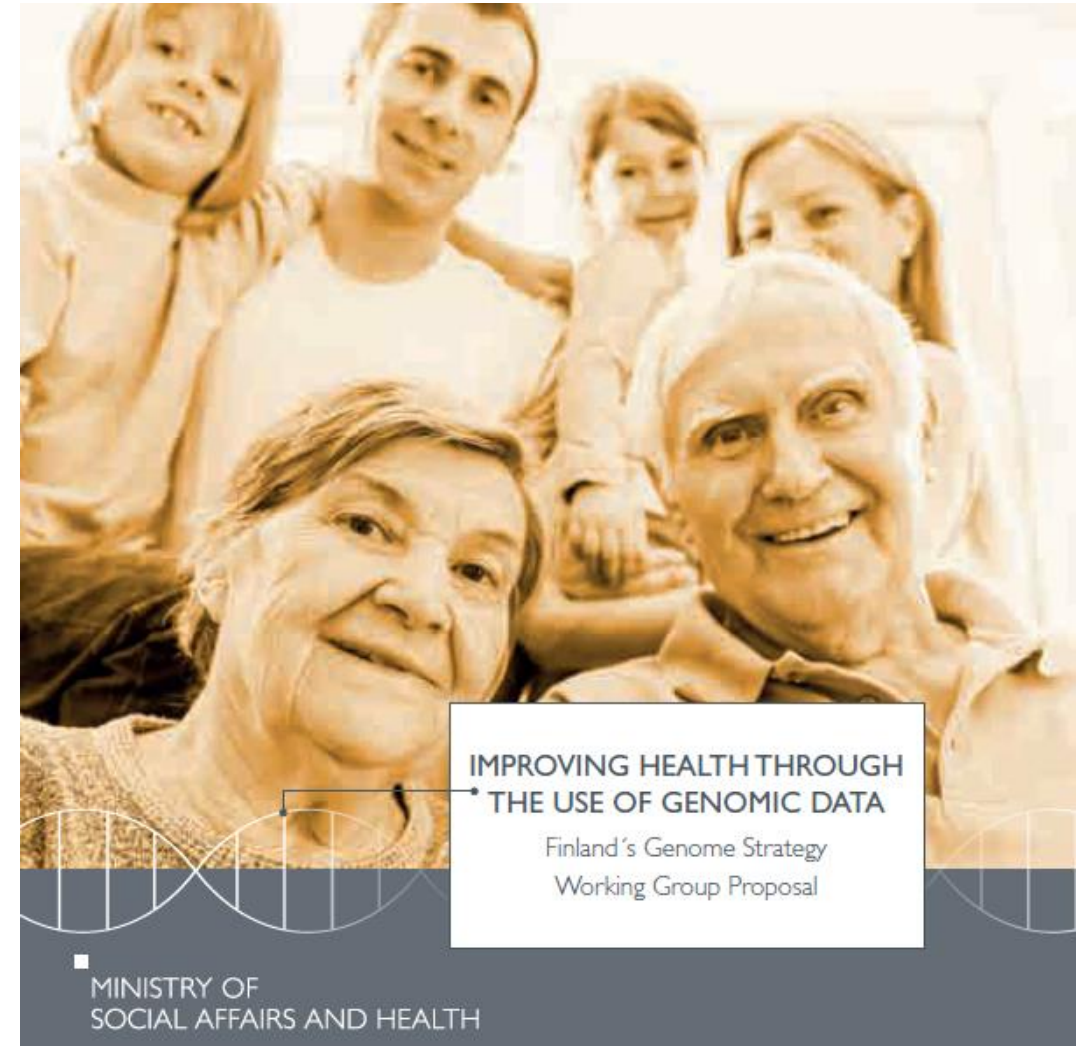
- **20 hospital districts and 5 medical universities** establish national cancer center
- Five regional cancer centers are in charge of the operations coordinated by a joint coordinating unit.
- **Combines high-quality research and education with diagnostics and treatment** (from prevention to rehabilitation)
- Forms a **nationwide cooperation and innovation environment**
- Safeguards the equality and high quality of cancer treatment also in future Finland
- Fully operating in 2019 (KickOff 22<sup>nd</sup> of Oct 2019).





