Imagine 2029: Our data, our health, our care – 20th anniversary of EHTEL

EHTEL 2019 Symposium

Kindly hosted by
TIC Salut Social
Technology, innovation and digital transformation.

13:30 – 14:45 [S9]

Aula 1
First Floor

Sharing in an AI-Friendly Environment: Data Donation and more

As addressed by initiatives of the Finnish EU-Presidency and the European Commission, secondary data use and data donation may contribute to an AI-friendly European Health Data Space.

Session Chair: Josuè Sallent, Director, Tic Salut Social Foundation, Barcelona, Spain

Ethics of Data Sharing and AI
Itziar de Lecuona, Bioethics & Law Observatory, UNESCO Chair Bioethics, Barcelona, Spain

Finland Legislation on Secondary Data Use
Joni Komulainen, Ministry for Social Affairs and Health, Helsinki, Finland

Salut Coop - Citizen Cooperative of Health Data
Joan Guanyabens, Salut Coop, Barcelona, Spain

Q&A and Conclusions by the Session Chair

Symposium Gold Sponsor SITRA

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#EHTEL_Symposium #EHTEL_BCN @ehtel_eHealth

Save the date!

Kindly hosted by TIC Salut Social

Imagine 2029: Our data, our health, our care – 20th Anniversary of EHTEL

EHTEL 2019 Symposium

3-4 December 2019 in Barcelona, Spain

Ethics of Data Sharing and Artificial Intelligence

Itziar de Lecuona, PhD

Associate Professor, Dept. of Medicine

Bioethics and Law Observatory

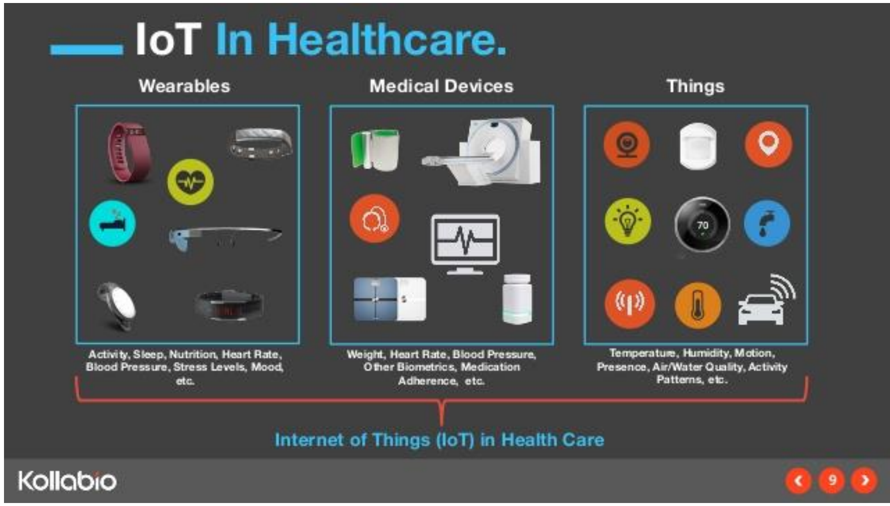
UNESCO Chair in Bioethics

University of Barcelona

UNIVERSITAT DE BARCELONA

Observatori de Bioètica i Dret
Universitat de Barcelona

Data driven society
The convergence of technologies
Big Data & Artificial Intelligence


IoT In Healthcare.

Wearables

Activity, Sleep, Nutrition, Heart Rate, Blood Pressure, Stress Levels, Mood, etc.

Medical Devices

Weight, Heart Rate, Blood Pressure, Other Biometrics, Medication Adherence, etc.

Things

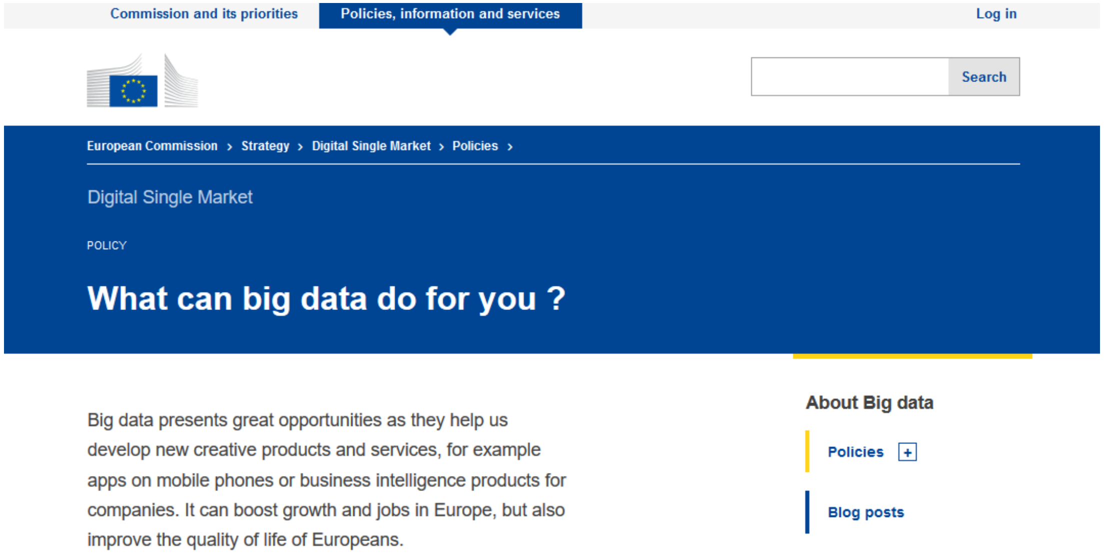
Temperature, Humidity, Motion, Presence, Air/Water Quality, Activity Patterns, etc.

Internet of Things (IoT) in Health Care

Kollabio

Ethics of Data Sharing in AI
To reflect on:

- The ethics of automated decision making
- The justice of algorithms and fairness of data gathered
- The responsability of all actors involved
- The quality of datasets and personal data
- The price and **value of personal data**
  - Personal interest and gain vs. Common good
- Autonomy and informed consent
  - opt in vs. opt out systems for data treatments



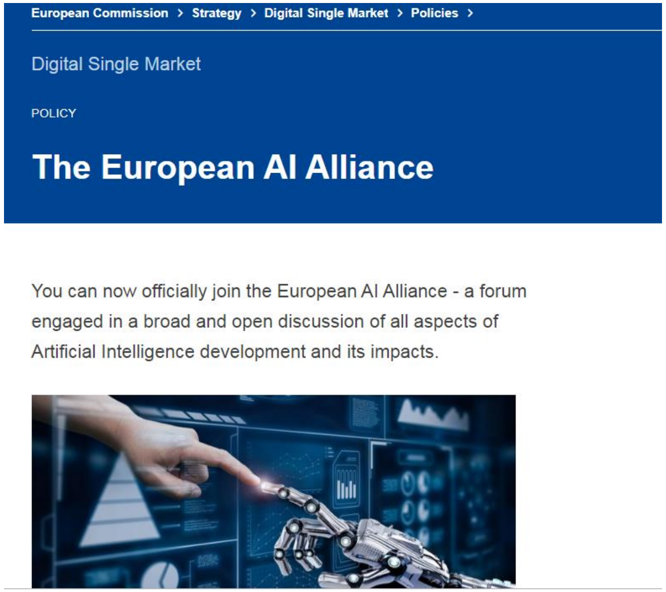
Digital Single Market

POLICY

What can big data do for you ?

Big data presents great opportunities as they help us develop new creative products and services, for example apps on mobile phones or business intelligence products for companies. It can boost growth and jobs in Europe, but also improve the quality of life of Europeans.

About Big data



Digital Single Market

POLICY

The European AI Alliance

You can now officially join the European AI Alliance - a forum engaged in a broad and open discussion of all aspects of Artificial Intelligence development and its impacts.

We are in a hurry
we are ten years late ...

- M. Vestager will have 100 days to draw up a strategy for the development of **artificial intelligence**, **which should also provide for the use of big data in innovations**

El País, “Europa ultima un plan para dar la batalla de los datos”, domingo, 24 de noviembre de 2019.
https://elpais.com/economia/2019/11/16/actualidad/1573926886_318836.html

Ethics of Data Sharing and AI

- Ethics is about happiness;
- Freedom;
- Free development of personality;
- Equality;
- Non discrimination (algorithmic discrimination)

- Society must set the limits
- Facts; values; principles; norms and procedures

- Ethics; politics and regulation
- Understanding the paradigm shift: we are not anonymous anymore

- Assure that data sharing to develop AI Systems is alligned with societal expectations

Healthcare: enhancing diagnosis and treatment while preserving privacy

Big data offers solutions for improved efficiency in healthcare information processing which in turn creates value for businesses, public sector and citizens. The analysis of large clinical datasets can result in the optimisation of the clinical and cost effectiveness of new drugs and treatments and patients can benefit from more timely and appropriate care. Data interoperability is of utmost importance since the data is derived from diverse and heterogeneous sources such as bio-signal streams, health records, genomics and clinical lab tests. Privacy-preserving technologies aim at providing access to health data for patients, healthcare professionals and clinical researchers in a uniform way and in an anonymized and aggregated form to develop better prevention or treatment options.

Projects:

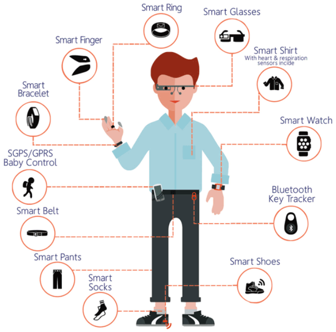
- Clinical decision support and integrated care: AEGLE
- Anonymisation and blockchain technology solution for healthcare: My

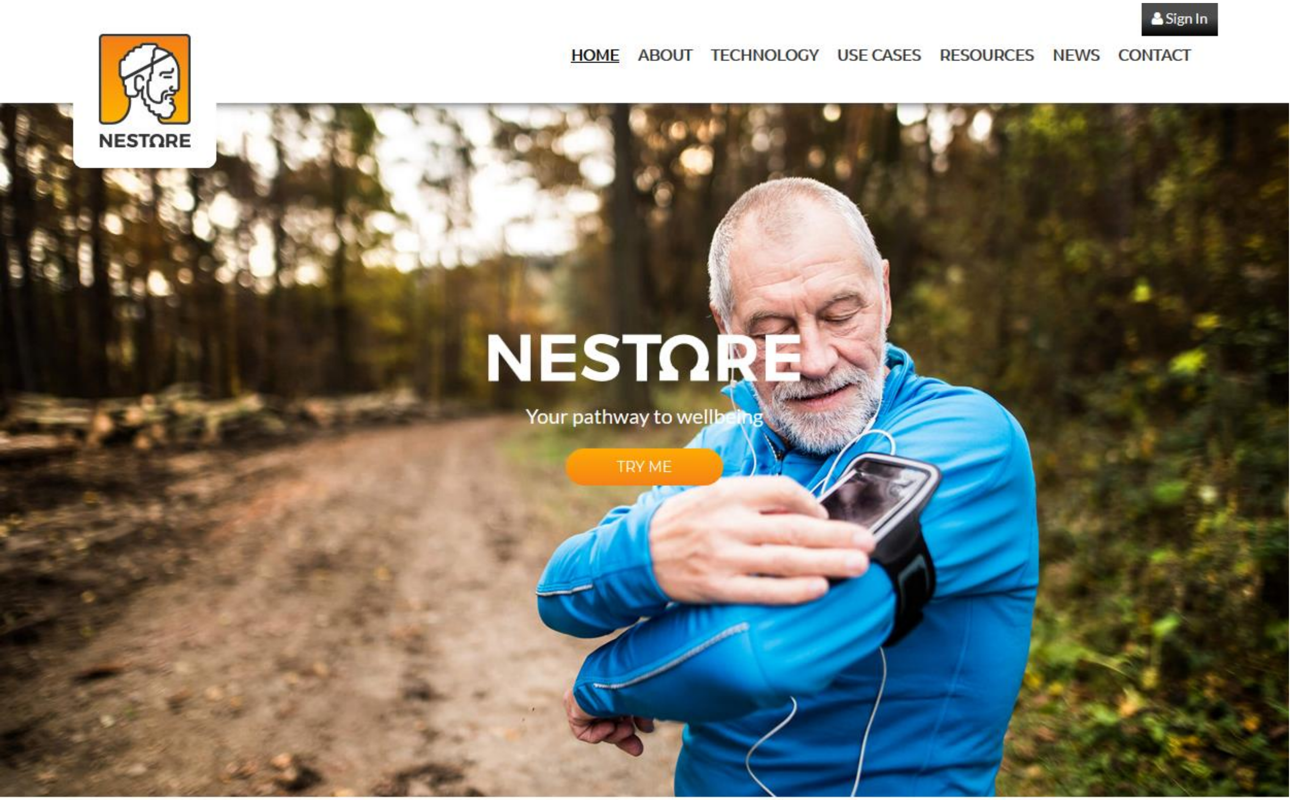
Data Markets

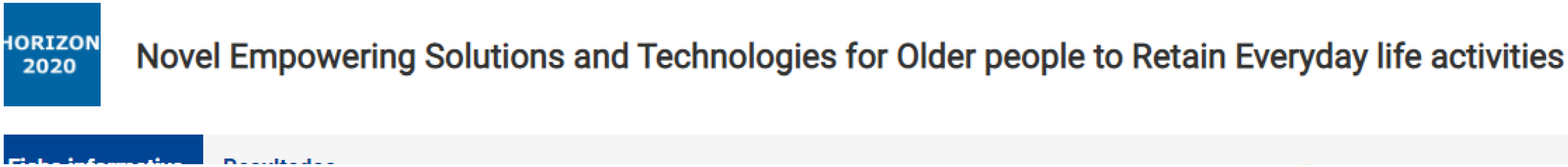
Information technology has driven, directly or indirectly, much of Europe's economic growth during the last decades as the role of data transitioned from the support of business decisions to becoming a good in itself. An open approach towards data value creation has become critical in the new networked economy, with Europe well placed to nurture this new revolution.

Projects:

- Automotive Big Data Marketplace for Innovative Cross-sectorial Vehicle Data Services: AutoMat







Novel Empowering Solutions and Technologies for Older people to Retain Everyday life activities

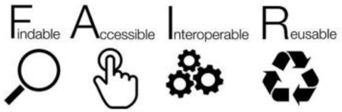
We must be concerned about the value of privacy

- We cannot remain indifferent to the use of our data
- We are important for the public & private
- Personal data feed business initiatives and models in
    - personalized medicine, ageing & wellbeing , and for developing more efficient healthcare systems.

- Turning our backs on the power of properly managed data would be detrimental. We would deprive ourselves of advantages for our health, quality of life and for the coming generations.

Responsable Research and Innovation (RRI) : transversal agendaS of the European Union

- **Ethics**
  - Research Ethics Committes reviewing **research and innovation** processes
  - Ethics label of AI, standardization and certification Systems to make AI trustworthy
- **Public engagement**
  - Empowering citizens and societies; integrate their needs and expectations
  - From anonymisation to seudononymisation
- **Open access**
  - Transparency and accountability
  - FAIR principles: Findable, Accessible, Interoperable, Reusable



- **Scientific education**
  - Digital literacy in the digital society; education, training
- **Gender equality**
  - Algorithmic discrimination perpetuate gender or racial biases

It is all about data (& personal data) the main asset

- Biomedicine and biotechnology
- Research should be reviewed by independent and interdisciplinary research ethics committees
- Lack of guidelines and procedures to properly review Big Data & AI research projects
- It is useless to use old solutions to new challeges posed by the convergence of tecnologies
    - Anomysation as a guarantee is not applicable

intel®

Personal data

- What is personal data today?
- **Special categories of data: Health related; genetic data, biometric data, etc.**
  - name, address, identification number, pseudonym, occupation, e-mail, CV, location data, Internet Protocol (IP) address, cookie ID, phone number, data provided by smart meters, data held by a hospital or doctor.
  - **Pseudonymisation: assuring non attribution**

L. Sweeney, Simple Demographics Often Identify People Uniquely. Carnegie Mellon University, Data Privacy Working Paper 3. Pittsburgh 2000.

