



**Governments for
personalized medicine –
to whom are we
accountable?**



1.10.2019

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Forska!Sverige



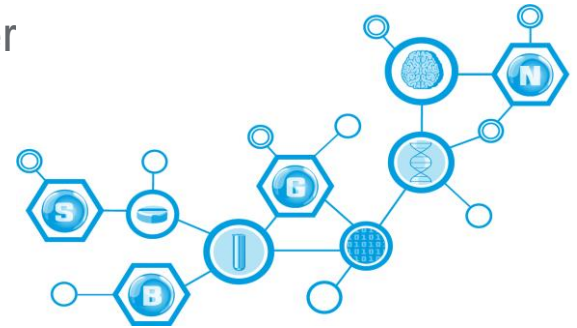
WHAT THE FINNISH GOVERNMENT HAS DONE TO PROMOTE PERSONALIZED MEDICINE?



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

Finnish governments are systematically investing in the **infrastructure** for personalized medicine research, innovation, education and data management clusters/center

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





HEALTH SECTOR GROWTH STRATEGY - Direction for Developing the Ecosystem

VIDEO: https://youtu.be/o5CSZK_6UFM

Enterprise and innovation department
26.9.2014

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



Innovating together

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



Health sector
growth strategy

Government backing the growth of the health sector

Founding of the
Finnish Biobank
Cooperative
FINBB

eHealth and eSocial
Strategy and
Legislation on the
Secondary of Use of
Health and Social
data

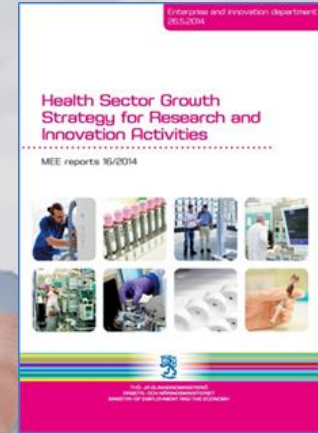
Developing of the
research and
innovation ecosystems
around university
hospitals

Legislation and
operating principles
for the digital health
data service operator

Preparing the founding of the
National Genome Centre, of the
Comprehensive Cancer Centre
Finland FICAN and of the
Neurocentre Finland

Preparation of the Genome Law and
updating the Biobank Law

Developing of the
MyKanta service
and its
ecosystem



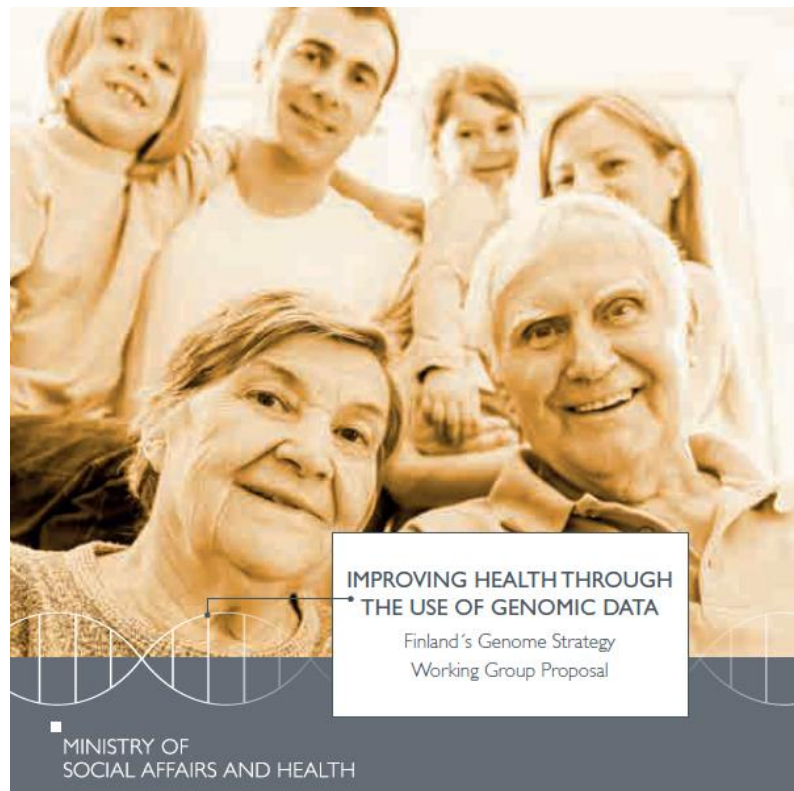
Evaluation of the Research Infrastructures 2018

