

FORUM OF INTERNATIONAL
RESEARCH & DEVELOPMENT
PHARMACEUTICAL COMPANIES, EIG

10th Strategic Conference **VALUE OF INNOVATION**

Digital transformation for informed decision-making in healthcare

10th Strategic Conference *THE VALUE OF INNOVATION*



How health data is driving innovation

The Value of Health

Economic context:

- Legacy of the crisis: high debts and deficits
- Continued increases in public health spending anticipated
- Concerns about how this will be paid for (sustainability of public finances)

Population health:

- Ageing and rising levels of chronic disease and comorbidity
- Public health problems and inequalities

Health systems:

- Challenge of responding to changing population needs
- Need for structural reforms – e.g. integrated care, eHealth
- Evidence of marked variation in clinical practices and significant levels of 'waste'



Individual level health data

EHR systems, apps, sensors, genomics, Clinical Decision Support, AI

Used for:

- Health status monitoring
- Continuity of care (including the patient and caregivers)
- Care pathway tracking, clinical workflow management
- Real-time feedback and guidance to patients and clinicians
- Personalised medicine
- Disease interception, prevention and wellness
- Healthcare provider reimbursement

Population level health data

EHR systems, regional & national eHealth infrastructures

Reused for:

- Healthcare provider performance and planning
- Quality and safety, care pathway optimisation
- Medical device and algorithm refinement
- Pharmacovigilance
- Public health surveillance
- Public health strategy
- Health services and resource planning

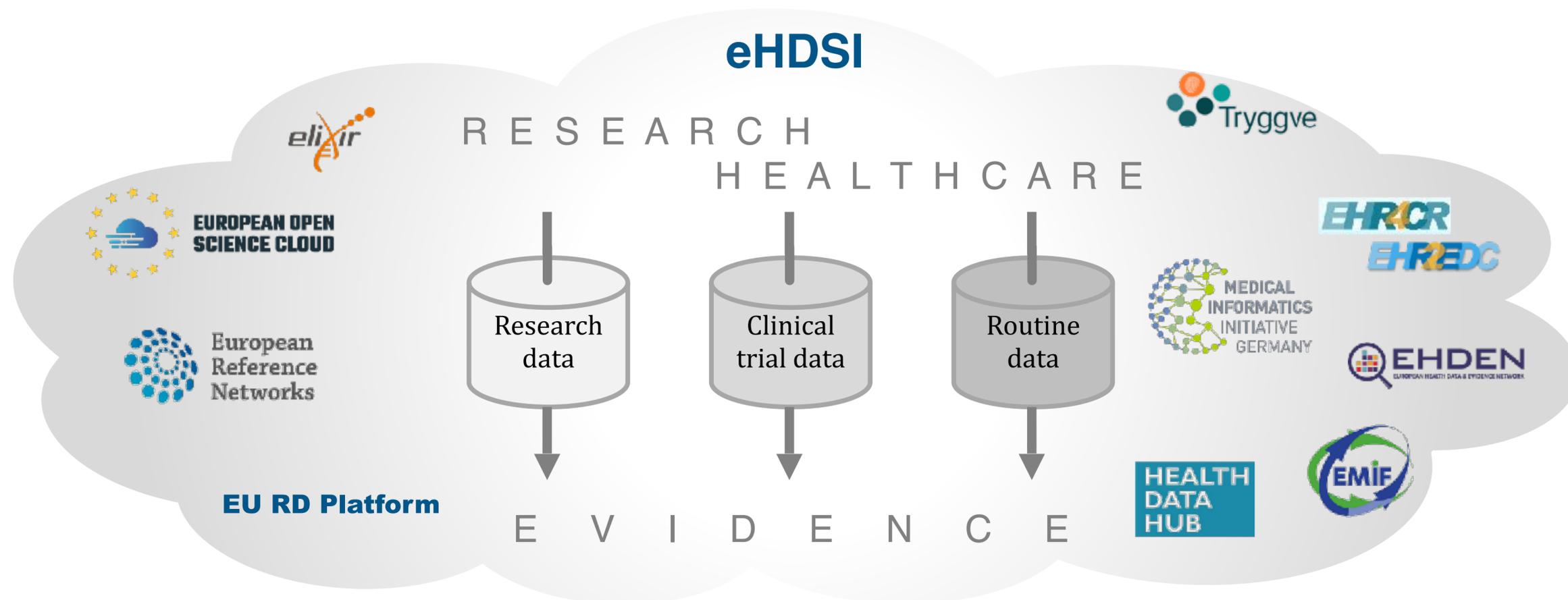
Big health data

national & international research infrastructures, federated query platforms + cross-sectoral services