# FINLAND'S GENOME STRATEGY PUBLISHED IN 2015

- We are aiming to establish, by the end of June 2020, a **national Genome Centre** and a **legal framework** that will enable genomic data to be used effectively in healthcare, research and development (public consultation, 2. round during summer 2019; planning and development of operations and ICT architecture).
- We want to make sure that everyone has an **equal opportunity to benefit from the use of genomic data.**





# AIMS OF THE FINNISH GENOME ACT

- support the **responsible, equal and secure use of genomic data** for the benefit of wellbeing and health.
- establish the National Genome Centre
- establish a **national centralized genomic database**
- support the use of genomic data for health care and research purposes
- regulate genetic testing
- The proposed law is intended to come into force in 2020.

*Integrating genomics into healthcare is a joint venture of different sectors and stakeholders, authorities, researchers, companies and citizens !*



# WORLD'S BEST PATIENTS OUTCOMES

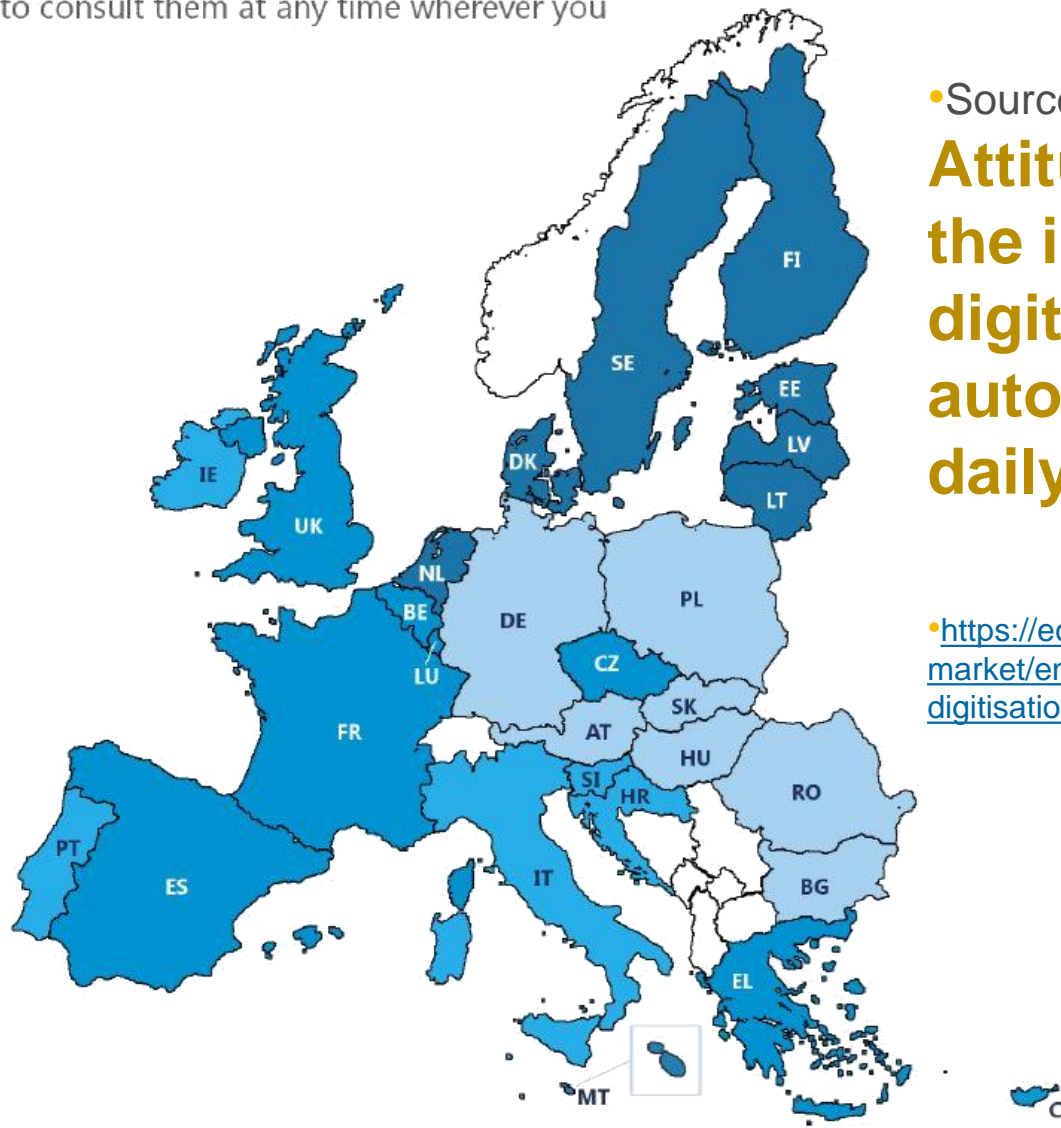
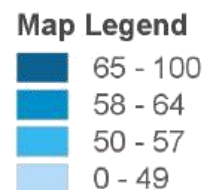
- At present, Finland demonstrates some of the world's best patient outcomes in e.g. oncology, pediatrics and acute neurology.
- Good outcomes are based on a fit-for-purpose health system.
- However, the system is challenged by
  - demographic change and increasing multimorbidity
  - demand for better performance at a lower cost
  - **emerging opportunities of precision medicine**
- It is absolutely necessary to make full use of all health-related data in research and innovation to meet people's needs.