Simple Demographics Often Identify People Uniquely

Processing of personal data:

- **‘pseudonymisation’ means the processing of personal data in such a manner that the personal data can no longer be attributed to a specific data subject without the use of additional information**, provided that such additional information is kept separately and is subject **to technical and organisational measures to ensure that the personal data are not attributed to an identified or identifiable natural person;**

To reflect on:

- The value of personal data in the digital society
  - We should take care of our data to protect ourselves and the coming generations
  - Avoiding data markets disguised as research

- Informed consent is not enough
- Transparency and accountability
  - Commodification of privacy vs. Common good
  - Creation of value instead of extraction of value
  - Tech companies and the role of governments

Newsroom

New Guidelines on Artificial Intelligence and Data Protection

STRASBOURG | 30/01/2019

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www.coe.int/AI

Towards an ethical and responsible AI
for human rights, rule of law and democracy

Follow: **#CoE4AI**

Guidelines on the protection of individuals with regard to the processing of personal data in a world of Big Data

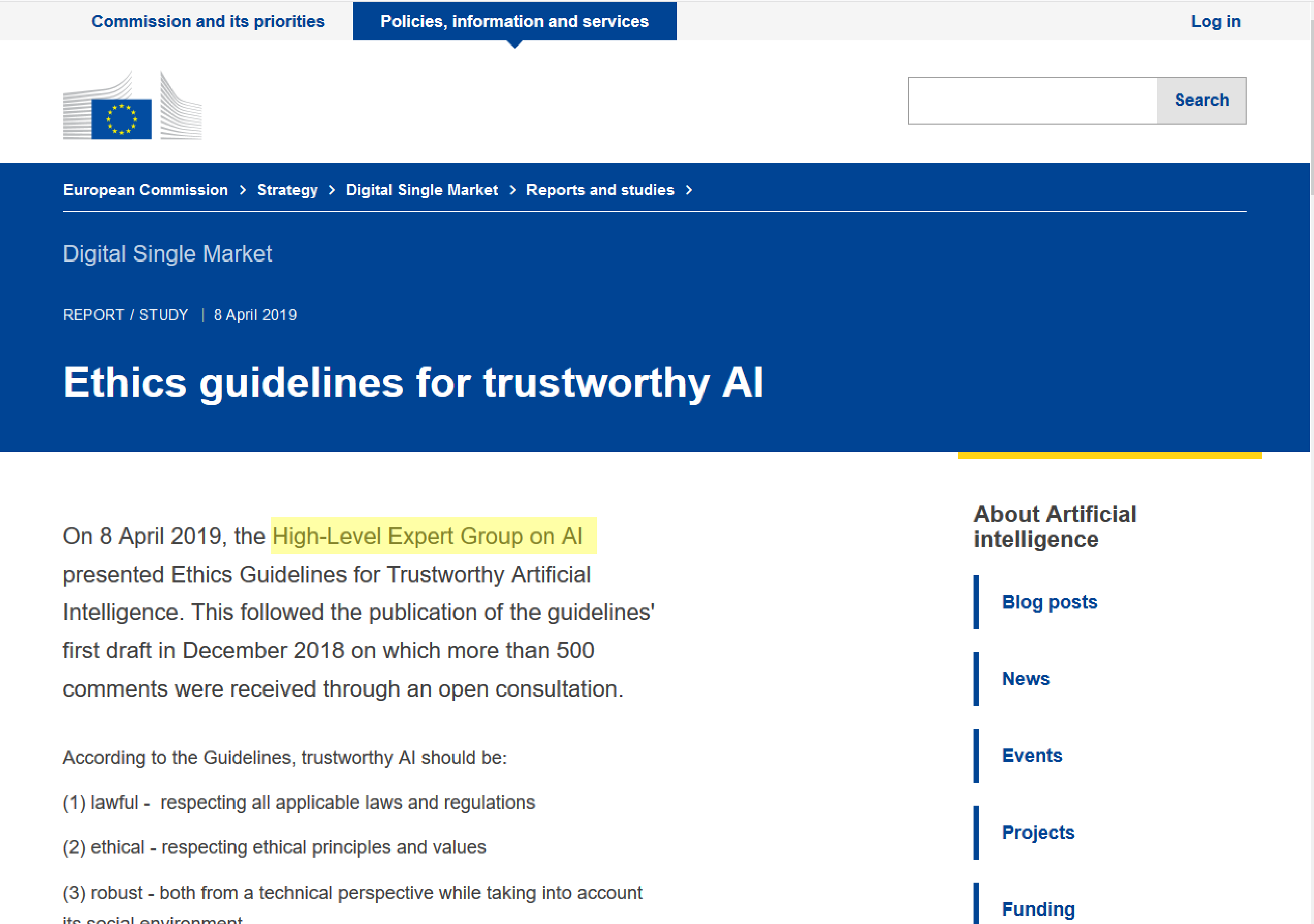
www.coe.int/data-protection

The **High-level Expert Group** on **Artificial Intelligence** will:

- Advise on AI-related challenges & opportunities
- Propose draft AI ethics guidelines
- Engage with members of the European AI Alliance

#AI

European Commission



REPORT / STUDY | 8 April 2019

Ethics guidelines for trustworthy AI

On 8 April 2019, the High-Level Expert Group on AI presented Ethics Guidelines for Trustworthy Artificial Intelligence. This followed the publication of the guidelines' first draft in December 2018 on which more than 500 comments were received through an open consultation.

According to the Guidelines, trustworthy AI should be:

(1) lawful - respecting all applicable laws and regulations

(2) ethical - respecting ethical principles and values

(3) robust - both from a technical perspective while taking into account its social environment

Guidelines for Trustworthy AI

Key Guidance for Ensuring Ethical Purpose

- Ensure that AI is **human-centric**
- Grounded in and reflective of **fundamental rights** and **societal values**
- **Principles of:**
  - **Beneficence and Non Maleficence**
  - **Autonomy of humans**
  - **Justice**
  - **Explicability**

Key Guidance for Ensuring Ethical Purpose

- **Evaluate possible effects of AI on human beings and the common good**
- **Pay particular attention to situations:**
  - **involving more vulnerable**
    - children, persons with disabilities or minorities
  - **with asymmetries of power or information**
    - i.e. between employers and employees, or businesses and consumers
- **Remain vigilant for areas of critical concern**

Key Guidance
for realising Trustworthy AI

- **Incorporate the requirements for Trustworthy AI from the earliest design phase:**
- Accountability,
- Data Governance,
- Design for all,
- Governance of AI Autonomy (Human oversight),
- Non-Discrimination,
- Respect for Human Autonomy,
- Respect for Privacy,
- Robustness,
- Safety,
- Transparency

Key Guidance for Assessing Trustworthy AI

- **Adopt an assessment list for Trustworthy AI when developing, deploying or using AI,**
- **and adapt it to the specific use case in which the system is being used**

- **ensuring Trustworthy AI <u>is not about ticking boxes</u>**
- **but about a continuous process of identifying requirements, evaluating solutions and ensuring improved outcomes**
  - **throughout <u>the entire lifecycle of the AI system</u>**

- **To enable Europe to become a globally leading innovator in ethical, secure and cutting-edge AI**
- **enhance the well-being of European citizens**

Assessment list example: 2. Data governance:

- Is proper governance of data and process ensured?
- What process and procedures were followed to ensure proper data governance?
- **Is an oversight mechanism put in place?**
- **Who is ultimately responsible?**
- What data governance regulation and legislation are applicable to the AI system?
- https://ec.europa.eu/digital-single-market/en/news/draft-ethics-guidelines-trustworthy-ai

GDPR

The General Data Protection Regulation

DALLASVICKY - dallas@9amlabs.com

- **Data Portability**
- **Right to be forgotten**
- **Right to object and automated individual decision-making**

- **Data Protection Impact Assessment**
- **Data Protection Officer**

- **‘profiling’ means any form of automated processing of personal** data consisting of the use of personal data to evaluate certain personal aspects relating to a natural person,
- in particular **to analyse or predict aspects concerning that natural person's performance at work, economic situation, health, personal preferences, interests, reliability, behaviour, location or movements**;

Principles relating to processing of personal data

- **Lawfulness, fairness and transparency in relation to the data subject**
- **Collected for specified, explicit and legitimate purposes** and not further processed in a manner that is incompatible with those purposes
- **Data minimization:** adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed
- **Accuracy:** accurate and, where necessary, kept up to date; every reasonable step must be taken to ensure that personal data that are inaccurate, having regard to the purposes for which they are processed, are erased or rectified without delay
- **storage limitation:** kept in a form which permits identification of data subjects for no longer than is necessary for the purposes for which the personal data are processed
- **Integrity and confidentiality:** processed in a manner that ensures appropriate security of the personal data, including protection against unauthorised or unlawful processing and against accidental loss, destruction or damage, using appropriate technical or organisational measures

- (article 5.1 GDPR)

- **Directive (EU) 2019/1024 of the European Parliament and of the Council of 20 June 2019 on open data and the re-use of public sector information**
- “Public sector information represents an extraordinary source of data that can contribute to improving the internal market and to the development of new applications for consumers and legal entities. **Intelligent data usage, including their processing through artificial intelligence** applications, can have a transformative effect on all sectors of the economy”

Value creation vs. Value extraction and societal impact

- **Rethink the governance of data and develop new institutions**
- **new vocabulary**
  - “For example, calling platform companies ‘**tech giants**’ implies they have invested in the technologies from which they are profiting, when it was really taxpayers who funded the key underlying technologies—from the internet to the Global Positioning System”
- **Co-creation vs. Regulation**
  - “Governments can and should be shaping markets to ensure that collectively created value serves collective ends”
- **Avoiding the extraction of value or abuse of individual rights**
- **Creating an environment that rewards genuine value creation and punishes value extraction**

MAZZUCATO, M., “Preventing digital feudalism”, Social Europe, 9th October 2019 https://www.socialeurope.eu/author/mariana-mazzucato. Professor in the Economics of Innovation and Public Value at University College London (UCL), and Founder/Director of UCL's Institute for Innovation and Public Purpose

“Tech companies” use and abuse?

- "Many companies have outsourced [the management, storage and processing of] their data to US companies,”Angela Merkel warned this week to dozens of entrepreneurs in direct reference to the dependency on Amazon, Google or Microsoft. “I am not saying that it is bad, I just want to say that the value-added products that come from there, with the help of artificial intelligence, will create dependencies that I am not sure will be good”

El País, “Europa ultima un plan para dar la batalla de los datos”, domingo, 24 de noviembre de 2019.
https://elpais.com/economia/2019/11/16/actualidad/1573926886_318836.html

Autonomy and informed consent

- Opt out systems
- Transparency and accountability
- Digital literacy
- Ethics training to avoid algorithmic discrimination

- Propportionate goals
- Set the priorities in the healthcare (RRI)

- Common good Vs. Personal interest
- Avoiding data markets disguised as research

UNIVERSITAT DE BARCELONA

Observatori de Bioètica i Dret
Universitat de Barcelona

Thank you!

Itziardelecuona@ub.edu

www.bioeticayderecho.ub.edu

As citizens we must be concerned about the value of privacy

- We cannot remain indifferent to the use of our data,
- We are important for the public authorities, private companies
- Personal data feed business initiatives and models in personalized medicine, ageing, and for developing more efficient healthcare systems.

- Turning our backs on the power of properly managed data would be detrimental. We would deprive ourselves of advantages for our health, quality of life and for the coming generations.

MINISTRY OF SOCIAL AFFAIRS AND HEALTH

6.12.2019

Joni Komulainen
Ministrial adviser
Master of Laws

MINISTRY OF SOCIAL AFFAIRS AND HEALTH

FINLAND LEGISLATION ON SECONDARY DATA USE

How to securely fully utilize the health and social data for research, statistics, development and innovation activities, education and knowledge management duties and steering and supervision of social and health care by authorities and planning and reporting duty of an authority

WORLD’S BEST DATABANKS

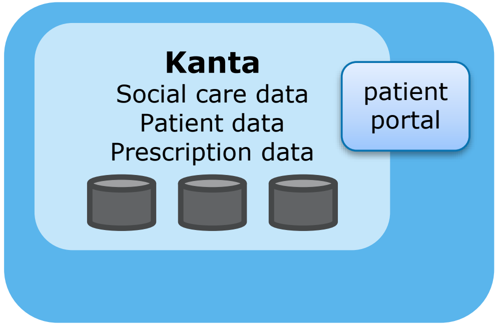
Health and social data is stored in various national and local databanks

- There is a large variety of different kind of patient record, well-being, social wellness and other data available
- The data has been collected for a long time. Time series are continual
- The quality of data is high
- Unique national person ID-number makes it possible to combine personnel records

UNIQUE NATIONAL PERSON ID-NUMBER

- Remains unchanged throughout life
- Given to Finnish citizens by birth and to foreign citizens moving to Finland once they have been registered in the Population Information System
- Used in identifying a person in various registers by various register controllers
- A key to accessing and linking personal information from various registers

EXAMPLES OF DATABANKS – UNIQUE NATIONAL KANTA SERVICES



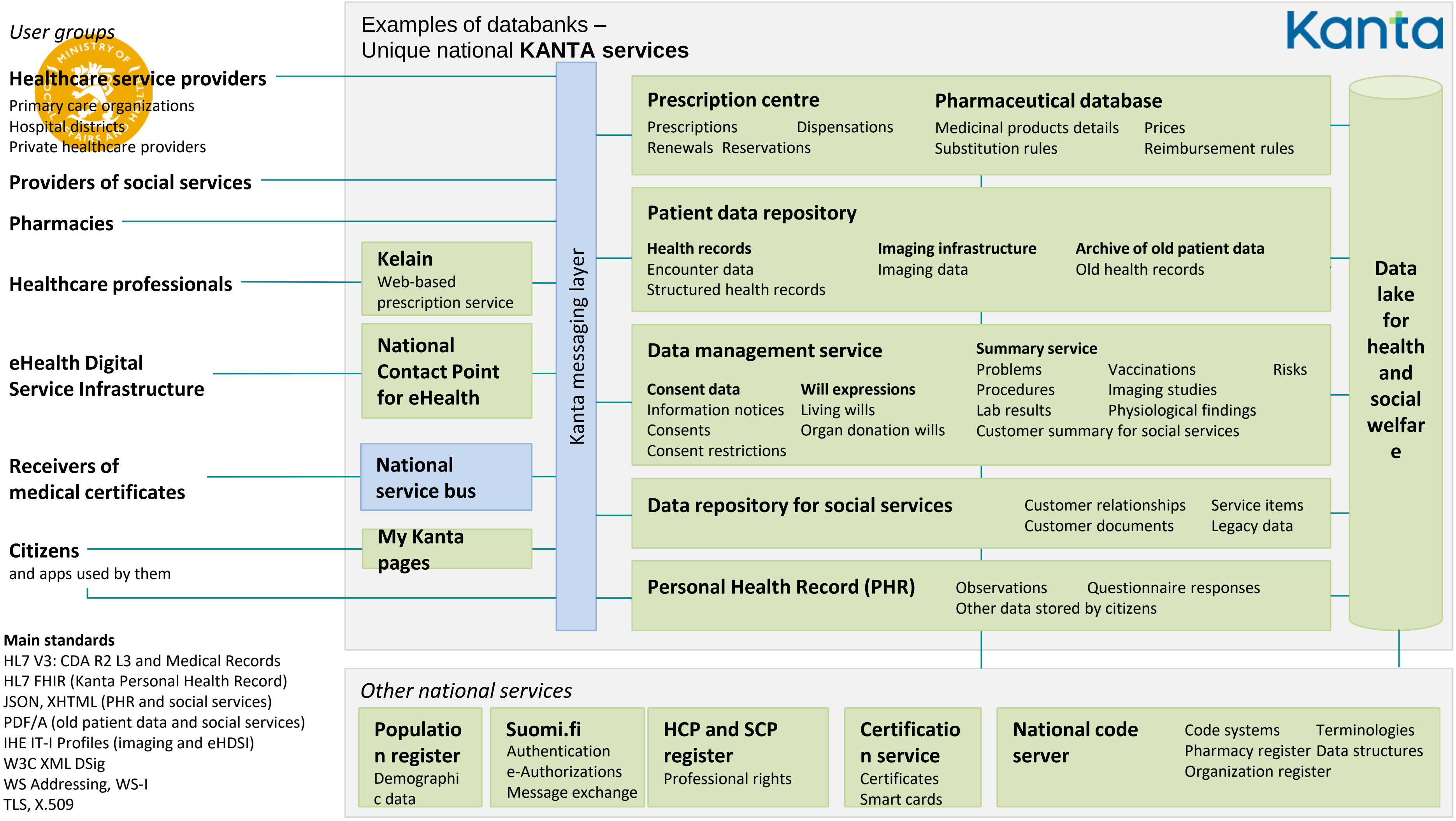
Kanta
Social care data
Patient data
Prescription data

patient portal

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

Patient, social care and prescription data gathered in a national databank

- Healthcare professionals can access the needed data nationwide, store patient records and make prescriptions.
- Citizens can browse own medical records and prescriptions and order repeat prescriptions in the online service.



User groups

Healthcare service providers
Primary care organizations
Hospital districts
Private healthcare providers

Providers of social services

Pharmacies

Healthcare professionals

eHealth Digital Service Infrastructure

Receivers of medical certificates

Citizens
and apps used by them

Main standards
HL7 V3: CDA R2 L3 and Medical Records
HL7 FHIR (Kanta Personal Health Record)
JSON, XHTML (PHR and social services)
PDF/A (old patient data and social services)
IHE IT-I Profiles (imaging and eHDSI)
W3C XML DSig
WS Addressing, WS-I
TLS, X.509

Examples of databanks – Unique national **KANTA services**

Kanta

Kelain
Web-based prescription service

National Contact Point for eHealth

National service bus

My Kanta pages

Kanta messaging layer

Prescription centre
Prescriptions
Dispensations
Renewals
Reservations

Pharmaceutical database
Medicinal products details
Prices
Substitution rules
Reimbursement rules

Patient data repository

Health records
Encounter data
Structured health records

Imaging infrastructure
Imaging data

Archive of old patient data
Old health records

Data management service

Consent data
Information notices
Consents
Consent restrictions

Will expressions
Living wills
Organ donation wills

Summary service
Problems
Vaccinations
Risks
Procedures
Imaging studies
Lab results
Physiological findings
Customer summary for social services

Data repository for social services
Customer relationships
Service items
Customer documents
Legacy data

Personal Health Record (PHR)
Observations
Questionnaire responses
Other data stored by citizens