- *BBMRI.fi* comprises an actively collaborating network of the Finnish bio-banks and **as such represents one of the largest bio-banks available in the world.**
- The **unique strength** of the Finnish sample collections lies in the sample-associated **data**. This puts *BBMRI.fi* in a strong position internationally
- As a **role model for collaborative work** it has influenced the efforts by the Finnish government to harmonize health care infrastructure.
- **Finland has an amazing synergy** between high level governmental strategies and local university strategies in the life and health sciences.



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.
- We want to make sure that everyone has an **equal opportunity to benefit from the use of genomic data.**

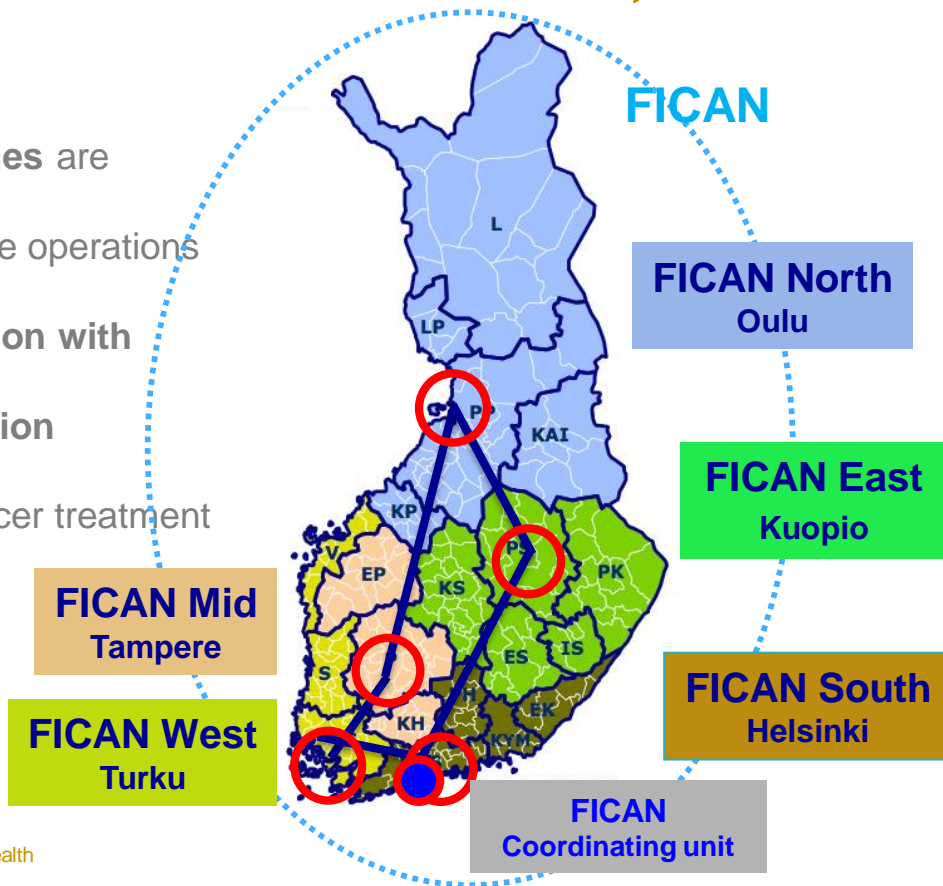




CLUSTER OF EXCELLENCE – FINNISH CANCER CENTER, FICAN

- 20 Hospital districts and 5 medical universities are establishing Finnish Cancer Center, FICAN
- Five regional cancer centers are in charge of the operations coordinated by 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 cancer treatment also in future Finland
- Fully operating in 2019 (KickOff 22nd of Oct 2019).