FI		82
DK		80
EE		73
NL		71
LT		70
LV		68
SE		67
MT		65
BE		62
LU		62
ES		62
CY		61
CZ		59
EL		58
UK		58
FR		58
HR		54
SI		54
IE		53
PT		53
EU28		52
IT		50
PL		48
SK		44
BG		44
RO		41
DE		38
AT		34
HU		32

**QD14** Would you like to have online access to your medical or health records (health data, prescriptions and medical records about you) allowing you to consult them at any time wherever you are?  
(% - YES)

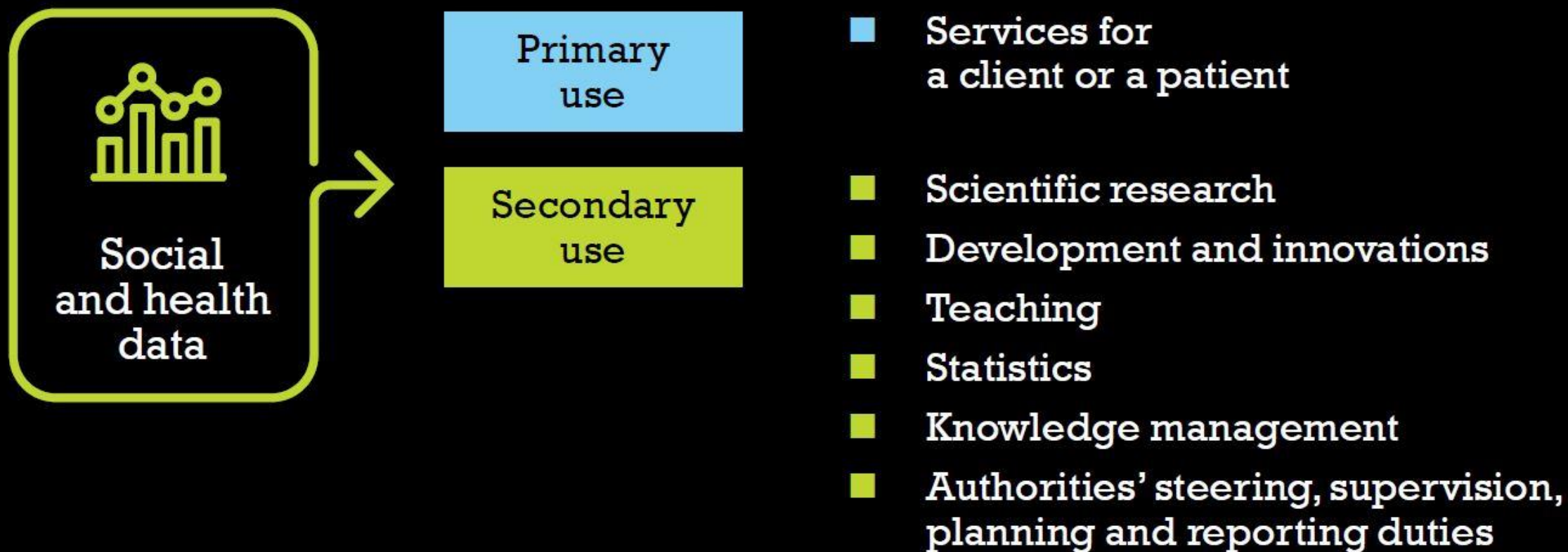


•Source: Eurobarometer,  
**Attitudes towards  
the impact of  
digitisation and  
automation on  
daily life**

•<https://ec.europa.eu/digital-single-market/en/news/attitudes-towards-impact-digitisation-and-automation-daily-life>

Base: All Respondents (N=27,901)

## Secondary use of social and health data





# FINDATA

## HEALTH & WELFARE

Operation of the new data  
permit authority will be  
launched in 2020

Social and Health  
Data Permit Authority

15.11.2019

Ministry of Social Affairs and Health - Tuula Helander



# FROM TREATING HEALTH PROBLEMS TO PREVENTION

- One of the objectives is to gradually shift the emphasis in healthcare; Genomics technology is increasing our ability to identify more accurately people at risk of developing disease and **to prevent diseases before their onset.**
- **People will be empowered to foster their own health by having access to more comprehensive information on the factors affecting it.** Risk profile-based prevention could be based on changes in lifestyle and also on medical treatment.
- With genetic risk profiling, screening can be better targeted at susceptible subgroups of the population.