Data lake for health and social welfare

Other national services

Population register
Demographic data

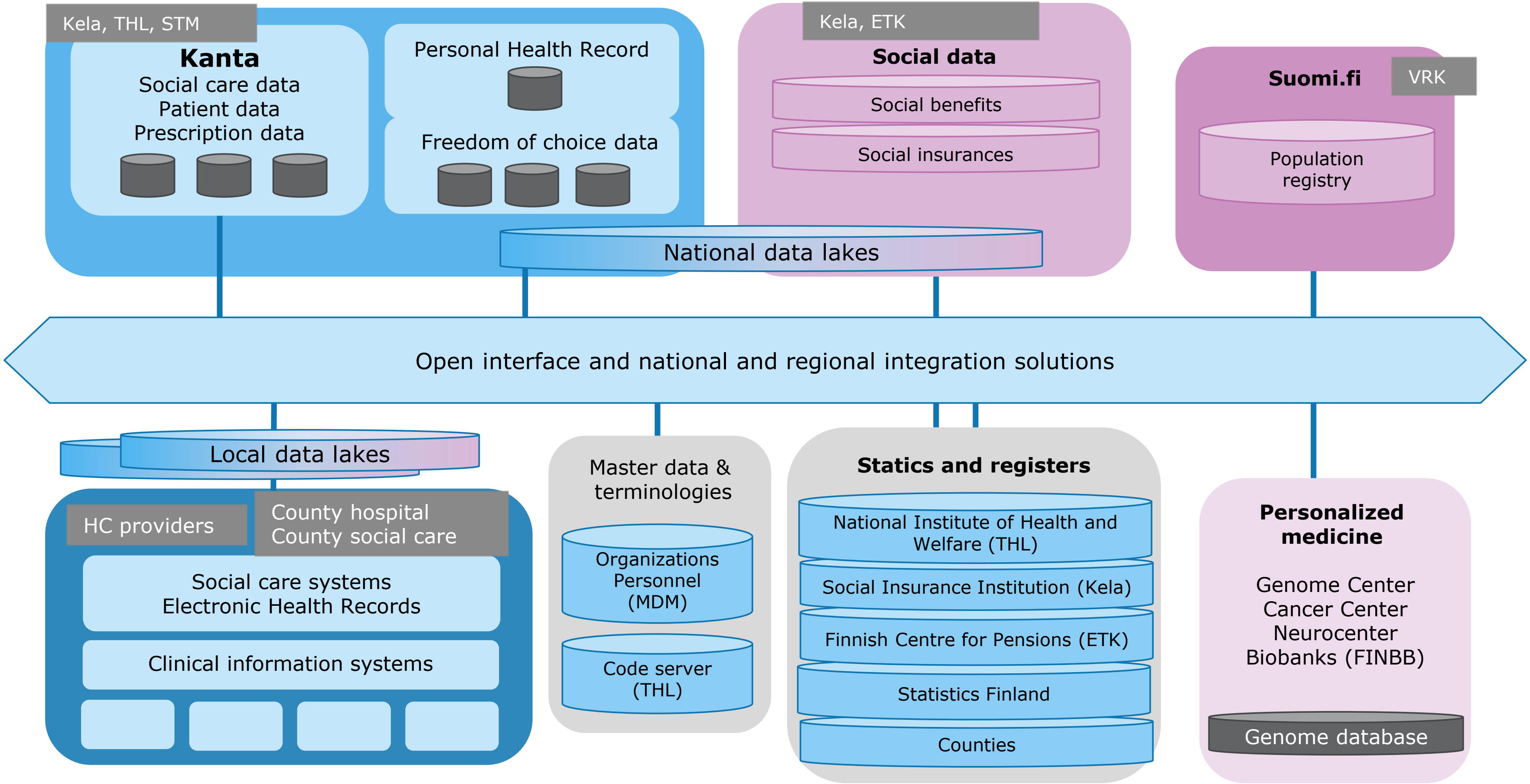
Suomi.fi
Authentication
e-Authorizations
Message exchange

HCP and SCP register
Professional rights

Certification service
Certificates
Smart cards

National code server
Code systems
Terminologies
Pharmacy register
Data structures
Organization register

EXAMPLES OF DATABANKS – IN ADDITION TO KANTA THERE IS A LOT MORE



Kela, THL, STM

Kanta
Social care data
Patient data
Prescription data

Personal Health Record

Freedom of choice data

Kela, ETK

Social data

Social benefits

Social insurances

Suomi.fi

VRK

Population registry

National data lakes

Open interface and national and regional integration solutions

Local data lakes

HC providers

County hospital
County social care

Social care systems
Electronic Health Records

Clinical information systems

Master data & terminologies

Organizations
Personnel
(MDM)

Code server
(THL)

Statics and registers

National Institute of Health and Welfare (THL)

Social Insurance Institution (Kela)

Finnish Centre for Pensions (ETK)

Statistics Finland

Counties

Personalized medicine

Genome Center
Cancer Center
Neurocenter
Biobanks (FINBB)

Genome database

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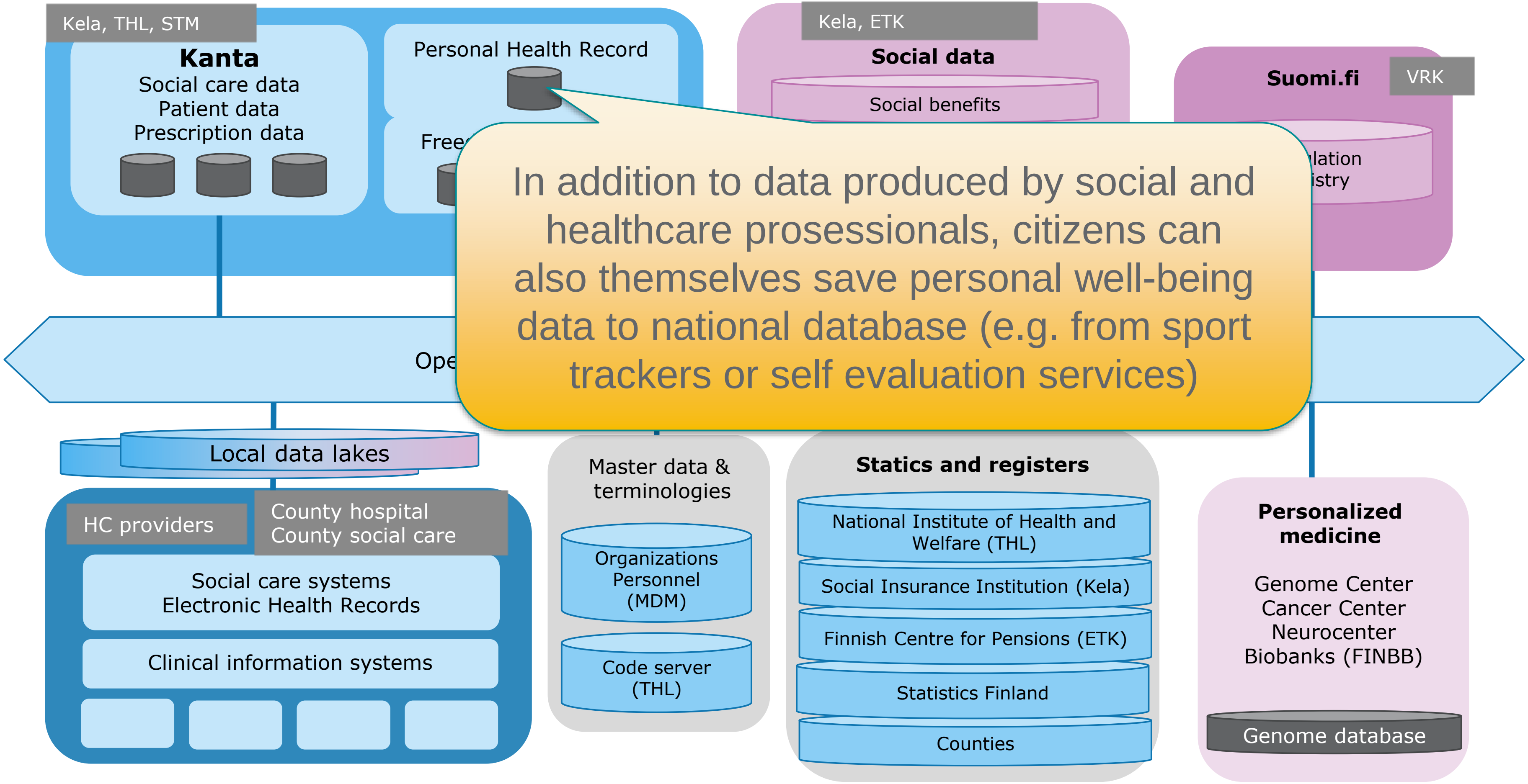
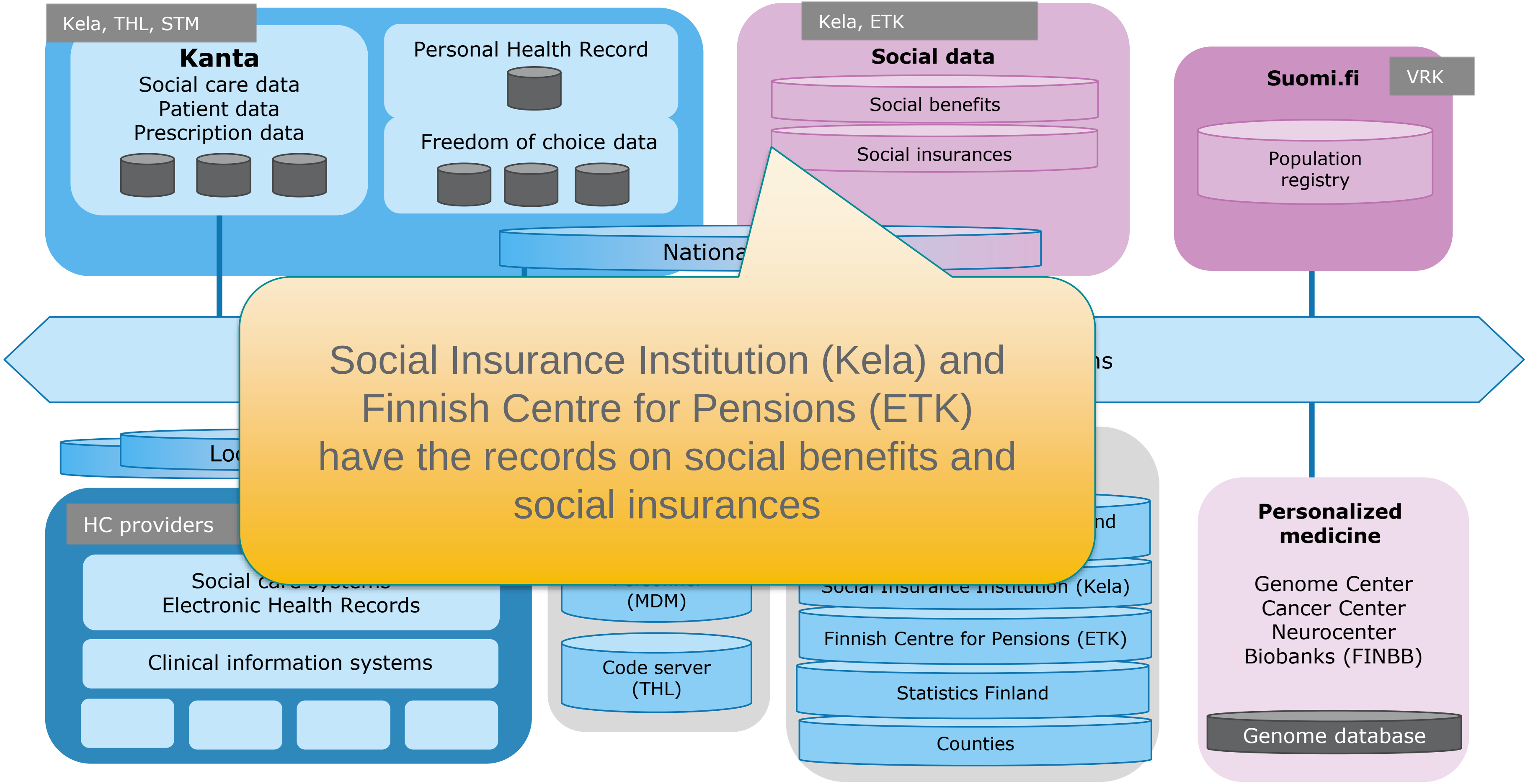


In addition to data produced by social and healthcare prosessionals, citizens can also themselves save personal well-being data to national database (e.g. from sport trackers or self evaluation services)

EXAMPLES OF DATABANKS – IN ADDITION TO KANTA THERE IS A LOT MORE



Kela, THL, STM

Kanta
Social care data
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Prescription data

Personal Health Record

Freedom of choice data

Nationa

Kela, ETK

Social data

Social benefits

Social insurances

Suomi.fi

VRK

Population registry

Social Insurance Institution (Kela) and Finnish Centre for Pensions (ETK) have the records on social benefits and social insurances

ns

Loc

HC providers

Social care systems
Electronic Health Records

Clinical information systems

(MDM)

Code server (THL)

nd

Social Insurance Institution (Kela)

Finnish Centre for Pensions (ETK)

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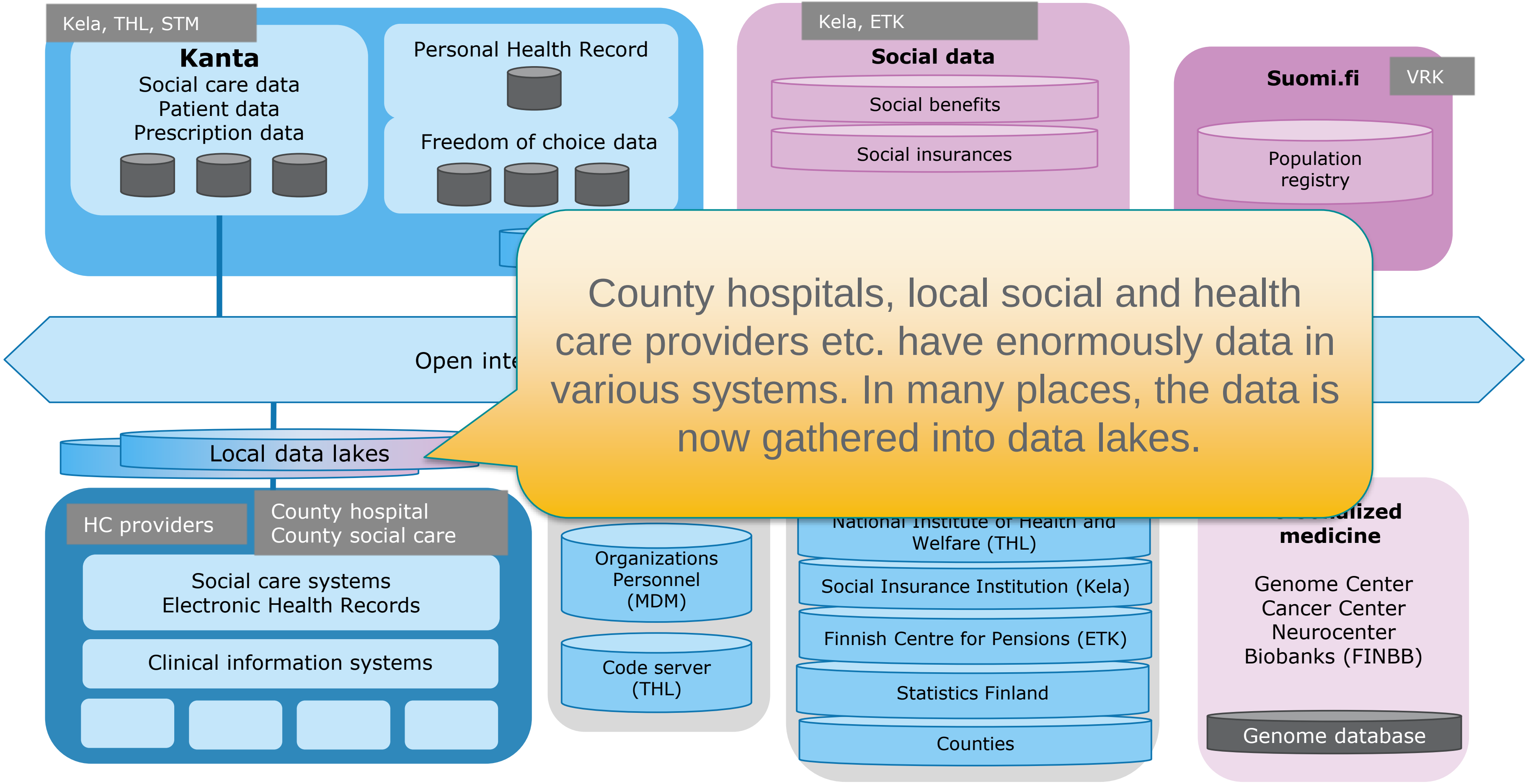

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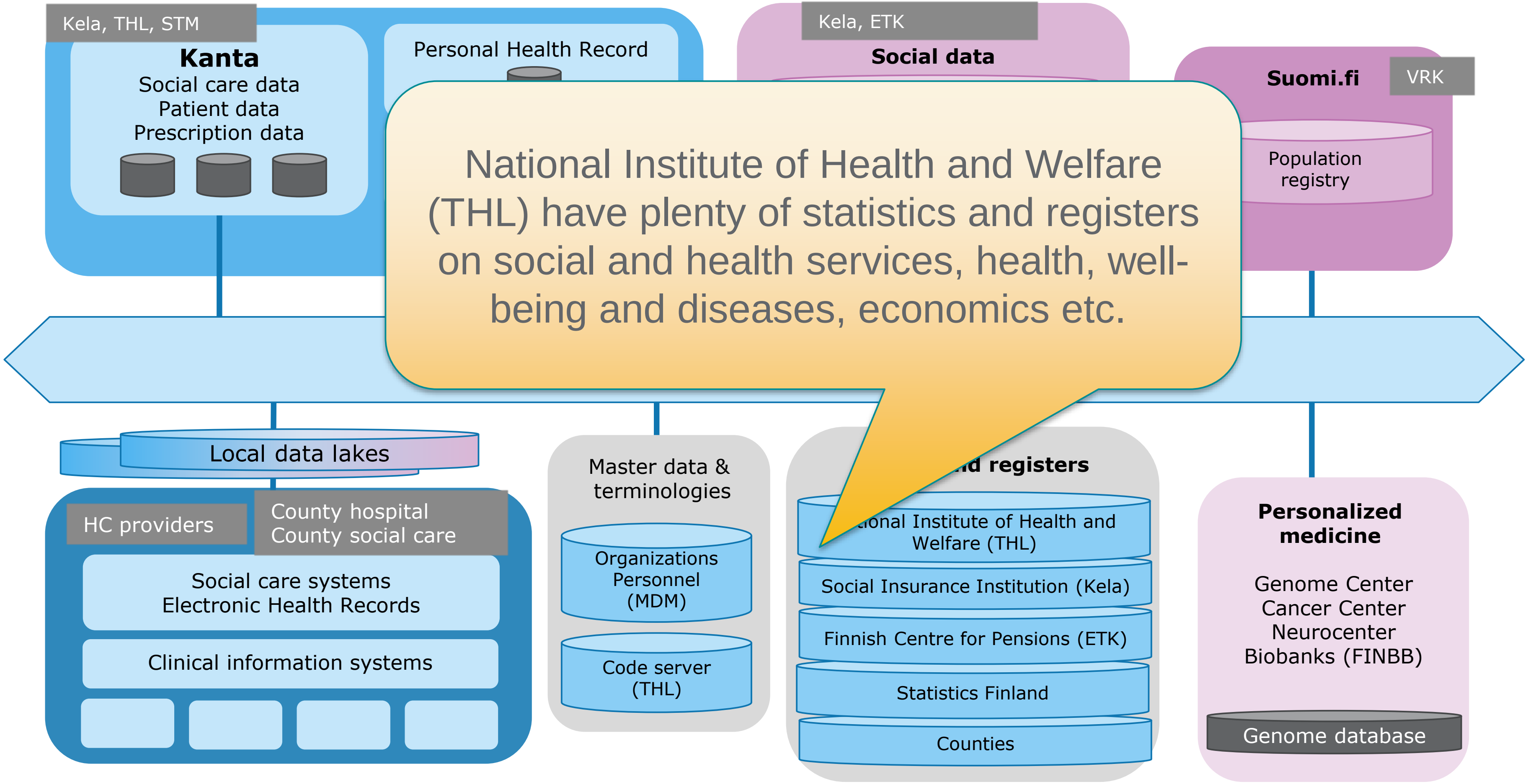
Genome database

County hospitals, local social and health care providers etc. have enormously data in various systems. In many places, the data is now gathered into data lakes.