Finland – one of the best cancer patients survival rates; Lancet Oncology, 2007, and 2014.



The public authorities shall guarantee for everyone adequate social, health and medical services and promote the health of the population.

The Constitution of Finland (731/99), 19 §

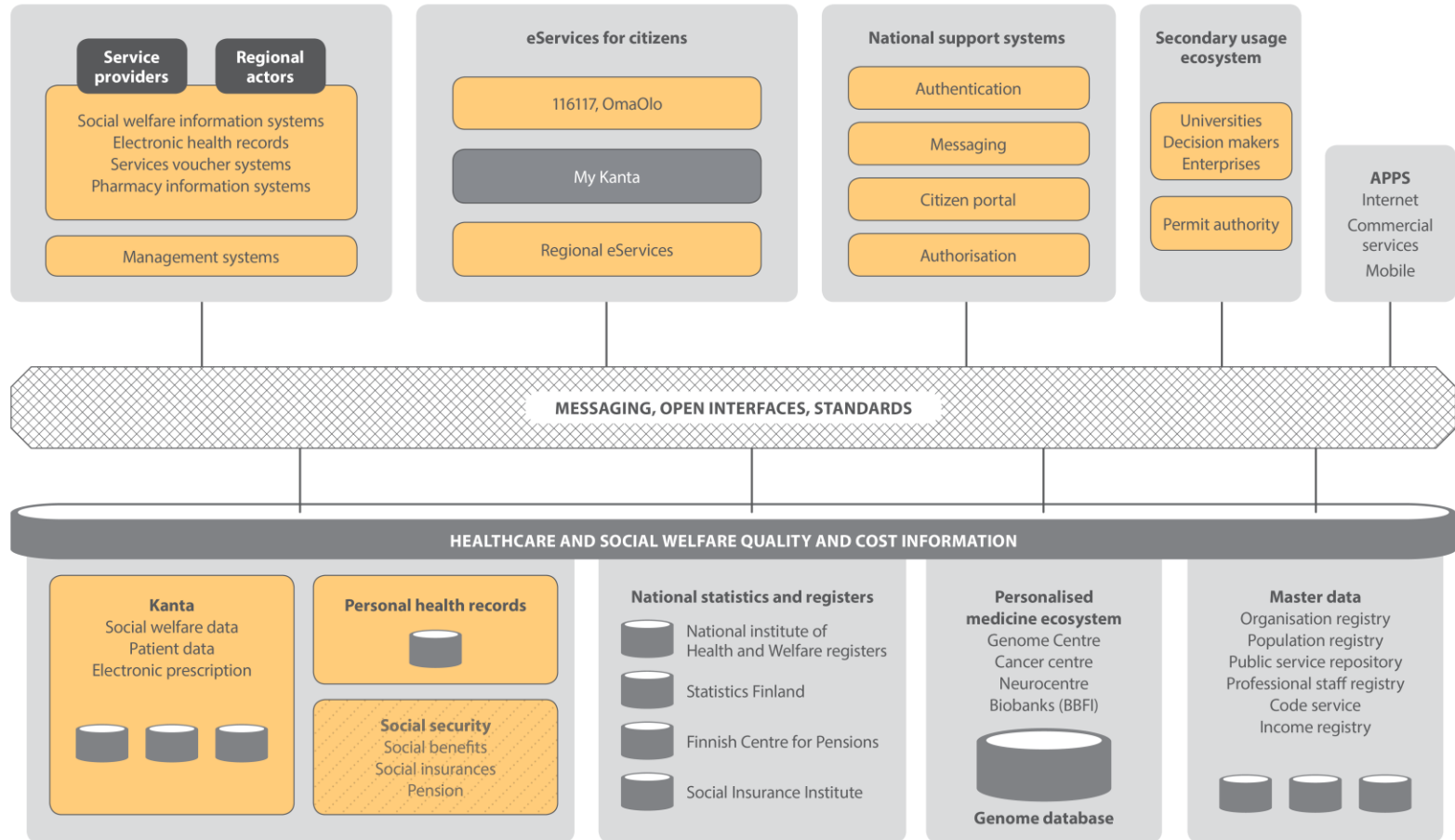


IT ALL DEPENDS ON DATA – AND WHAT ELSE?

