



EU2017.EE



Estonian Presidency
of the Council of the
European Union

TASK FORCE 2 DATA DONORS & CITIZEN-CONTROLLED DATA GOVERNANCE FOR SECONDARY USE



REPUBLIC OF ESTONIA
MINISTRY OF SOCIAL AFFAIRS



TF2 – Data Donors & Citizen-controlled data governance for secondary use

Where we are I/II

Technical solutions & tools:

e.g.

- Bitcoin/Blockchain
- Artificial Intelligence (AI)
- European Open Science Cloud
- Integrated Health Care Enterprise (IHE) Standard

Political commitment & tools:

e.g.

- “citizen-centered” approaches
- Health in All Policies (HiAP)/Health in All Politics
- X-Border Healthcare Directive

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Where we are II/II

European frameworks & principles:

e.g.

- Four common values and principles in EU healthcare systems: solidarity, universality, access to good quality care, equity (“Together for Health” strategy, 2007)
- Solidarity, Subsidiarity, Proportionality (!)
- Digital Single Market (DSM) Strategy: “Access to own health data”
- Estonian Presidency: “Fifth” EU freedom -“Digitalisation/Gigabit Society”?

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What needs to change

- Current models for governing data for better health and health care are based on an outdated assumption of data protection and data security: This does not work for the future!
- A good governance model is missing!

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What we need

A Good Governance Model

- for citizen-owned and -controlled data
- allowing for both, (1) free flow of non-personal data and (2) access and re-use of data for future known and unknown purposes
- going beyond health, health data and IT solutions for health
- understanding data as the essential part for health research, healthcare and health improvement
- in line with e.g.
 - the forthcoming EU Commission policy paper on “The Transformation of Health and Care in the Digital Single Market”
 - “Cloud Council” recommendations

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The Solution

**“A pan-European Good Governance Model putting the citizen in the driver’s seat to make best use of technological innovations and (health) data for individual benefit and the common good
= (Health) Data Cooperatives”**

This means:

The citizen is the creator, the “natural” interpreter, the controller, the owner and the sharer of the data for primary and secondary use for all kinds of purposes in a trusted entity – even beyond the health sector.

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Development of an European good governance model for citizen-owned and -controlled data: within the global context, going beyond the health sector

Definition:

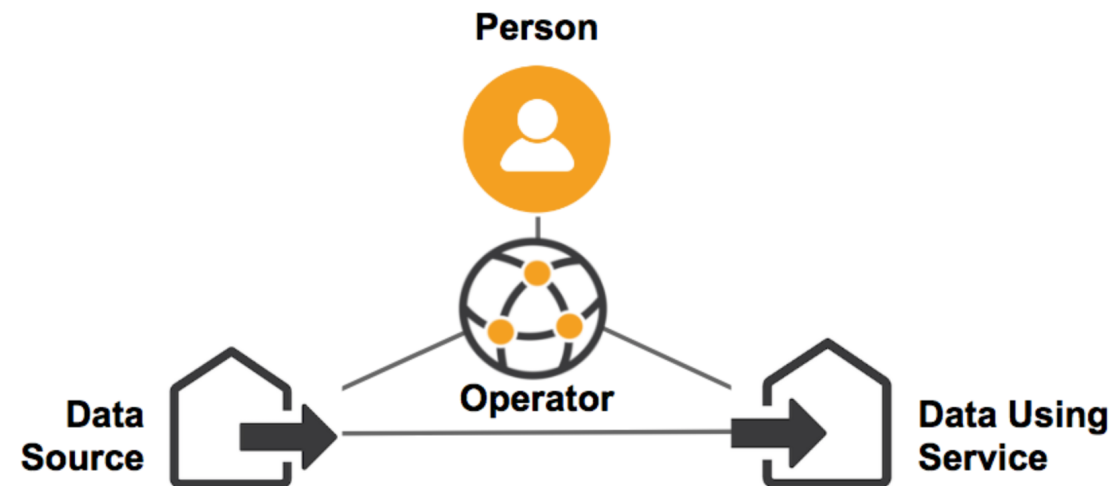
A cooperative is "an autonomous association of persons united voluntarily to meet their common economic, social, and cultural needs and aspirations through a jointly-owned and democratically-controlled enterprise".

(International Cooperative Alliance)

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Development of an European good governance model for citizen-owned and -controlled data: within the global context, going beyond the health sector

In line with “My Data” movement:



More at: <https://mydata.org/declaration>

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Why a cooperative model?

for secondary use

- Truly Bottom-up solution (citizen in the driver's seat) and truly democratic solution for Europe and beyond
- Can include various types of data donors (citizens, companies, administration, etc.)
- One person = one vote
- Data can be stored in an intelligent cloud
- All over Europe established = all legal problems solved
- Citizen (human being) as the interface („super-computer“/holistic data integrator)
- Horizontal use of data/Health in all Policies (HiAP)
- Data commons/knowledge commons/commons arrangements
- Balancing personal benefit and common good
- Benefit/ incentives for provider and user (business models)
- Useful for primary and secondary use of data
- There is even a statute for a European Cooperative Society⁽¹⁾

(1) „The European Cooperative Society (SCE) is an optional legal form of a cooperative. It aims to facilitate cooperatives' cross-border and trans-national activities. The members of an SCE cannot all be based in one country. The SCE is required to unite residents from more than one EU country"

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Next steps I/II

Funding & Pilots

Funding:

e.g.

- Smart cities
- European Investment Bank (EIB)
- EU Member States
- DG CONNECT and DG SANTE
- IMI

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Next steps II/II

Funding & Pilots

Pilots:

e.g.

- “Tool box” for (Health) Data Cooperatives
- Business to business money initiatives (VKB)
- X-border implementation
- Depending on stakeholders and local needs:
 - Quartier/neighbourhood management
 - Hospital management
 - Disease-specific self-help groups
 - Social networks
 - Smart city

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Members

Phase 1

- Angela Brand (Maastricht University, NL) / lead
- Robert Madelin (Strategy Consultant, BE)
- Matthias Reumann (IBM Research, CH)
- Richard Bergstrom (SICPA & Hoelzle Consulting, CH)
- Antti Poikola (Helsinki University of Technology, FI)
- Ricardo Baptista Leite (Member of National Parliament, PT)
- Nikolaos Evangelatos (Paracelsus Medical University Nuremberg, DE)
- Helmut Brand (Maastricht University, NL)
- Lada Leyens (swissmedic, CH)
- Peter Kapitein (Inspire2Live, NL)

Phase 2

Any organisations willing to join the initial group and commit to the roadmap defined by the TF2 recommendations

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