EXAMPLES OF DATABANKS – IN ADDITION TO KANTA THERE IS A LOT MORE



Kela, THL, STM

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Personal Health Record

Kela, ETK

Social data

Suomi.fi

VRK

Population registry

National Institute of Health and Welfare (THL) have plenty of statistics and registers on social and health services, health, well-being and diseases, economics etc.

Local data lakes

HC providers

County hospital
County social care

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Electronic Health Records

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Master data & terminologies

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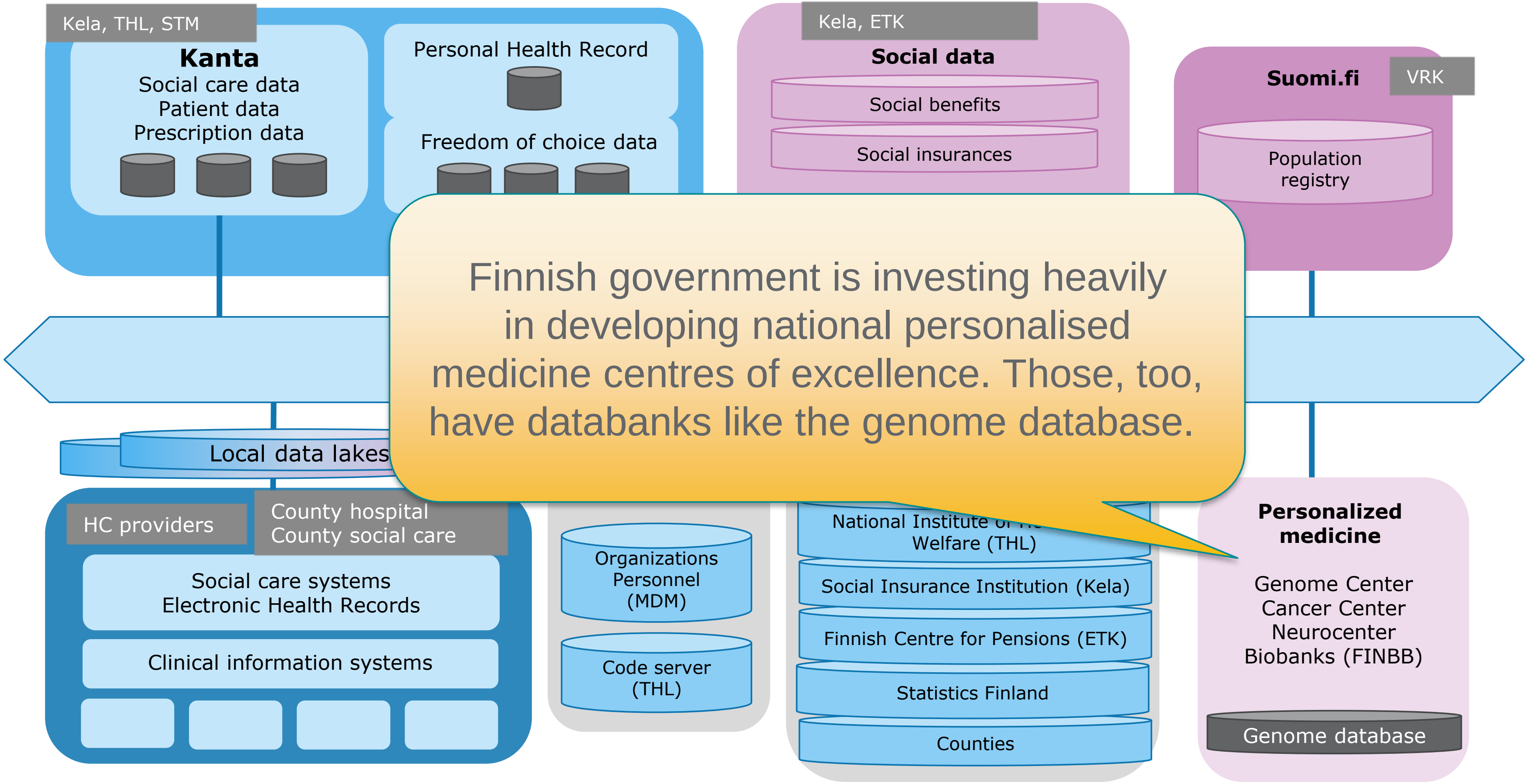
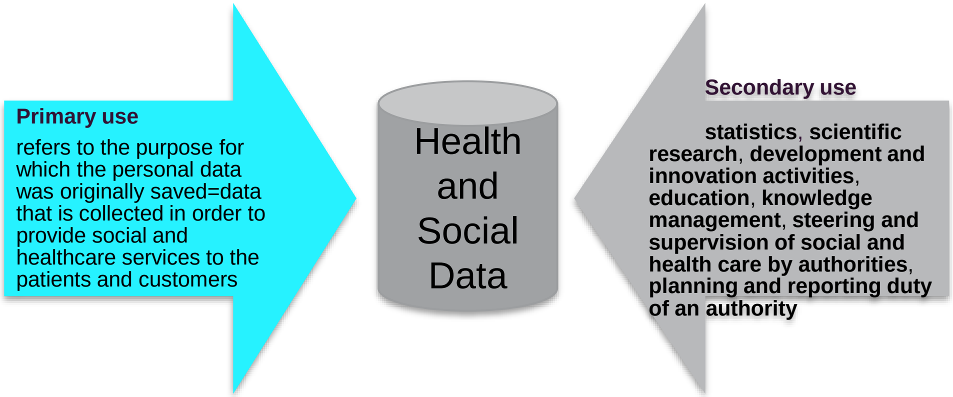


Finnish government is investing heavily in developing national personalised medicine centres of excellence. Those, too, have databanks like the genome database.

PRIMARY USE VS. SECONDARY USE



Primary use

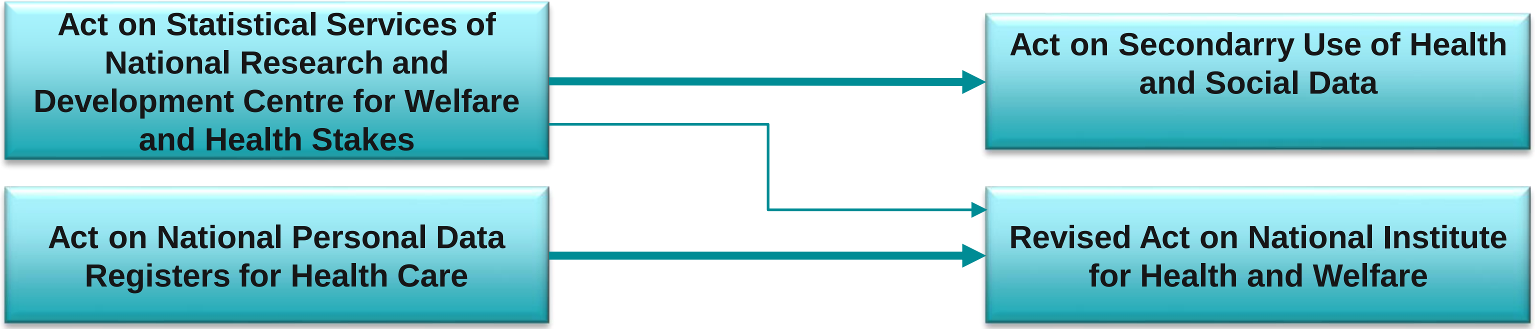
refers to the purpose for which the personal data was originally saved=data that is collected in order to provide social and healthcare services to the patients and customers

Health and Social Data

Secondary use

statistics, scientific research, development and innovation activities, education, knowledge management, steering and supervision of social and health care by authorities, planning and reporting duty of an authority

ENABLING LEGAL FRAMEWORK



Legislation to be reformed:

Act on Statistical Services of National Research and Development Centre for Welfare and Health Stakes

Act on National Personal Data Registers for Health Care

New acts:

Act on Secondarry Use of Health and Social Data

Revised Act on National Institute for Health and Welfare

Related legislation to be amended:

Act on the Electronic Handling of Client Information in Healthcare and Social Welfare

Act on Organising Health and Social Services

Other acts to be amended:
Personal Data Act, Act on the Openness of Government Activities, Biobank Act, Communicable Diseases Act, Act on the Status and Rights of Social Welfare Clients,
Act on the Investigation of the Cause of Death,
Act on Electronic Prescriptions

EU:

General Data Protection Regulation

Regulation on Clinical Trials on Medicinal Products

AFTER THE REFORM

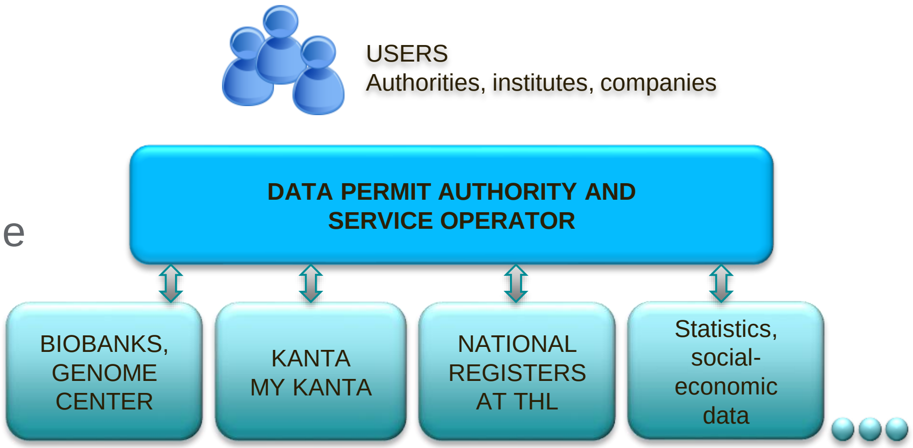
- Data permit authority gives the permit to use the registers and is responsible for the service: data management, combination and transfer
- Data permit authority shall ensure that the combined data is handled in conformity with data protection legislation
- Seperate permits for combining registers will become unnecessary → smoother and simpler process
- Wider use of data: scientific research and statistics, development, innovations, education and information management
- Electronic permit portal for describing the data required (what, why, where) and for saving permit applications
- Data is handled in a secure use environment
- Data controllers give advice on how to use the data
- In conformity with EU Data Protection Regulation

LEGISLATION THAT ENABLES

Act on **Secondary Use of Health and Social Data**

- To ensure authorities, institutes and companies access to the health and social data in Finland.
- To provide efficient and secure procedures to utilize the data in research, development and innovation activities, education and knowledge management duties.

Based on the Act a **Single point of contact** (data permit authority and service operator) will be established



OBJECTIVE OF THE ACT

1. Enable efficient and secure processing of personal data collected during the provision of **social and health care** as well as personal data collected for the purpose of **steering, supervision, researching and collecting statistics** on the social and health care sector.
2. Allow the collected personal data to be **combined with** the personal data held by **Social Insurance Institution of Finland, Population Register Centre, Statistics Finland and Finnish Centre for Pensions**.
3. Secure the legitimate expectations, **rights and freedoms** of individuals when processing personal data. **TRUST!**

Toisiolaki:1 §

SCOPE OF APPLICATION

Act supplements the GDPR when the personal data referred to in section 1 are used for the following purposes, even if the data were not originally stored for such a purpose:

1) statistics;
2) scientific research;
3) development and innovation activities;
4) education;
5) knowledge management;
6) steering and supervision of social and health care by authorities; and
7) planning and reporting duty of an authority.

AUTHORITIES AND ORGANISATIONS RESPONSIBLE FOR THE SERVICES AND RESTRICTIONS ON DATA SETS

1) **Ministry of Social Affairs and Health**;

2) **National Institute for Health and Welfare**, notwithstanding the data it has collected for statistical purposes as a statistical authority.

3) **Social Insurance Institution of Finland** insofar as the data needed for the purposes stated in this Act is personal data stored during the processing of benefits in a customer relationship or concerns drug prescriptions and associated delivery information stored in a prescription centre referred to in section 3, paragraph 4 of the Act on Electronic Prescriptions (61/2007) and in a prescription archive referred to in paragraph 5 of the Act.

4) **National Supervisory Authority for Welfare and Health Valvira**;

5) **Regional State Administrative Agencies** insofar as they process matters related to social and health care;

6**) Finnish Institute of Occupational Health** in sofar as the data needed for the purposes stated in this Act comes from occupational disease registers and exposure measurement registers and the Institute's patient registers;

7) **Finnish Medicines Agency Fimea**;

8) **Public service organisers of social and health care**;

9) **Statistics Finland** insofar as the data needed for the purposes stated in this Act is data referred to in the Act on Determining the Cause of Death (459/1973);

10) **Finnish Centre for Pensions** insofar as the data needed for the purposes stated in this Act is necessary personal data stored in the Finnish Centre for Pensions's registers and concerns employment and earnings information stored during the implementation of earnings-related pension, granted benefits and their justifications, including disability pension diagnoses; and

11) **Population Register Centre** insofar as the data needed for the purposes stated in this Act comes from the Population Information System and is basic data on individuals, their family relationships and places of residence as well as data on buildings.

6 §

COMPETENCE ASSOCIATED WITH THE PROCESSING OF A DATA PERMIT

- **The Data Permit Authority is always responsible** for making a decision on a data permit when the data permit application concerns the following:
  - Data of **several controllers**.
  - Data stored in the **Kanta services**; or
  - Data stored in the registers of one or more **private organisers** of social or health care services.

- If the data permit application only concerns **the data stored in the personal data registers of a single organisation, the organisation will be responsible for making the decision on the data permit**.
- However, **if the organisation* has notified the Data Permit Authority that they will discontinue the maintenance of services the Data Permit Authority will be responsible for making decisions on data permits that concern personal data referred** to in this Act held by the organisation.

*Ministry of Social Affairs and Health, National Institute for Health and Welfare, Social Insurance Institution of Finland, National Supervisory Authority for Welfare and Health Valvira, Regional State Administrative Agencies, Finnish Institute of Occupational Health, Finnish Medicines Agency Fimea, Public service organisers of social and health care

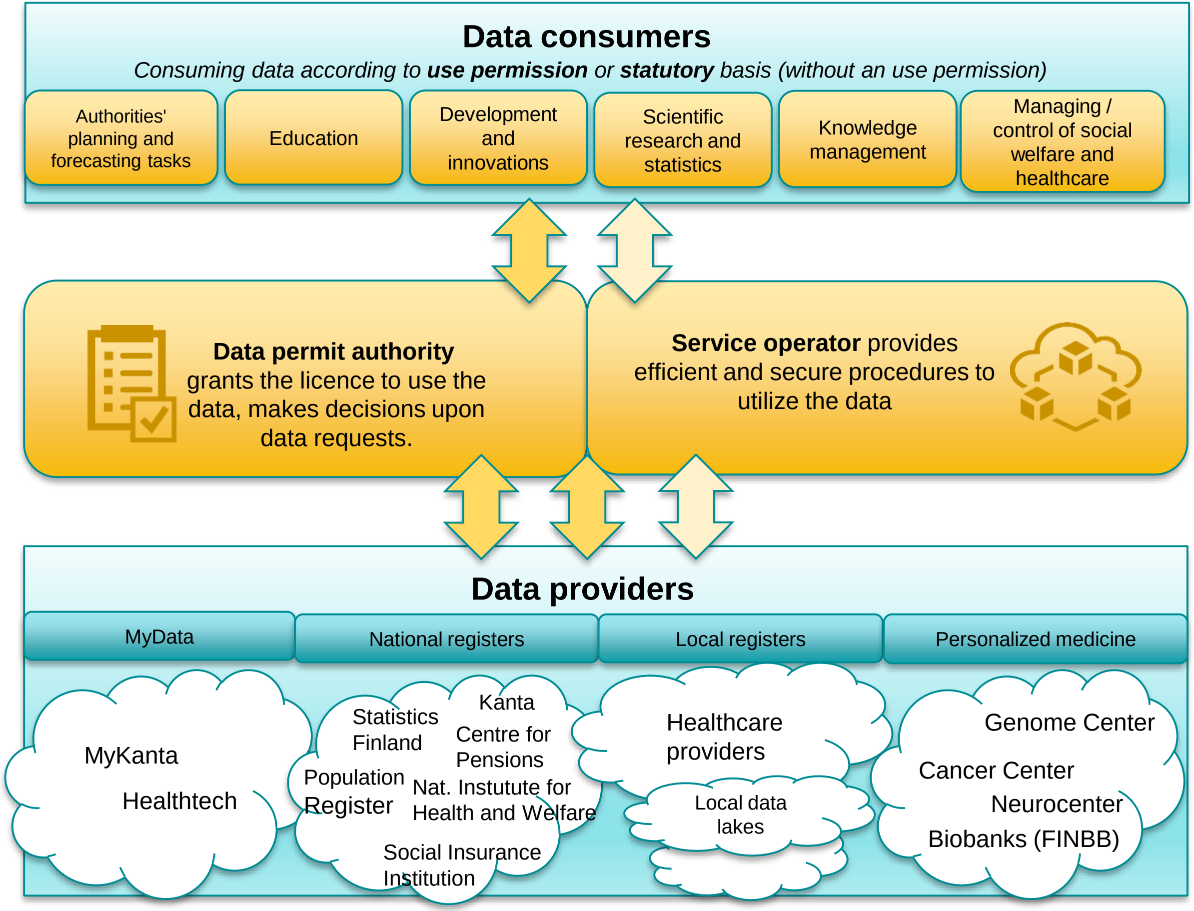
DATA CONTROLLERS

- If the data permit application **only concerns the data stored in the personal data registers of a single organisation**, the organisation will be responsible for making the decision on the data permit
- If the data permit application only concerns the data stored in the personal data registers of a single organisation that organisation will always be responsible data set **descriptions and advisory service**
- **The Data Permit Authority** maintains, either alone or jointly with other authorities, a **secure operating environment** in which the data disclosed by the Data Permit Authority or other authority can be processed securely and in accordance with the permit.
- The processing must be possible by several technical means and the operating environment must be accessible from different locations.
- If the data permit application requests that data sets be disclosed for processing in another operating environment than the one maintained by the Data permit authrority