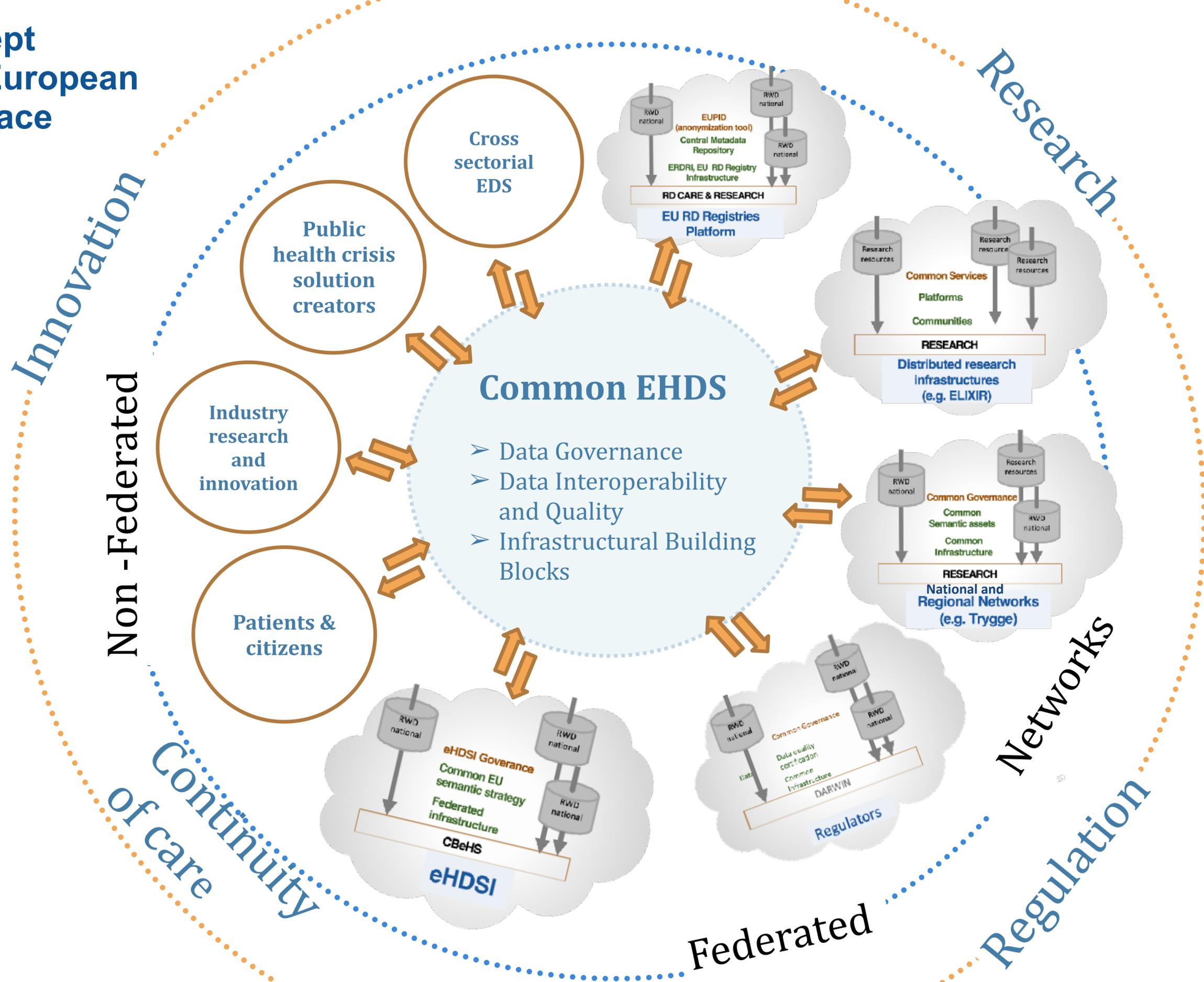
Reused for:

- Epidemiology
- Digital innovation: devices, sensors, apps
- AI development
- Personalised medicine and bio-marker research
- Diagnostics development
- Drug development
- Disease understanding and stratification

- Myriad of initiatives to share health data across jurisdictional, institutional and domain borders:
 - Sharing data for cross-border care or for research
- Emerging paradigm for analysing personally-identifiable health data:
 - federated infrastructure model: network of repositories with an overarching governance and interoperability layer