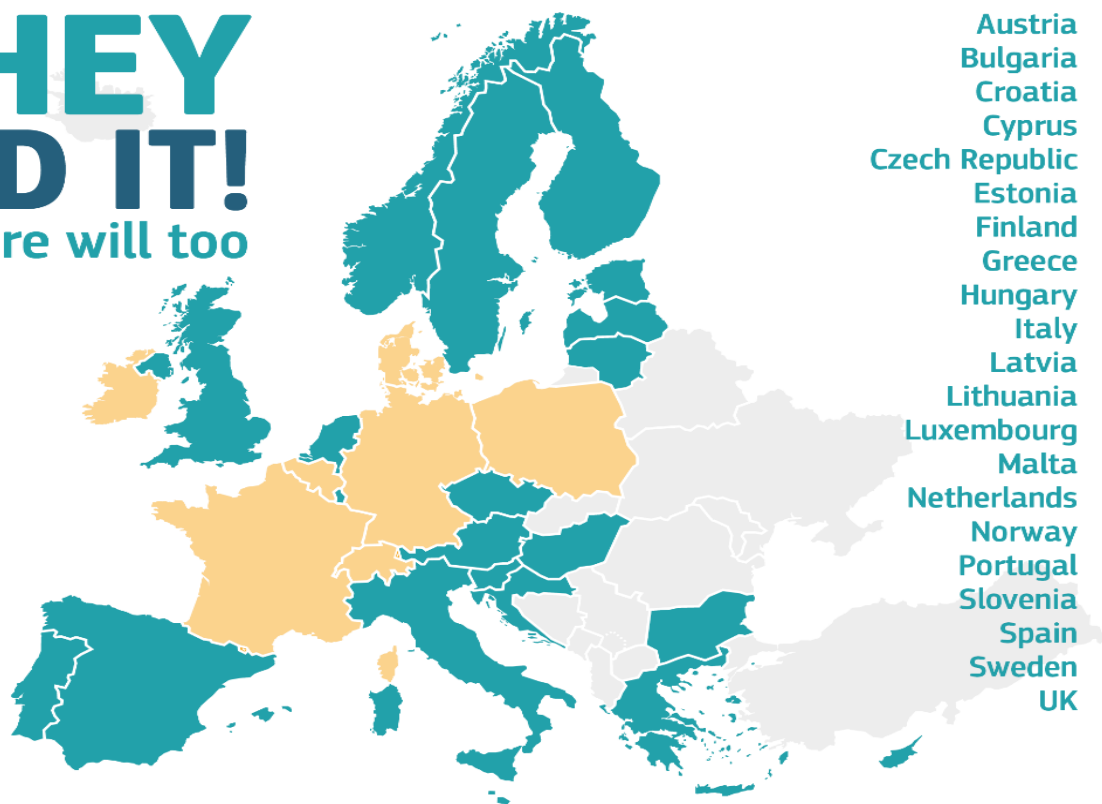




# DECLARATION ON LINKING GENOMIC DATABASES ACROSS BORDERS: "TOWARDS ACCESS TO 1 MILLION GENOMES IN THE EU BY 2022" SIGNED BY 20 EU MS AND NORWAY

EU countries agreed to cooperate in linking genomic data across borders

**THEY  
DID IT!**  
& more will too



- Austria
- Bulgaria
- Croatia
- Cyprus
- Czech Republic
- Estonia
- Finland
- Greece
- Hungary
- Italy
- Latvia
- Lithuania
- Luxembourg
- Malta
- Netherlands
- Norway
- Portugal
- Slovenia
- Spain
- Sweden
- UK

● *Observer countries*



**7 Observer countries:  
BE, CH, DE, DK, FR, IE, PL**