Toisiolaki: 6, 10 ja 11§

MINISTRY OF SOCIAL AFFAIRS AND HEALTH

BIG PICTURE OF THE SECONDARY USE OF HEALTH AND SOCIAL DATA



Data consumers

Consuming data according to ***use permission*** *or* ***statutory*** *basis (without an use permission)*

- Authorities' planning and forecasting tasks
- Education
- Development and innovations
- Scientific research and statistics
- Knowledge management
- Managing / control of social welfare and healthcare

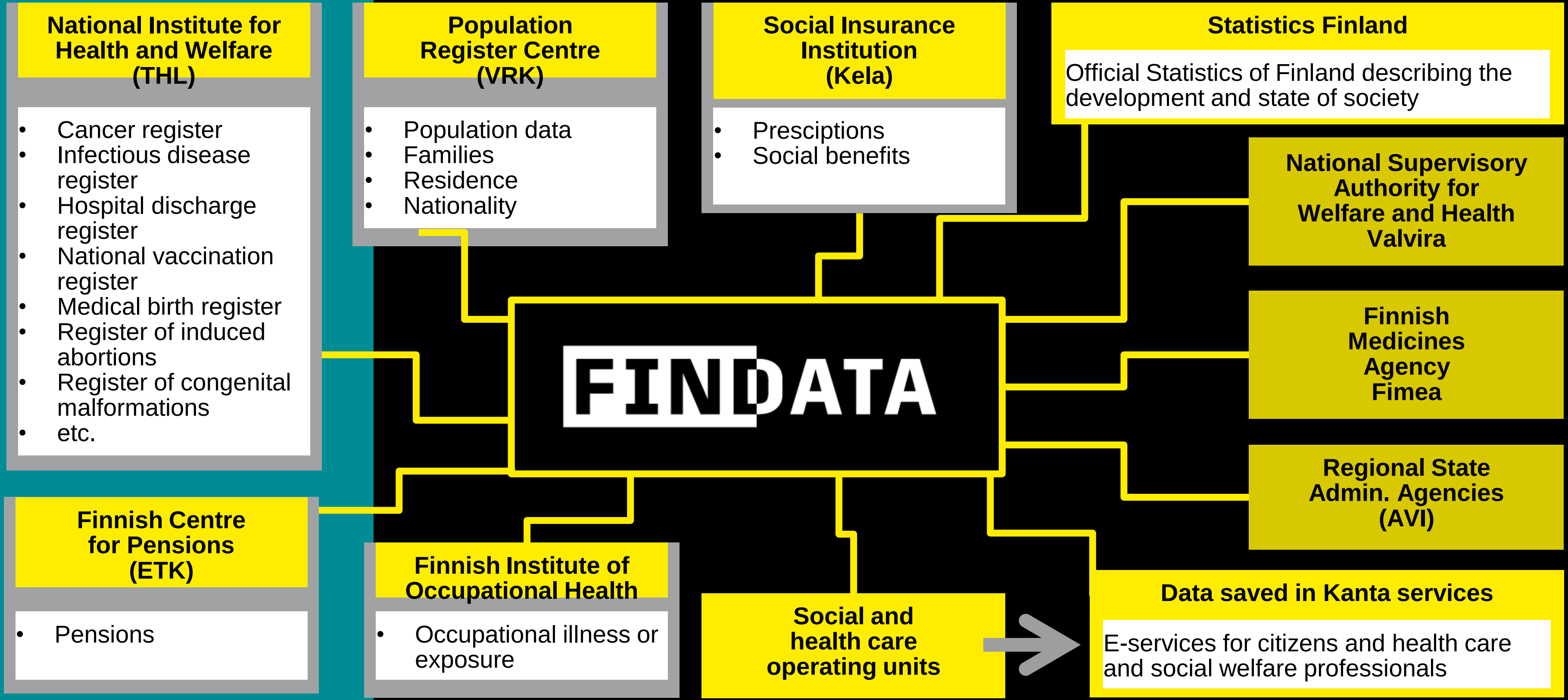
Data permit authority grants the licence to use the data, makes decisions upon data requests.

Service operator provides efficient and secure procedures to utilize the data

Data providers

MyData	National registers	Local registers	Personalized medicine
MyKanta Healthtech	Statistics Finland Kanta Centre for Pensions Population Register Nat. Instutute for Health and Welfare Social Insurance Institution	Healthcare providers Local data lakes	Genome Center Cancer Center Neurocenter Biobanks (FINBB)

THE DATA



National Institute for Health and Welfare (THL)

- Cancer register
- Infectious disease register
- Hospital discharge register
- National vaccination register
- Medical birth register
- Register of induced abortions
- Register of congenital malformations
- etc.

Population Register Centre (VRK)

- Population data
- Families
- Residence
- Nationality

Social Insurance Institution (Kela)

- Presciptions
- Social benefits

Statistics Finland

Official Statistics of Finland describing the development and state of society

National Supervisory Authority for Welfare and Health Valvira

Finnish Medicines Agency Fimea

Regional State Admin. Agencies (AVI)

FINDATA

Finnish Centre for Pensions (ETK)

- Pensions

Finnish Institute of Occupational Health

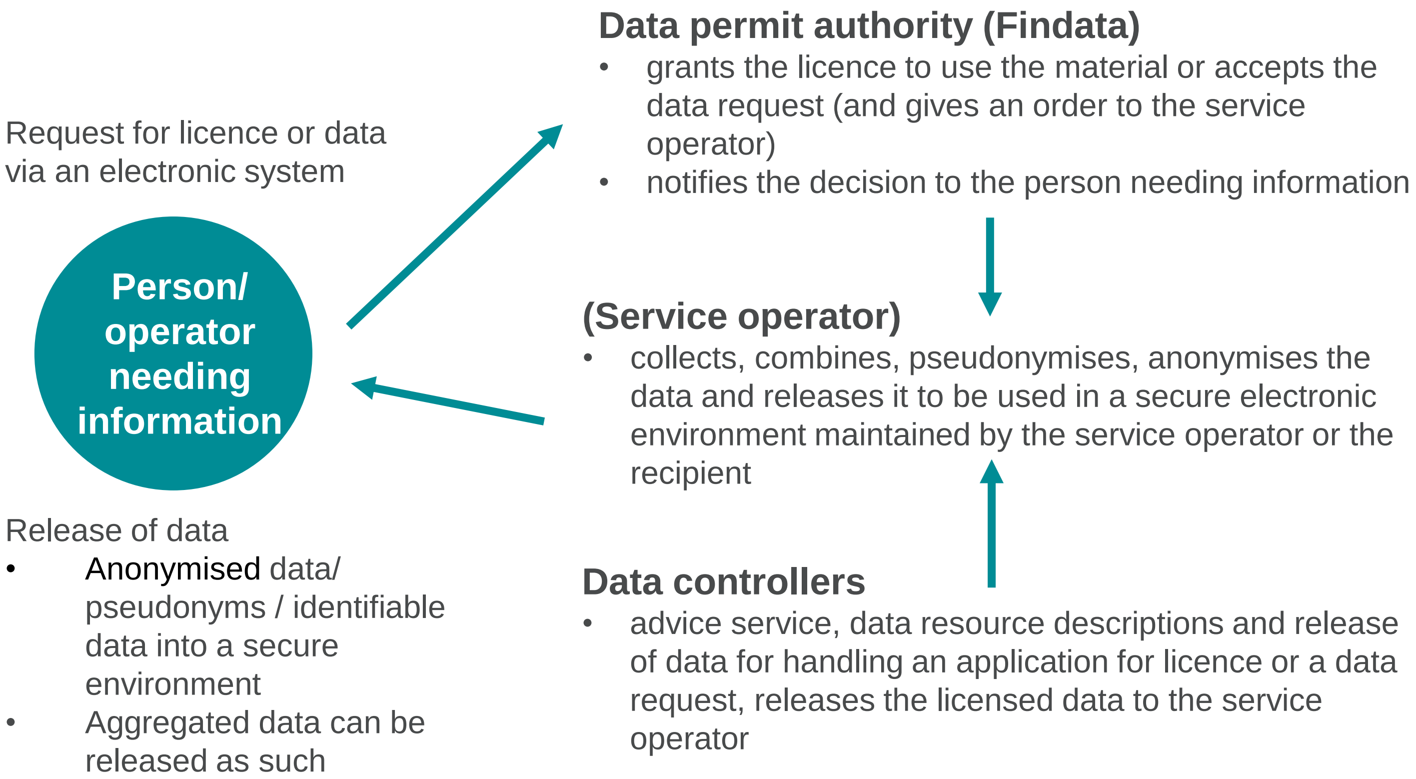
- Occupational illness or exposure

Social and health care operating units

Data saved in Kanta services

E-services for citizens and health care and social welfare professionals

HOW TO GET A LICENCE AND THE DATA?



Request for licence or data via an electronic system

Person/ operator needing information

Release of data

- Anonymised data/ pseudonyms / identifiable data into a secure environment
- Aggregated data can be released as such

Data permit authority (Findata)

- grants the licence to use the material or accepts the data request (and gives an order to the service operator)
- notifies the decision to the person needing information

(Service operator)

- collects, combines, pseudonymises, anonymises the data and releases it to be used in a secure electronic environment maintained by the service operator or the recipient

Data controllers

- advice service, data resource descriptions and release of data for handling an application for licence or a data request, releases the licensed data to the service operator

GENERAL JUSTIFICATIONS FOR SECONDARY USE

Data permit 44 §

Decision maker:
The data permit authority or
The data controller/organsation/authority responsible for a single organization

Data request 45 §

Decision maker:
The data permit authority

- **Scientific research and statistics 38 §**
- **Development and innovation activities 37 § (only by data requests)**
- **Education 39 §**
- **Planning and reporting duty of an authority 40 §**

Processing data under law but without a separate data permit

Data request 45 §

Decision maker:
The data permit authrority

- **Knowledge management 41 §**
- **Steering and supervision of social and health care by authorities42 §**

GENERAL JUSTIFICATIONS FOR SECONDARY USE

Data permit 44 §
Decision maker:
The data permit authority or
The data controller/organsation/authority responsible for a single organization

Data request 45 §
Decision maker:
The data permit authority

DATA SETS, WHERE THERE IS A RISK THAT PERSONAL DATA CAN BE REVEALED/DATA SUBJECT IDENTIFIED

- Personal data (=data containing identifiers**)**
- Pseudonymised data
- Anonymised data, where there is theoretical risk of being identified.

Data can only be processed in the safe and secure environment

NOT PERSONAL DATA aggregated statistics (refers to reliably anonymised data in a statistical format)

Can be freely processed, even published

PRINCIPLES ON HOW TO ENSURE ANONYMITY OF THE DATA SUBJECTS

- **The Data Permit Authority is always responsible for anonymising the data** and has a **high-level expert group for creating guidelines on anonymisation**, data protection and data security for the Data Permit Authority’s operations.
- **Process for verifying that the data to be published is anonymised**.

- **Data request/permit –process** for aggregated statistics and Data permit -process for data where the data subject can be identified
- **Safe and secure environment**(-s), and data request management system and secure hosting service (enables flexible central anonymisation)
- **Anonymisation process and the process for verifying, that the data, to be published, is anonymized**, was represented already in the Parliamental Committee hearings

PROCESS FOR VERIFYING THAT THE DATA TO BE PUBLISHED IS ANONYMISED.

Conditions

- **Only the data sets that has been disclosed for processing in a secure operating environment** and
- Concernes the **results that are generated to be published based on those data sets**
- Concernes **all the different legal bases where you need a data permit**

Decision maker

- **The Data Permit Authority is responsible for verifying that the data to be published is anonymized**
- This responsibility in **centralised in order gaurantee the best resources, skills, processes for this work and in order to uniform data protection processes**

Toisiolaki: 52 §

PROCESSES BY PURPOSES

- Development and innovation activities
- Scientific research and statistics
- Education
- Planning and reporting duty of an authority
- Knowledge management
- Steering and supervision of social and health care by authorities

DEVELOPMENT AND INNOVATION ACTIVITIES

Refers to the application and use of engineering and business data and other existing data together with the personal data referred to in this Act for the purpose of developing new or significantly improved products, processes or services

Definitions 3 § 4

Examples
- Devolopment of new personalised medicines and personalised care
- Evalutation of new products, new processes, new tools
- Development of healthcare technologies, new products and new solutions
- Development of the social and health care services or the service system
- Use of modern tools: data-analytics, machine learning, algorithms

NOT for example
- Sales or marketing
- Insurances

3 and 37 §

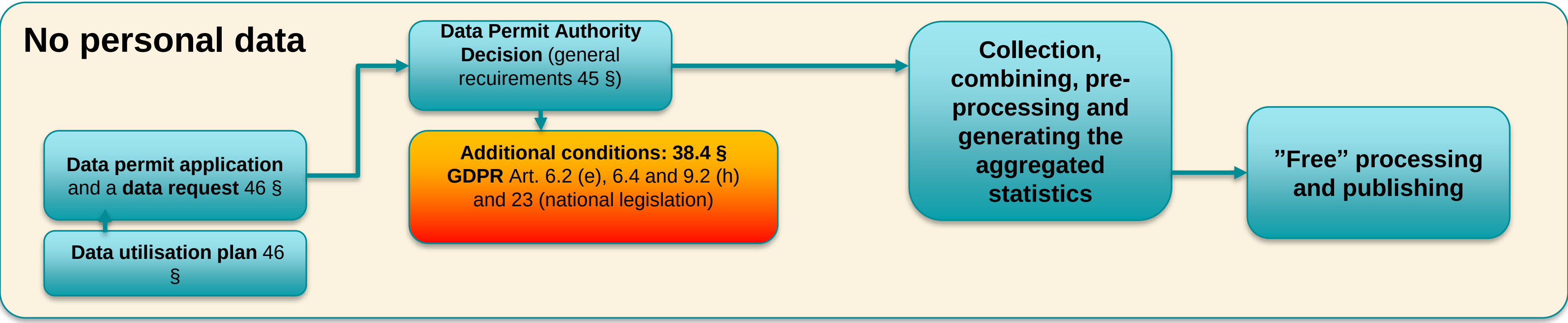
THE CONDITION OF THE DEVELOPMENT AND INNOVATION ACTIVITIES*

The data request and the data utilisation plan attached to it states that the purpose of the activity is to:

- promote public health or social security; or
- develop the social and health care services or the service system; or
- protect the health or wellbeing of individuals or secure their rights and liberties associated with health or wellbeing.