1.10.2019

Ministry of Social Affairs and Health - Tuula Helander

National information systems architecture for healthcare and social welfare



A woman wearing a cycling helmet and a black and white jersey is sitting on a bicycle in a field of tall grass. She is looking off to the side with her hand near her chin. The background is a soft-focus field of tall grass.

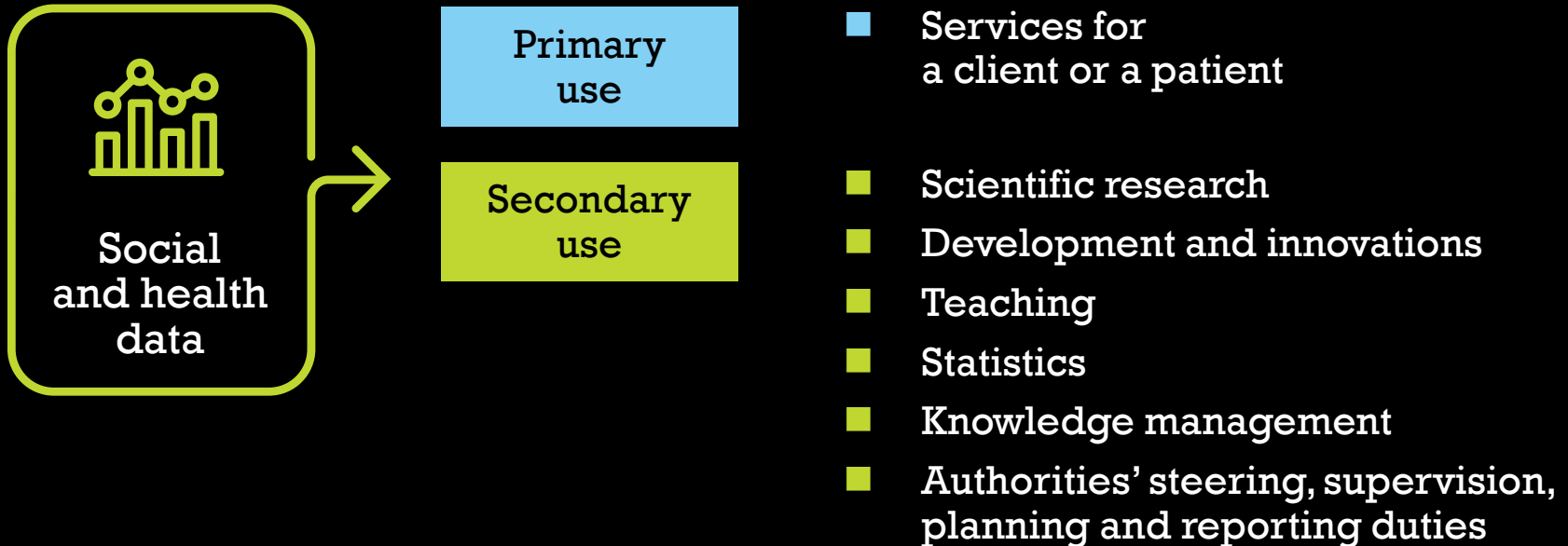
FINDATA

HEALTH & WELFARE

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

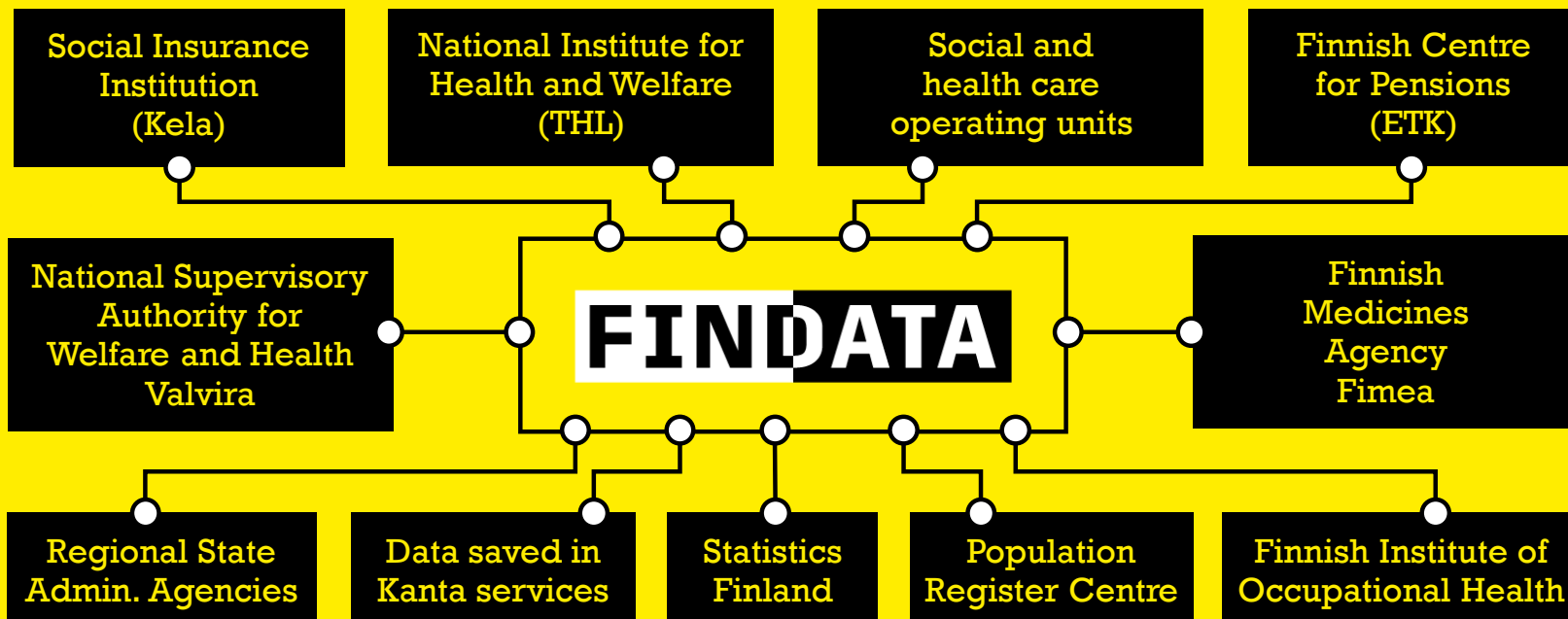
Social and Health
Data Permit Authority

Findata is a one-stop shop for the secondary use of social and health data



FINDATA

The following controllers will provide access to data specified in the Act through Findata





TO WHOM ARE WE ACCOUNTABLE?

Health ecosystem players in Finland

Data analytics

Bio, pharma and medical technology

Prevention

Test beds and accelerators

Biobanks and research platforms

- Finnish Genome Center
- Cancer Center Finland (FICAN)
- Neuro Center Finland
- Finnish Biobank (FINBB)
- Suomen Terveystalo Biobank
- Red Cross Biobank
- NIH Biobank



"Technology enablers"