Possible concept model for the European Health Data Space



Scaling up cross border reuse of health data

eHealth Stakeholder Group - Working Group 2

10th September 2021

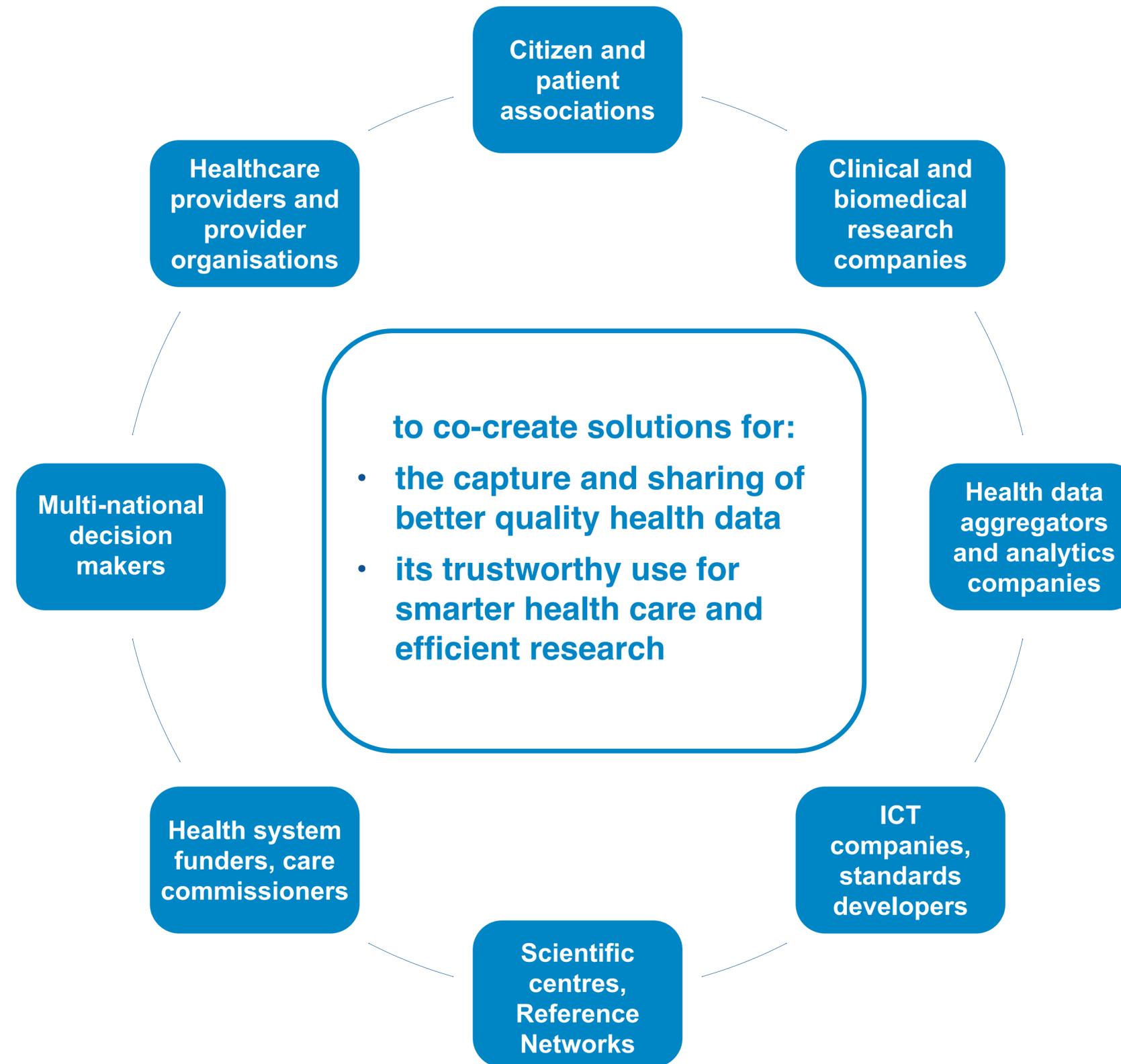
We envision a world where health data can be legitimately shared for research and policy-making

- Citizens, patients and providers understand the importance of data usage for healthcare and for evidence generation
- Citizens have the skills and user-friendly tools to, if they wish, determine and oversee access to their personal health data
- All stakeholders/data holders (patients, health and care professionals, researchers, health care and research organisations) are motivated to and can contribute their data for the benefit of citizens and patients
- All researchers, in academia and industry, have the opportunity to access health data for research and innovation that benefits citizens and patients, adhering to clear, ethical and well-accepted criteria and conditions including GDPR compliance
- All key stakeholders provide input to the establishment of the EHDS infrastructure, advance data quality and interoperability as well as standards and conditions for reuse of data including data protection safeguards and cybersecurity requirements
- GDPR is interpreted and implemented in a harmonised manner at all levels across the EU, facilitating health data use and sharing for R&I and policy-making

Priority actions for scaling up cross border reuse of health data

- **Improve the availability of robust health data and facilitate accessibility**
- **Improve data re-use conditions**
- **Scale up the capability and capacity to leverage health data**
- **Grow public trust**

i~HD is a neutral, not-for-profit, European institute uniting stakeholders



Thank you!

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