*these are derived from GDPR Art. 23

DEVELOPMENT AND INNOVATION ACTIVITIES 37 §



No personal data

Data utilisation plan 46 §

Data permit application and a **data request** 46 §

Data Permit Authority Decision (general recuirements 45 §)

Additional conditions: 38.4 § **GDPR** Art. 6.2 (e), 6.4 and 9.2 (h) and 23 (national legislation)

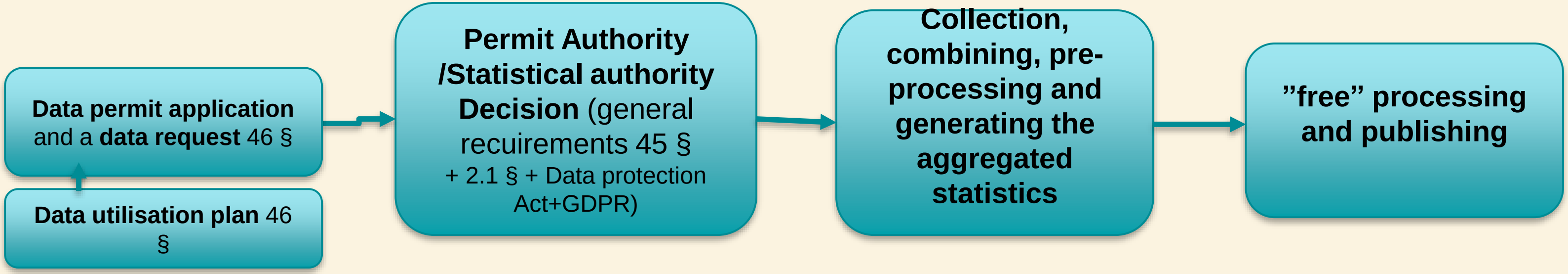
Collection, combining, pre-processing and generating the aggregated statistics

”Free” processing and publishing

MINISTRY OF SOCIAL AFFAIRS AND HEALTH

SCIENTIFIC RESEARCH AND STATISTICS 38 §

No personal data



Data permit application and a **data request** 46 §

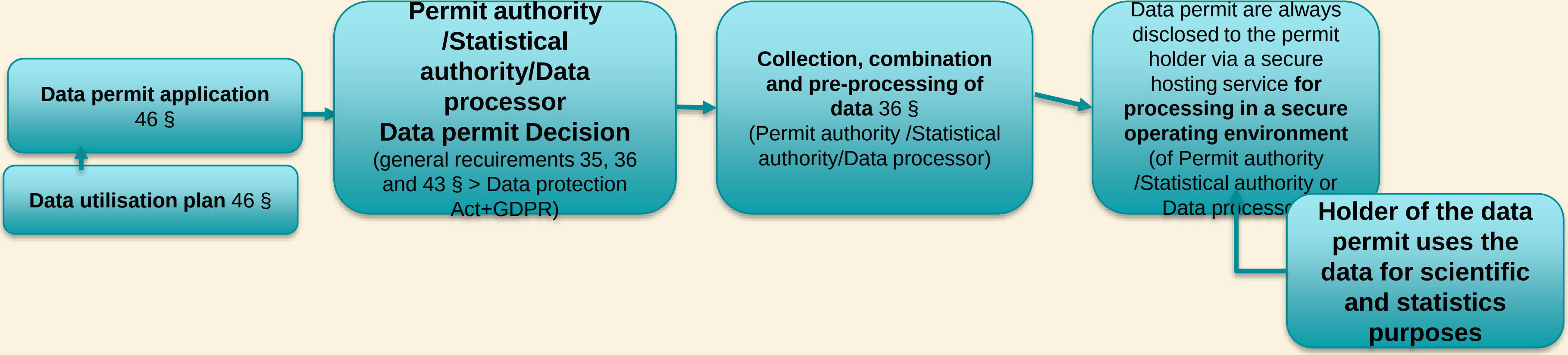
Data utilisation plan 46 §

Permit Authority /Statistical authority Decision (general recuirements 45 § + 2.1 § + Data protection Act+GDPR)

Collection, combining, pre-processing and generating the aggregated statistics

”free” processing and publishing

Personal data



Data permit application 46 §

Data utilisation plan 46 §

Permit authority /Statistical authority/Data processor Data permit Decision (general recuirements 35, 36 and 43 § > Data protection Act+GDPR)

Collection, combination and pre-processing of data 36 § (Permit authority /Statistical authority/Data processor)

Data permit are always disclosed to the permit holder via a secure hosting service **for processing in a secure operating environment** (of Permit authority /Statistical authority or Data processo

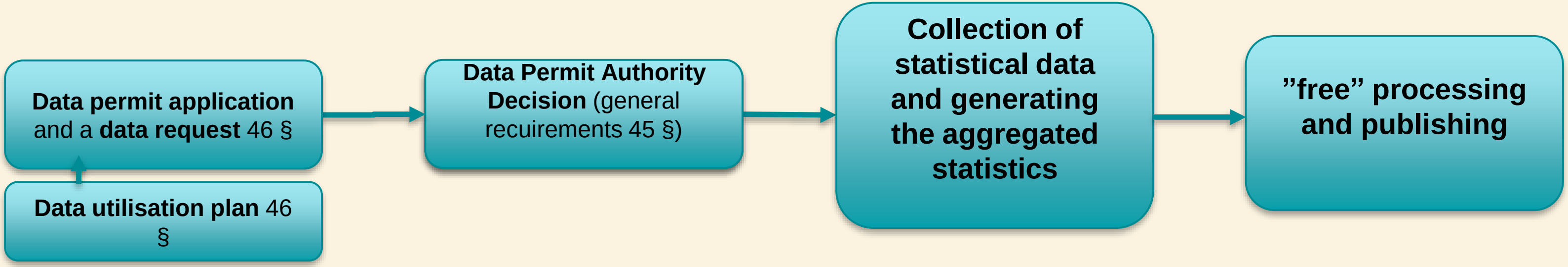
Holder of the data permit uses the data for scientific and statistics purposes

EDUCATION 39 §.

- **The client data** of a social or health care service provider may be processed without prejudice to secrecy obligations and pursuant to the Article 9 (2g) GDPR **in** order to **produce educational materials for people processing client data in social and health care** and **for people studying to become professionals in social and health care**, if the materials are necessary to fulfill the goals of the education.
- A further condition to processing is a granted **data permit**
- **Data containing identifiers** may be used for education **only when the education cannot be carried out using anonymous data due to the rarity of the case being taught, the nature of teaching or other such reason.**
- People undertaking the education needs to be **informed of the statutory secrecy obligation and the sanctions**.
- A data subject **does not** have **the right to object** to the processing of his or her personal data for educational purposes, if the processing of personal data is necessary due to the rarity of the case.
- The permit holder **must erase the separate data sets** collected for educational purposes **when the data sets are no longer needed for their intended purpose**.

EDUCATION 39 §

No personal data



Data permit application and a **data request** 46 §

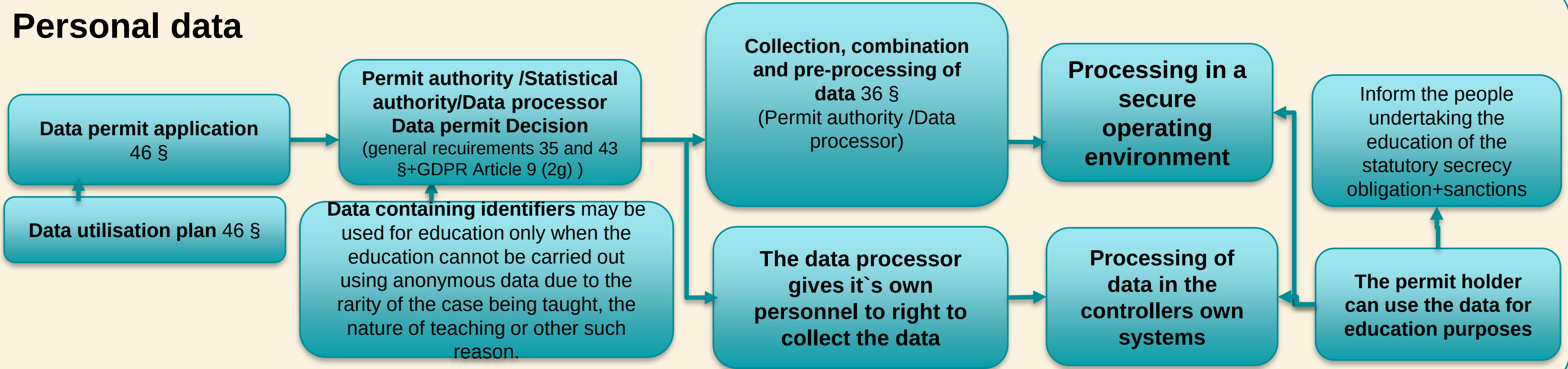
Data utilisation plan 46 §

Data Permit Authority Decision (general recuirements 45 §)

Collection of statistical data and generating the aggregated statistics

”free” processing and publishing

Personal data



Data permit application 46 §

Data utilisation plan 46 §

Permit authority /Statistical authority/Data processor Data permit Decision (general recuirements 35 and 43 §+GDPR Article 9 (2g))

Data containing identifiers may be used for education only when the education cannot be carried out using anonymous data due to the rarity of the case being taught, the nature of teaching or other such reason.

Collection, combination and pre-processing of data 36 § (Permit authority /Data processor)

The data processor gives it`s own personnel to right to collect the data

Processing in a secure operating environment

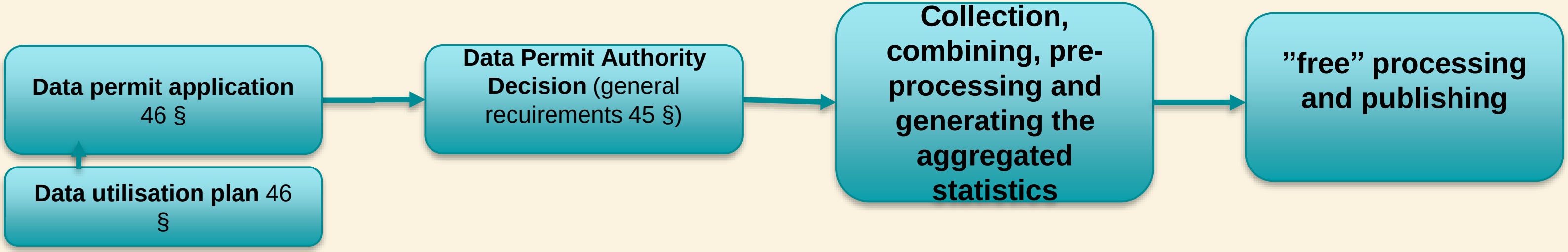
Processing of data in the controllers own systems

Inform the people undertaking the education of the statutory secrecy obligation+sanctions

The permit holder can use the data for education purposes

PLANNING AND REPORTING DUTY OF AN AUTHORITY 40 §

No personal data



Data permit application 46 §

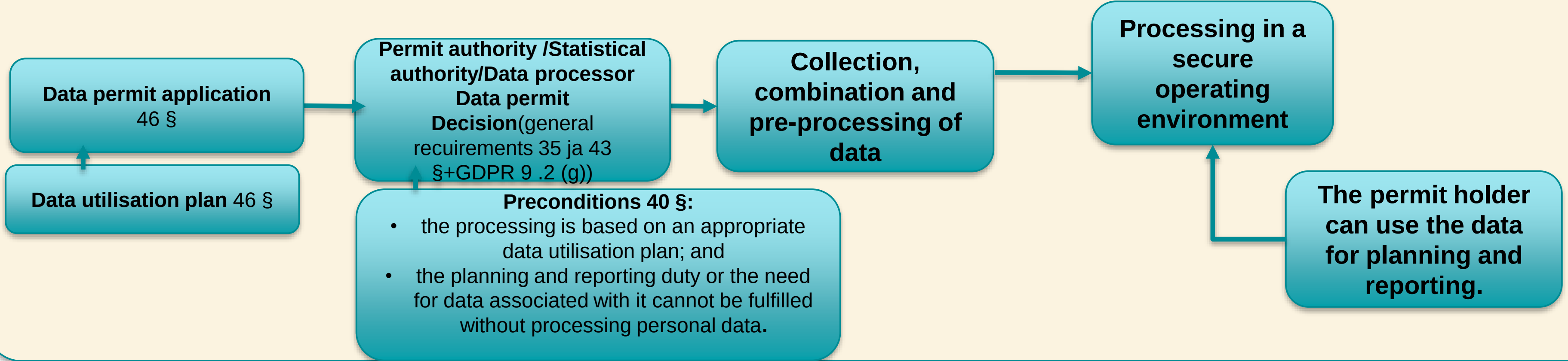
Data utilisation plan 46 §

Data Permit Authority Decision (general recuirements 45 §)

Collection, combining, pre-processing and generating the aggregated statistics

”free” processing and publishing

Personal data



Data permit application 46 §

Data utilisation plan 46 §

Permit authority /Statistical authority/Data processor Data permit Decision(general recuirements 35 ja 43 §+GDPR 9 .2 (g))

Preconditions 40 §:

- the processing is based on an appropriate data utilisation plan; and
- the planning and reporting duty or the need for data associated with it cannot be fulfilled without processing personal data.

Collection, combination and pre-processing of data

Processing in a secure operating environment

The permit holder can use the data for planning and reporting.

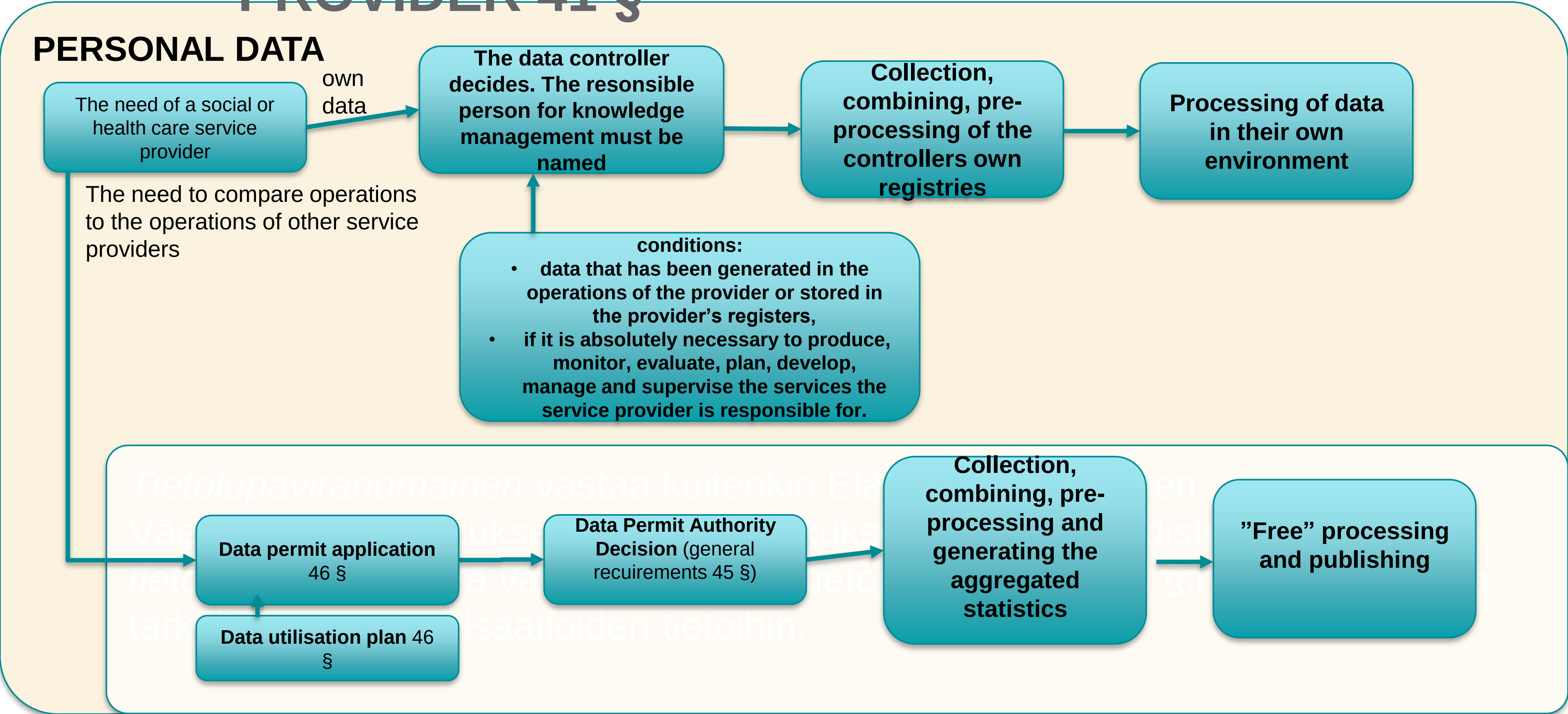
KNOWLEDGE MANAGEMENT BY A SOCIAL OR HEALTH CARE SERVICE PROVIDER

41 §

- A **social or health care service provider** has the right, without prejudice to secrecy obligations and pursuant to Article 9 (2h) GDPR, to **process and combine identifiable customer data that has been generated in the operations** of the provider or **stored in the provider’s registers**, if absolutely necessary to **produce, monitor, evaluate, plan, develop, manage and supervise the services the service provider is responsible for**.

- If the service provider **needs to compare their operations to the operations of other service providers in order to evaluate, plan or develop the services or service chains they are responsible for**, the **Data Permit Authority** may generate the **data sets required** for comparison as **aggregated statistical data**
- In addition a **municipality** or a **joint municipal** authority has the right to process and combine **identifiable client data stored in a joint register** referred to in section 9(1) of the Health care Act (1326/2010), when the purpose of such processing and combination is knowledge management.

KNOWLEDGE MANAGEMENT BY A SOCIAL OR HEALTH CARE SERVICE PROVIDER 41 §



PERSONAL DATA

The need of a social or health care service provider

own data

The data controller decides. The resonsible person for knowledge management must be named

Collection, combining, pre-processing of the controllers own registries

Processing of data in their own environment

The need to compare operations to the operations of other service providers

conditions:

- **data that has been generated in the operations of the provider or stored in the provider's registers,**
- **if it is absolutely necessary to produce, monitor, evaluate, plan, develop, manage and supervise the services the service provider is responsible for.**

Data permit application 46 §

Data utilisation plan 46 §

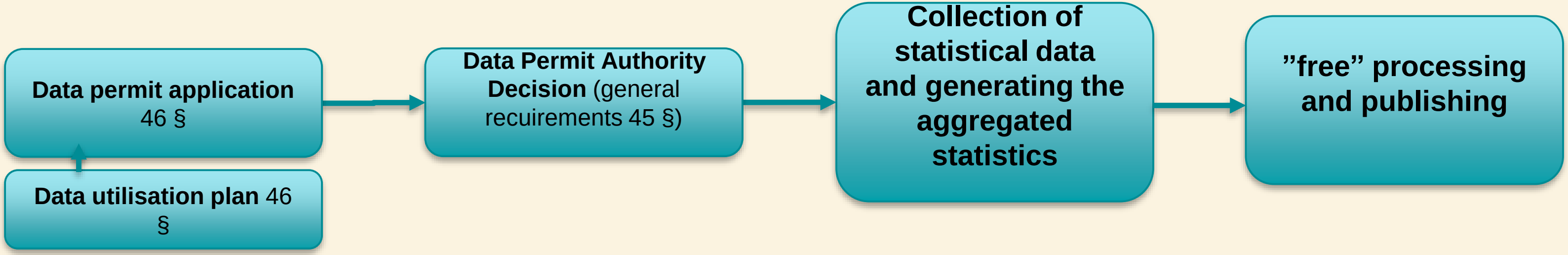
Data Permit Authority Decision (general recuirements 45 §)