# Declaration for delivering cross-border access to **genomic databases**



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



**Linking access** to existing and future genomic databases across the EU



Providing **proper scale** for research with clinical impact



# EU2019.FI

Finland's Presidency  
of the Council  
of the European Union

PROVISIONAL 2.10.2019

## Genomics and Personalised Medicine in Public Health 10 October 2019

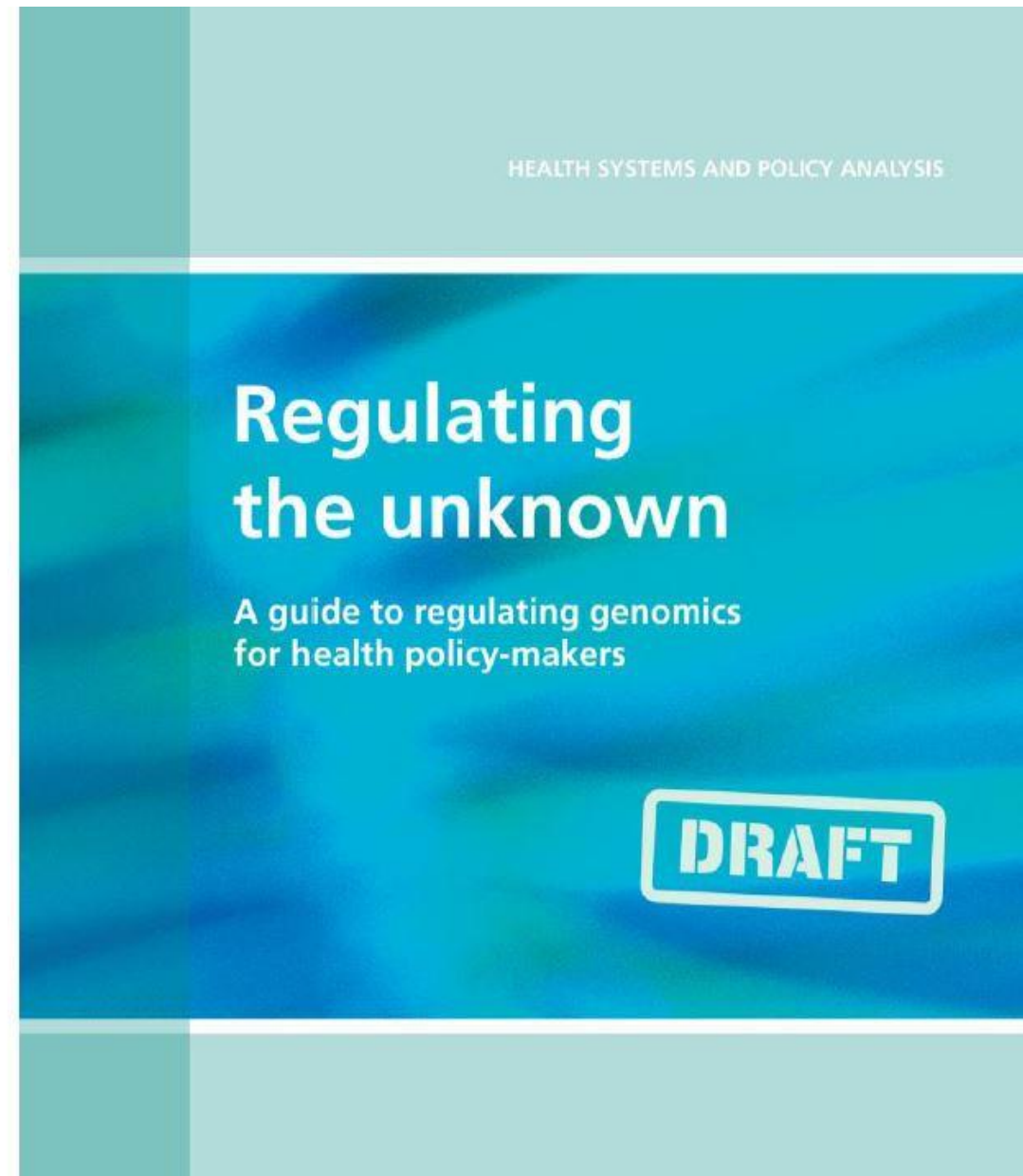
Permanent Representation of Finland to the EU  
Avenue de Cortenbergh 80, 1000 BRUSSELS

