



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



Where we are I/II

Technical solutions & tools:

e.g.

- **Bitcoin/Blockchain**
- **Artificial Intelligence (AI)**
- **European Open Science Cloud**
- **Integrating 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**
- **B20 recommendations to G20 (Policy Paper “Stepping Up Global Health” 5/2017)**

Where we are III/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”, 2007)
- Solidarity, Subsidiarity, Proportionality (!)
- Digital Single Market (DSM) Strategy: “Access to own health data”
- Horizon 2020: IMI
- Estonian Presidency goal: “5th EU freedom” -“Digitalisation/Gigabit Society”

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.

Why a cooperative model?

Regulatory

- **Bottom Up Solution**
- **All Europe – Resolved Legal Issues**
- **Horizontal Data Access – Health in all Policies**
- **Primary and Secondary Use**
- **Interoperability with existing Initiatives**
- **Statute for European Cooperative Society**
- **Stakeholder = Vote**

Utility

- **Data Donors (Corporates , Societies & Services)**
- **Citizen as the interface**
- **Data Commons / Knowledge Commons**
- **Business Models (Incentives for providers and users)**
- **Cloud Access and Utility**
- **Balancing Personal Benefit and Common Good**