Collection, combining, pre-processing and generating the aggregated statistics

”Free” processing and publishing

STEERING AND SUPERVISION OF SOCIAL AND HEALTH CARE BY AUTHORITIES 42 §

No personal data



Data utilisation plan 46 §

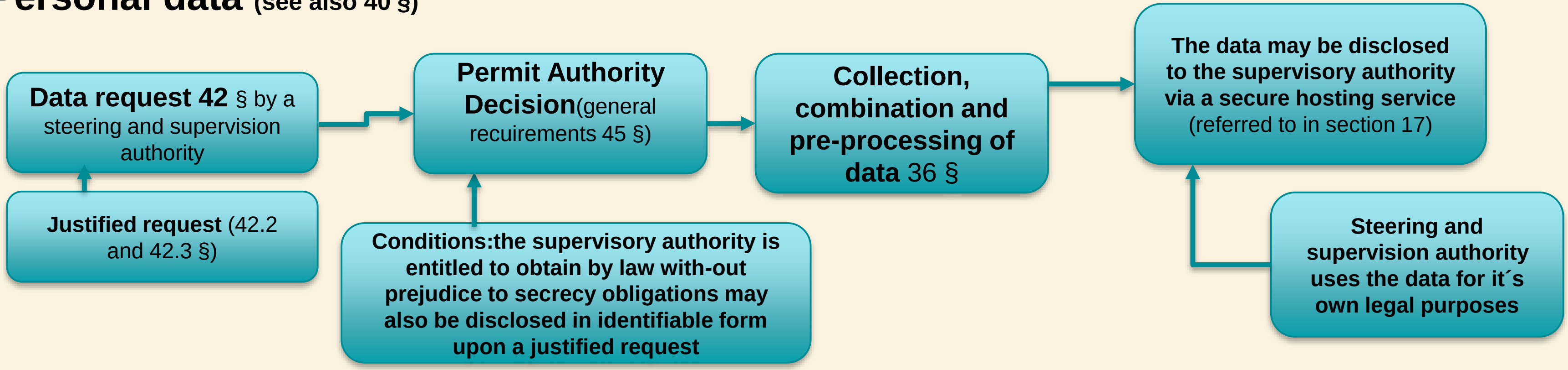
Data permit application 46 §

Data Permit Authority Decision (general recuirements 45 §)

Collection of statistical data and generating the aggregated statistics

”free” processing and publishing

Personal data (see also 40 §)



Justified request (42.2 and 42.3 §)

Data request 42 § by a steering and supervision authority

Conditions:the supervisory authority is entitled to obtain by law with-out prejudice to secrecy obligations may also be disclosed in identifiable form upon a justified request

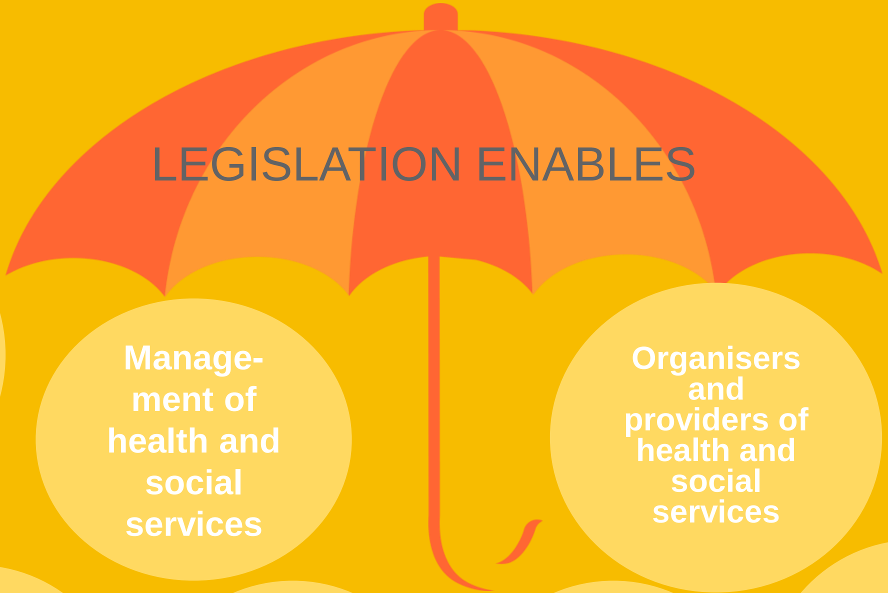
Permit Authority Decision(general recuirements 45 §)

Collection, combination and pre-processing of data 36 §

The data may be disclosed to the supervisory authority via a secure hosting service (referred to in section 17)

Steering and supervision authority uses the data for it´s own legal purposes

Who benefits from secondary use of health and social data



LEGISLATION ENABLES

People, clients of health and social services

Management of health and social services

Organisers and providers of health and social services

Healthcare and social welfare professionals

ICT enterprises

Startups

Pharmaceutical companies

Development organisations

National economy

Research institutions and universities

IMPACTS OF THE NEW ACT

Centralised licensing and secure electronic environment → Faster access to information, wider range of purposes of data use

Enables individual use and combining of data → Effective treatments and new medicines, e.g. for risk groups

Improved opportunities for research and product development → New business activities, products and services

BENEFITS FOR RESEARCHERS

- one single authority would decide on licences to use registers which contain client data from health and social services
- more extensive data, easier access
- shorter waiting times and simpler processes for accessing the data
- data is already compiled and homogenised
- stronger research and competence

BENEFITS FOR ENTERPRISES

- more research data
- more extensive data, access via one-stop shop
- better innovation opportunities
- new areas for applications
- better opportunities to develop services and business environments
- better opportunities for product development
- easier to operate as an enterprise offering health and social services

BENEFITS FOR PEOPLE

- more research data → better functioning services, more effective medicines
- better treatment and care when data is easier available to operators
- more effective health and social services
- data is handled in a secure environment and cannot fall in the wrong hands

ACT ON SECONDARY USE OF HEALTH AND SOCIAL DATA

Solid GDPR-compliant legal basis for secondary use

LEGAL BASES ON THE ACT ON SECONDARY USE OF HEALTH AND SOCIAL DATA AND RELATED LEGISLATION

- **Research**: Act on Secondary Use of Health and Social Data, Permit authority gives the permit to use the registers and is responsible for the service. Permit authority shall ensure that the combined data is handled in conformity with data protection legislation. (GDPR recital 159, GDPR article 5 paragraph 1 b subparagraph, article 6 paragraph 1 a (consent), e and f subparagraphs and article 9 paragraph 2 j subparagraph and article 9 2 subparagraph)

- **Development and innovations**: Act on Secondary Use of Health and Social Data (anonymized data: (GDPR article 6 e subparagraph, GDPR article 23 1 and 2 subparagraphs).

- **Education**: Act on Secondary Use of Health and Social Data (GDPR article 6 e subparagraph and article 9 a g subparagraph, GDPR article 23 1 and 2 subparagraphs).

- **Knowledge management**: Act on Secondary Use of Health and Social Data (GDPR article 6 1 e subparagraph, article 23 1 subparagraph, article 9 2 h subparagraph and article 9 3 subparagraph).

- **Steering and supervision of social and health care by authorities**: Act on Secondary Use of Health and Social Data (GDPR article 9 2 i subparagraph).

- **Planning and reporting duty of an authority**: Act on Secondary Use of Health and Social Data (GDPR article 6 1 e subparagraph, article 23 1 subparagraph, article 9 2 g subparagraph and article 9 2 e subparagraph and article 23 e subparagraph and articles 28 and 29).

- **Statistics**: Act on Secondary Use of Health and Social Data, Permit authority gives the permit to use the registers and is responsible for the service. (GDPR recital 157 and 162, GDPR article 5 paragraph 1 b subparagraph, article 6 paragraph 1 a, e and f subparagraphs and article 9 paragraph 2 j subparagraph and article 9 2 subparagraph)

How to securely fully utilize the health and social data together

Further information:

The Ministry's web pages on the new law
https://stm.fi/en/secondary-use-of-health-and-social-data
Sitra's book about the new law
https://www.sitra.fi/en/publications/a-finnish-model-for-the-secure-and-effective-use-of-data/

Findata
https://thl.fi/en/web/thlfi-en/statistics/data-and-services/data-permit-authority-findata

Joni Komulainen
E-mail: joni.komulainen@stm.fi

Ministry of Social Affairs and Health
Internet: stm.fi
Twitter: SHM_News

SALUS COOP

Citizen data cooperative for health research

#salusCoop
@saluscoop

www.saluscoop.org

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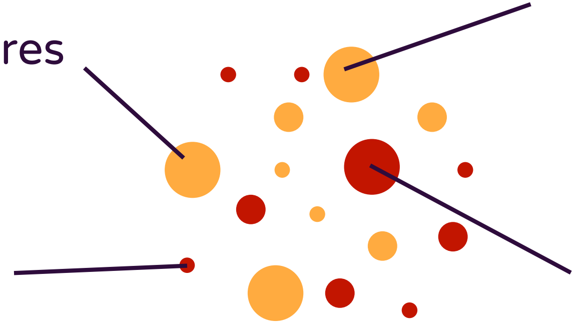
"Data is the raw material of the 21st century, and the question 'Who owns that data?' will decide in the end whether democracy, a participatory social model, and economic prosperity can be combined."

ANGELA MERKEL

SOCIAL / TECHNOLOGICAL / ECONOMIC

Current context



Our data cures

My data is mine

Revolution in genetics

Data is not easily accessible

Changes in the capacity of citizens and social demands

Data-driven innovations in technological developments & research

Economic pressure on public health systems

OUR DATA CURE

Understanding Diseases and Health

Behaviour

Substance Exposure

Lifestyle

Physiological parameters

Environmental exposure

Genetics

DATA IS NOT EASILY ACCESSIBLE

Medical Records

Apps

Social Networks

Insurance

Wearables

Others...

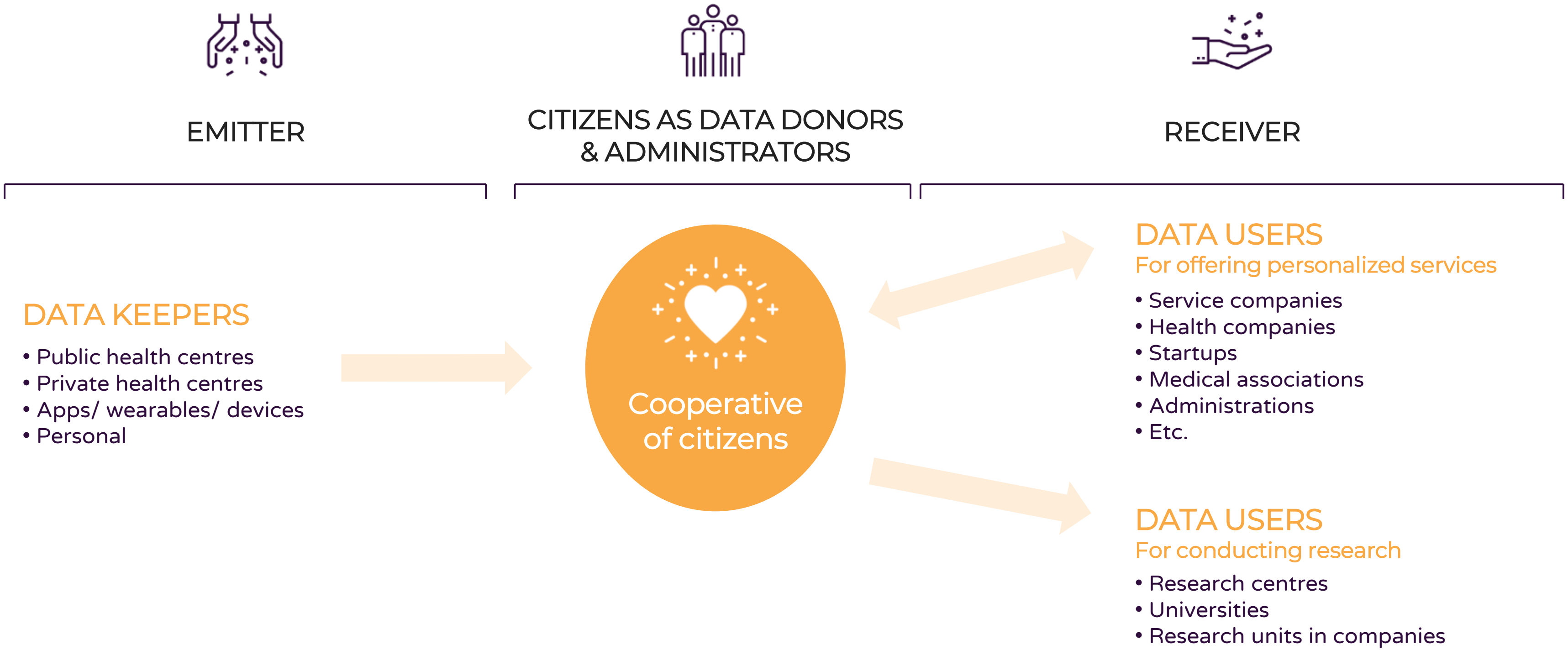
Objective

To explore a citizen-driven model of collaborative governance & management of health data.

This model should enable citizens to share their health data to accelerate research and innovation in healthcare, thus maximizing social and collective benefits.

SALUS COOP

Envisioned scenario



EMITTER

CITIZENS AS DATA DONORS & ADMINISTRATORS

RECEIVER

DATA KEEPERS

- Public health centres
- Private health centres
- Apps/ wearables/ devices
- Personal

Cooperative of citizens

DATA USERS

For offering personalized services

- Service companies
- Health companies
- Startups
- Medical associations
- Administrations
- Etc.

DATA USERS

For conducting research

- Research centres
- Universities
- Research units in companies

First feasibility study

Barcelona, Spain

July to December, 2016

Focus: Breast cancer

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First feasibility study

OBJECTIVE

To explore, define and validate the hypothesis of creating a cooperative of citizens willing to govern the use of their health data, by analyzing the social, technological and legal viability.

+35 INTERVIEWS

Actors interviewed:

- Patient associations
- Researchers
- Physicians
- Bioethics experts
- Entrepreneurs in the health sector
- Open data promoters
- Blockchain experts
- Legal experts

Topics covered during the interviews:

- Perceived benefits and values
- Perceived risks
- Possible barriers
- Relationship between groups of agents

2 VALIDATION SESSIONS

34 participants

Representatives of the three main actors groups:

- Citizens
- Data keepers
- Data users

Main topics covered in the sessions:

Benefits and risks of four models of data governance:

- Individual
- Public
- Private
- Collective

FIRST FEASIBILITY STUDY

Triggers for systemic change

Perceived universal benefits

Terms

Barriers

Systemic change

Data: scarcity → abundance
Management: individual → collective
Channels: intermediaries → direct
Knowledge: asymmetry → symmetry of information
Publications: selective → integral
Actors: a certain number → multiplicity
Innovation: on products → on processes

FIRST FEASIBILITY STUDY

Initial findings

PERCEIVED UNIVERSAL BENEFITS

Provision:

- Prevention & personalization
- Management of healthcare services

Innovation:

- Research
- New business models in healthcare

TERMS

Control & transparency:

- Clear and understandable information
- Who has access to data? What for?
- What are the results of data use?

Anonymity & Security:

- Prevent re-identification as much as possible
- Not central repository of data

Collective benefits:

- No individual return
- Citizen-driven research agenda

BARRIERS

Entry barriers to citizens:

- Motivate citizens to participate
- > Help citizens understand the health data ecosystem and the value of sharing data
- Consider possible technological / educational barriers that might prevent access to certain groups

Barriers among agents:

- Possible changes in the relationship between patient and physician
- Possible changes in the practices of physicians
- Distrust towards business-driven research

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Data governance principles

CONDITIONAL DONATION

Citizens should have the right to decide under which conditions they want to donate their health data.

COLLECTIVE BENEFITS

The use of data by any agents should generate a clear and unequivocal benefit to society.

MOTIVATIONAL INCENTIVES

In order to reach a significant data sample for conducting research, it is key to motivate the greatest number of citizens to donate their data. Incentives to individuals shouldn't be put ahead of the common good. Incentives could be given in form of services.

RIGHTS MANAGEMENT

Mechanisms of collective governance that allow to guarantee the collective benefits from data use, and manage citizens' conditions on data donation

TRIEM: www.ideasforchange.com/triem

Conditions for data donation

Let's decide the future of our data

Participate here www.ideasforchange.com/triem

TRIEM
by SalusCoop & IdeasForChange

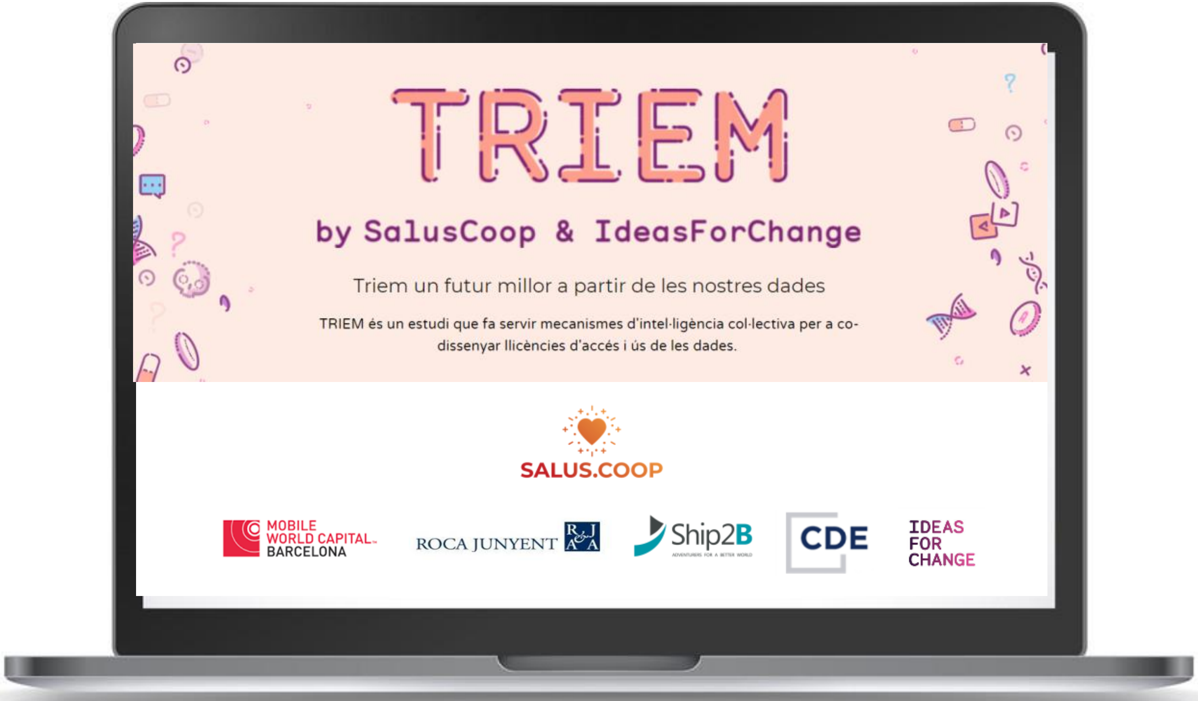
Conditions for data donation

- Who requests data
- Which data is requested
- What is research conducted for
- How will results be shared