Multomics and research

Health services

Diagnostics and imaging

Remote solutions

Education and research

National strategies, legislation & political guidelines

Finngen ecosystem for personalised medicine

BIOBANKS

UNIVERSITIES

HEALTHCARE
INDUSTRY

HOSPITALS

500 000 samples

10 % of the
population
genotyped

HOSPITAL
DISTRICTS

THE FINNISH
FUNDING AGENCY
FOR INNOVATION

FINNISH
CITIZENS

abbvie

AstraZeneca

NEGEN
PRECISION HEALTH

Blueprint Genetics

BCB
medical

PHARMA-
CEUTICAL
COMPANIES

MSD

Genentech
A Member of the Roche Group

BC Platforms

Terveystalo

woble
HELSINKI

ORION

Pfizer

Biogen

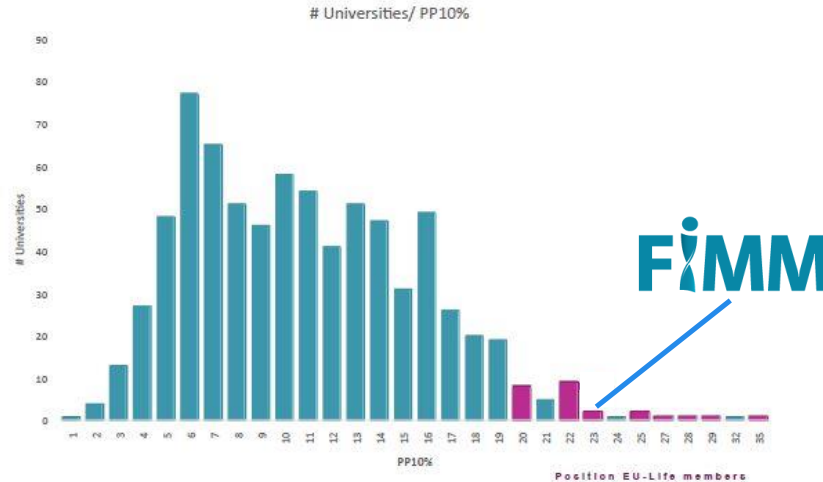
Celgene



How we traditionally keep score



LEIDEN RANKING (BIOMED & HEALTH)



Courtesy of
FIMM Director
Dr. Mark Daly

Great – but is this really how we should be evaluated?



- 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 will be presented in Brussels during the Finnish EU Presidency event on “*Genomics and Personalized Medicine in Public Health*” 10th October 2019.
- Take home message: Integrating genomics into healthcare is a joint venture of different sectors and stakeholders, authorities, researchers, companies and citizens.

20 1.10.2019

Regulating the unknown

A guide to regulating genomics
for health policy-makers

DRAFT



WHAT MAKES A SUCCESSFUL ECOSYSTEM?

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

- Well educated citizens eager to test innovations and participate in research.
- Dynamic network of authorities, health service providers, academia and companies.
- Especially active start-up community.
- Legislation and ethical principles => established procedures and an open, innovative environment for public-private cooperation.
- Professional excellence (medical, legal, ICT).
- Trust.



Secondary use of data will benefit the entire society



ENABLING LEGISLATION

Public health

National economy

Social and health service clients, citizens

Authorities steering social and health service activities

Social and health sector management

Social and health sector service providers

Social and health care professionals

ICT companies

Startups

Research institutes and universities

Pharmaceutical companies

Development organisations



Fair Data Ecosystem and Platform Principles: Beyond the Finnish Experience

- *”Europe must lead the transition to a healthy planet and a new digital world... Action plan to complement European Pillar of Social Rights”*
Political Guidelines for the Next European Commission 2019-2024
- EU legislation and policy on data, data protection and platforms have a wide impact on digitalisation including the digitalisation in the health care and realisation of service integration
- Context-sensitive union law (incl. data protection law) and coherent EU approach across the sectors. Convergence of the medical tech with general purpose technologies is significant.
- **Tuomas Pöysti:** Trust on Digital Administration and Platforms in Peter Wahlgren (ed): 50 years of Law and IT, The Swedish Law and Informatics Research Institute 1968-2018. Scandinavian Studies in Law, Vol. 65 (2018), 321-363.

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



DATA-DRIVEN INNOVATIONS ARE MOONSHOTS OF THE 2020´S

- *significant health problems*
- *radical solutions*
- *breakthrough technologies*

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