The purpose of the event is to promote discussion between representatives of the EU Member States and experts on the application of personalised medicine in health services and in the advancement of public health. The discussions will draw inspiration, inter alia, from the joint declaration "Towards access to at least 1 million sequenced genomes in the European Union by 2022" which has been signed by 20 Member States and Norway. The objective of this EU project is to create a secure and privacy-protected knowledge base in order to investigate multifactorial diseases and to make use of this information in health care.

The European Observatory of Health Systems and Policies will launch the Policy Brief on genomics during the event.



- 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*” 10<sup>th</sup> October 2019.





# BUILDING IT TOGETHER - Acting and growing ecosystem

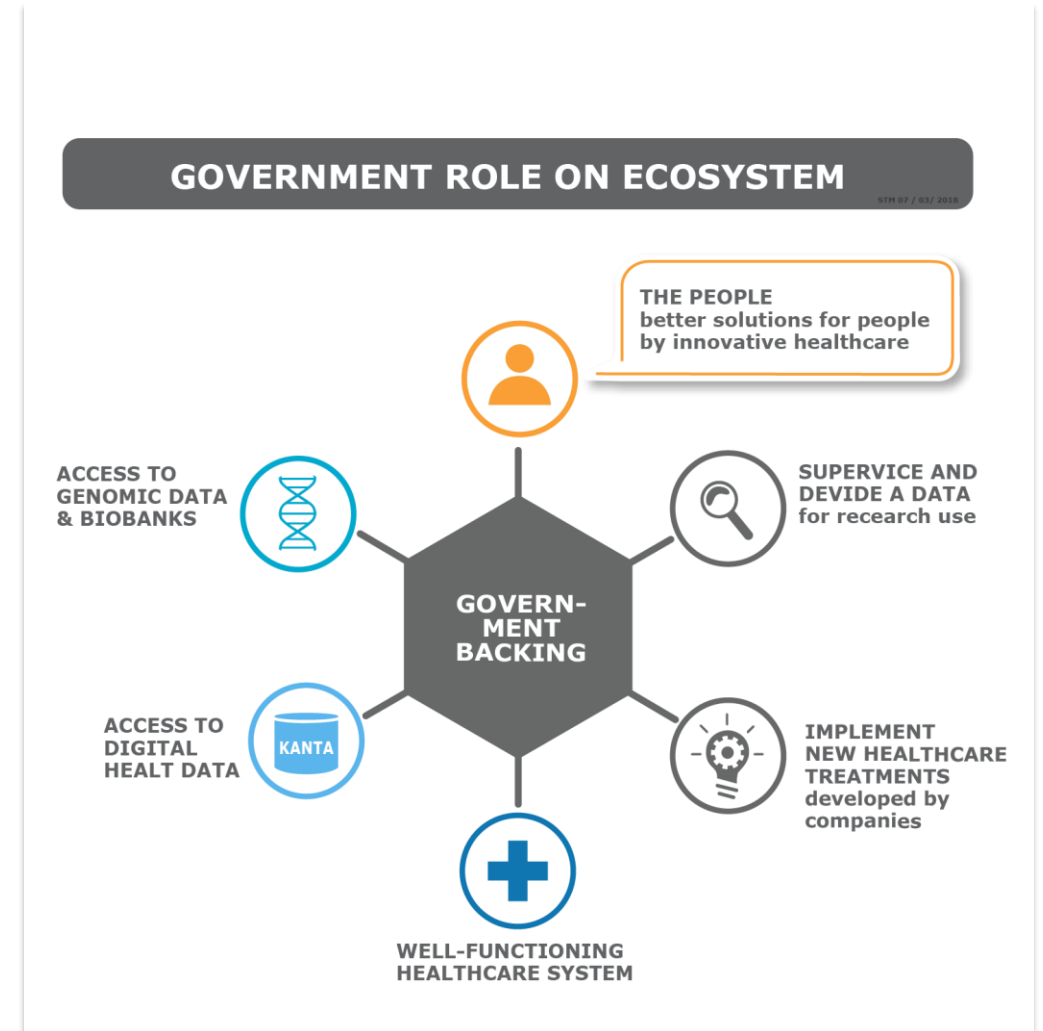
Building the health ecosystem is a joint venture of citizens, companies, authorities and others.