TRIEM

Conditions for data donation

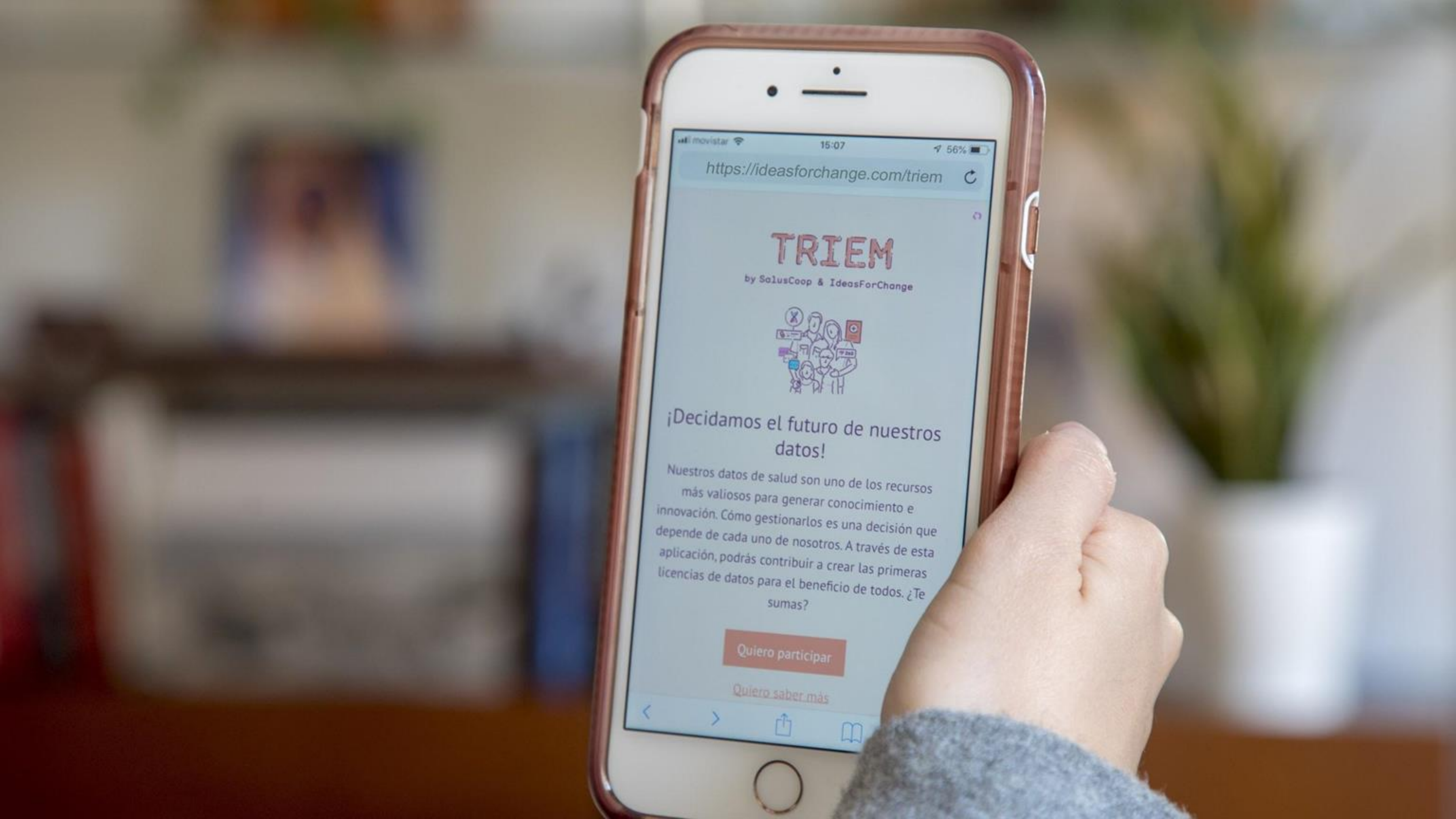
TRIEM Web



Triem un futur millor a partir de les nostres dades

TRIEM és un estudi que fa servir mecanismes d'intel·ligència col·lectiva per a co-dissenyar llicències d'accés i ús de les dades.

Veure vídeo!



TRIEM

by SalusCoop & IdeasForChange

¡Decidamos el futuro de nuestros datos!

Nuestros datos de salud son uno de los recursos más valiosos para generar conocimiento e innovación. Cómo gestionarlos es una decisión que depende de cada uno de nosotros. A través de esta aplicación, podrás contribuir a crear las primeras licencias de datos para el beneficio de todos. ¿Te sumas?

www.ideasforchange.com/triem

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○●○○○○○○

Imagina que **una universidad** te pide **datos de actividad online** para investigar **enfermedades raras.** Los resultados serían publicados **en abierto.**

¿Donarías tus datos?

○●○○○○○○

Si has decidido **no donar** tus datos, ahora imagina que te ofrecen incentivos a cambio de ellos.

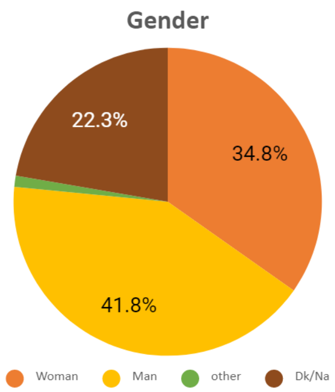
¿Donarías tus datos ante estos incentivos?

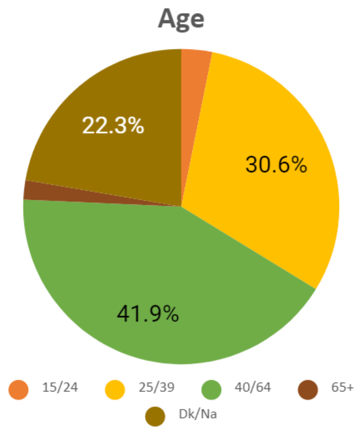
Análisis personalizados

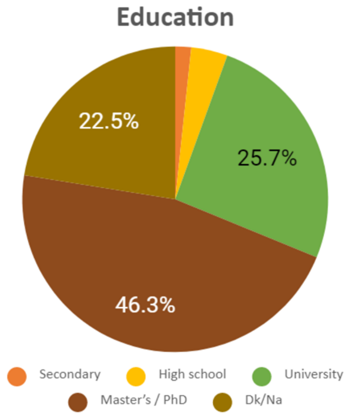
A cambio de donar tus datos te ofrecen información personalizada sobre tu salud basada en los datos que compartiste.

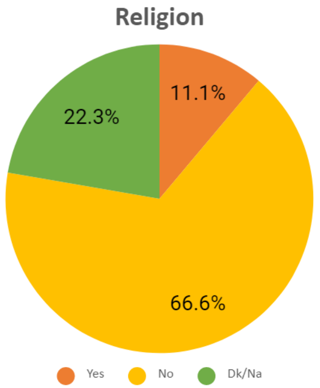
TRIEM

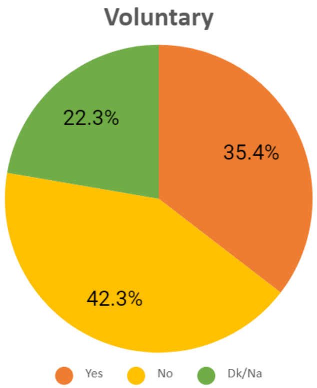
600 identified respondents to more than 8.000 scenarios

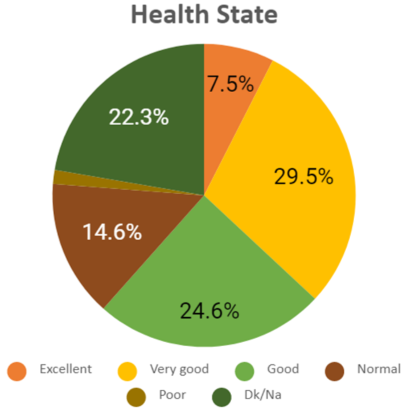












% Donation = “yes”..
8.000 scenarios. TRIEM 2018. SalusCoop

SEGMENTO	PUBLICACIÓN	ENTIDAD	ENTIDAD	% DONACIÓN
Salus	Open	Pública & University	Chronic & rare	87%
+Private	Open	Private	Chronic & rare	72%
+Aesthetics	Open	Publica & university	Aesthetic	71%
+Closed	Closed	Public & university	Chronic & rare	64%
Rest of others	otras combinaciones	otras combinaciones	otras combinaciones	38%

Main conclusions

% Donation drivers:

1st. Open/shared Results
2nd. Non-profit entities
3rd. Only critical diseases

- No risks
- No incentive changes donation (money included)

SALUS CG LICENSE

Salus Common Good Data License for Health Research

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1. **Only health:** your data will only be used for research of chronic and rare illnesses.
2. **Non-commercial:** research projects will be promoted by entities who support general interest such as public institutions, universities and foundations.
3. **Shared results:** results of the research will be accessible at no cost.
4. **Maximum privacy:** all data will be anonymized prior to use.
5. **Complete control:** you will be able to cancel or change the conditions under which your data can be accessed at any time.

SALUS CG LICENSE

Salus Common Good Data License for Health Research

100%

Chronic &
Rare diseases

100%

Non Commercial entities

100%

Shared free results

100%

Privacy protection

100%

Change preferences any time

When you apply ***Salus Data License for Health Research*** to any data you are contributing to public interest, relevant issues, open knowledge discoveries to improve our collective health.

Supporting entities: SALUS CG license has been developed by SalusCoop a citizen cooperative of data for health research created in Barcelona, 2017. Learn more & join at: **www.saluscoop.org**

REGISTRATION OF DONATIONS

FONTS
DE DADES

Proveïdors de Salut

Apps,
Wearables

Altres fonts
de dades

DONANT
DE DADES

Salus APP

Gestió de dades personals

Donació de dades

Consulta de situació donació

LLICÈNCIA SALUS CG

Assignació llicencia a dades

Registre de Donacions

Lista de donants

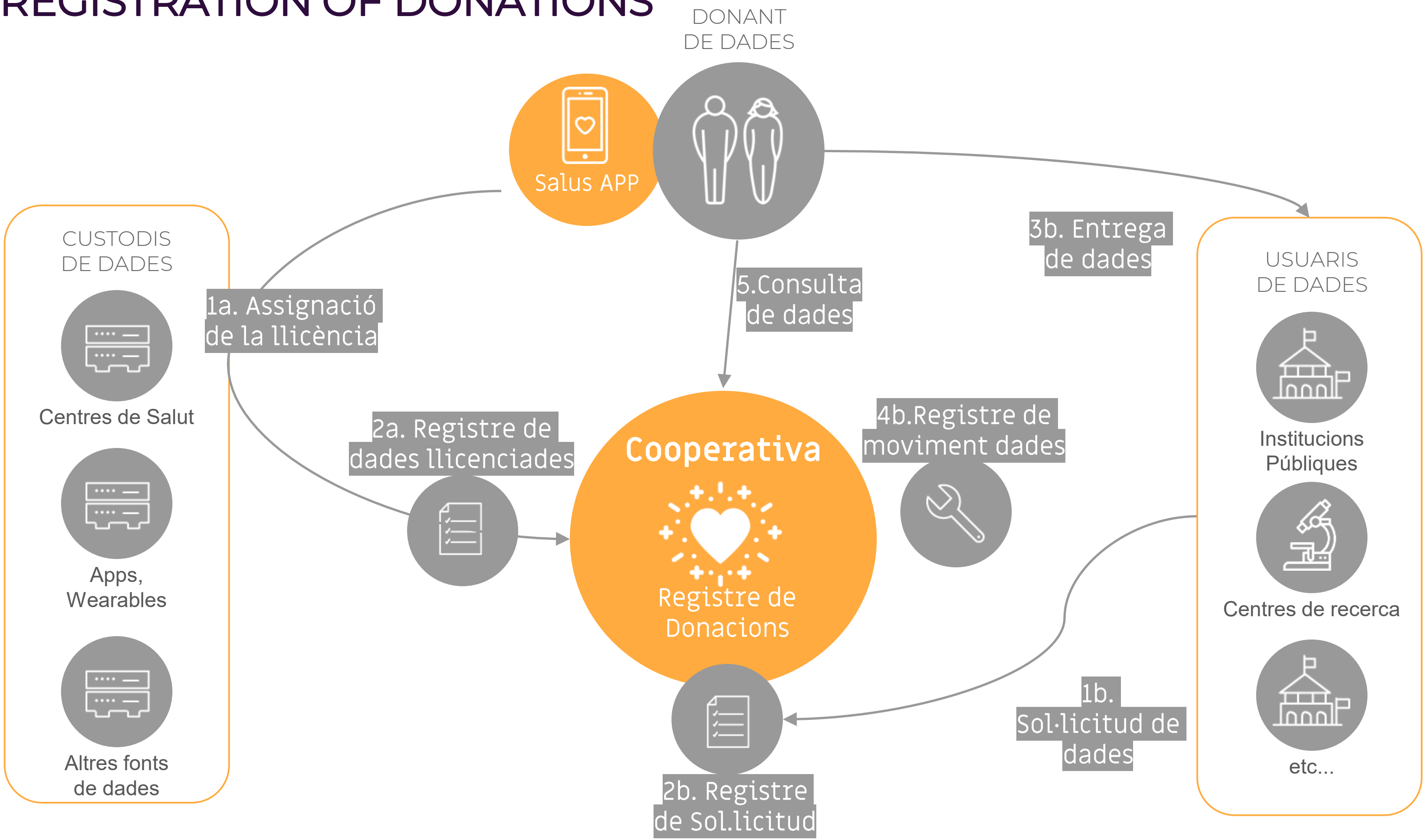
Registre de dades donadas

Registre de Us de les donacions

consulta

INVESTIGADORS

REGISTRATION OF DONATIONS



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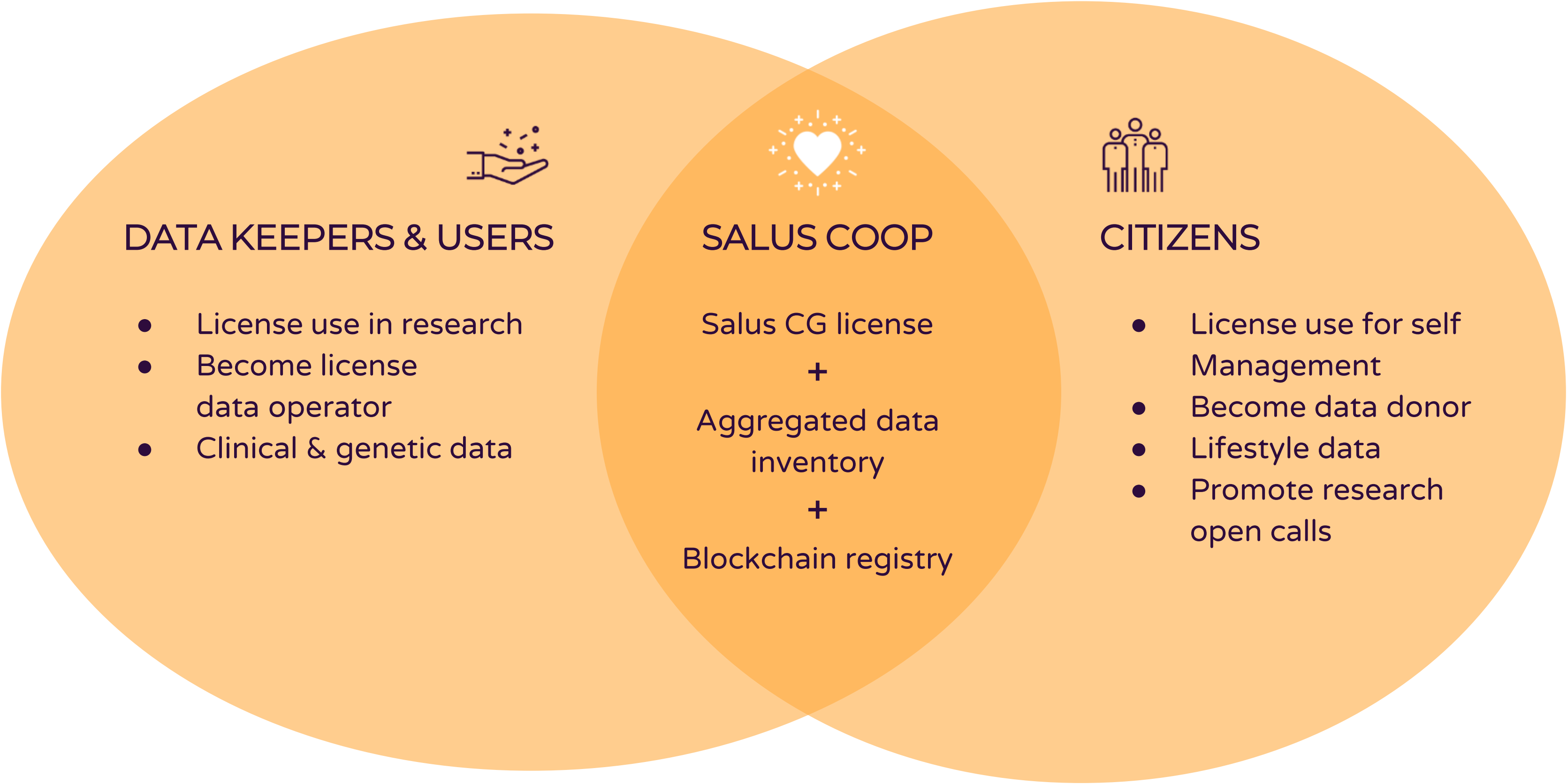
Development vision



DATA KEEPERS & USERS

- License use in research
- Become license data operator
- Clinical & genetic data

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Salus CG license

+

Aggregated data inventory

+

Blockchain registry

CITIZENS

- License use for self Management
- Become data donor
- Lifestyle data
- Promote research open calls

THANK YOU!

#salusCoop
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