## Highlights of the Finnish ecosystem

- Well educated citizens eager to test innovations and participate research.
- Global dynamic network of competent enterprises. Especially active start-up community.
- Major authorities, public and private health and social service providers working together.
- Established procedures and open, innovative environment for public-private cooperation.

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# Health ecosystem players in Finland

Data analytics	Bio, pharma, medical technology	Prevention	Test beds, accelerators

## Clusters of excellence and research platforms

- Finnish Genome Center
- Finnish Cancer Center (FICAN)
- Neuro Center Finland
- Finnish Biobank (FINBB)
- Suomen Terveystalo Biobank
- Red Cross Biobank
- NIHW (THL) Biobank
- Drug development center



## "Technology enablers"

## Multomics and research

## Health services

## Diagnostics and imaging

## Remote solutions

## Education and research

**Legislation & policies:** Biobank Law, Clinical Research, Secondary Use of Social & Health data, Genome Law, Health Sector Growth Strategy

## Economy of Wellbeing supports societal stability, trust and security

- One of the greatest challenges facing the EU is the persistent inequality between and within the Member States
- Poverty, unemployment and certain health risks are in global context recognized as a security threats
- Equity and measures promoting equal opportunities are key aspects of fairness, which is a building block of a stable and resilient society
- Wellbeing is pertinent to legitimacy of public policies including EU policy and decision making
- Upward wellbeing and economic convergence are necessary with a view to strengthen the EU; its macroeconomic framework as well as to improve its societal resilience and stability



**BUILDING TOGETHER  
THE ECOSYSTEM -  
WORLD'S BEST  
PATIENTS OUTCOMES  
BY LEVERAGING  
HEALTH DATA AND  
PERSONALIZED  
MEDICINE TO  
ACCELERATE  
RESEARCH &  
INNOVATION**

- **Common direction**  
- Health Sector Growth Strategy
- **Unique national eServices and ICT-architecture**
- **Secondary use of data legislation**  
- one stop shop for the data
- **Highest-class knowhow, research and education – Centres of excellence**
- **Finland the Test Bed**
- **World's best patients outcomes**
- **Building it together**  
- Acting and growing ecosystem





## ***DATA-DRIVEN INNOVATIONS ARE MOONSHOTS OF THE 2020'S***

- SIGNIFICANT HEALTH PROBLEMS***
- RADICAL SOLUTIONS***
- BREAKTHROUGH TECHNOLOGIES***

# **THANK YOU!**

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**Ministry of Social Affairs and Health**

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