Recommendations for responsible health data sharing and use

Presentation ERRIN Webinar 22nd September
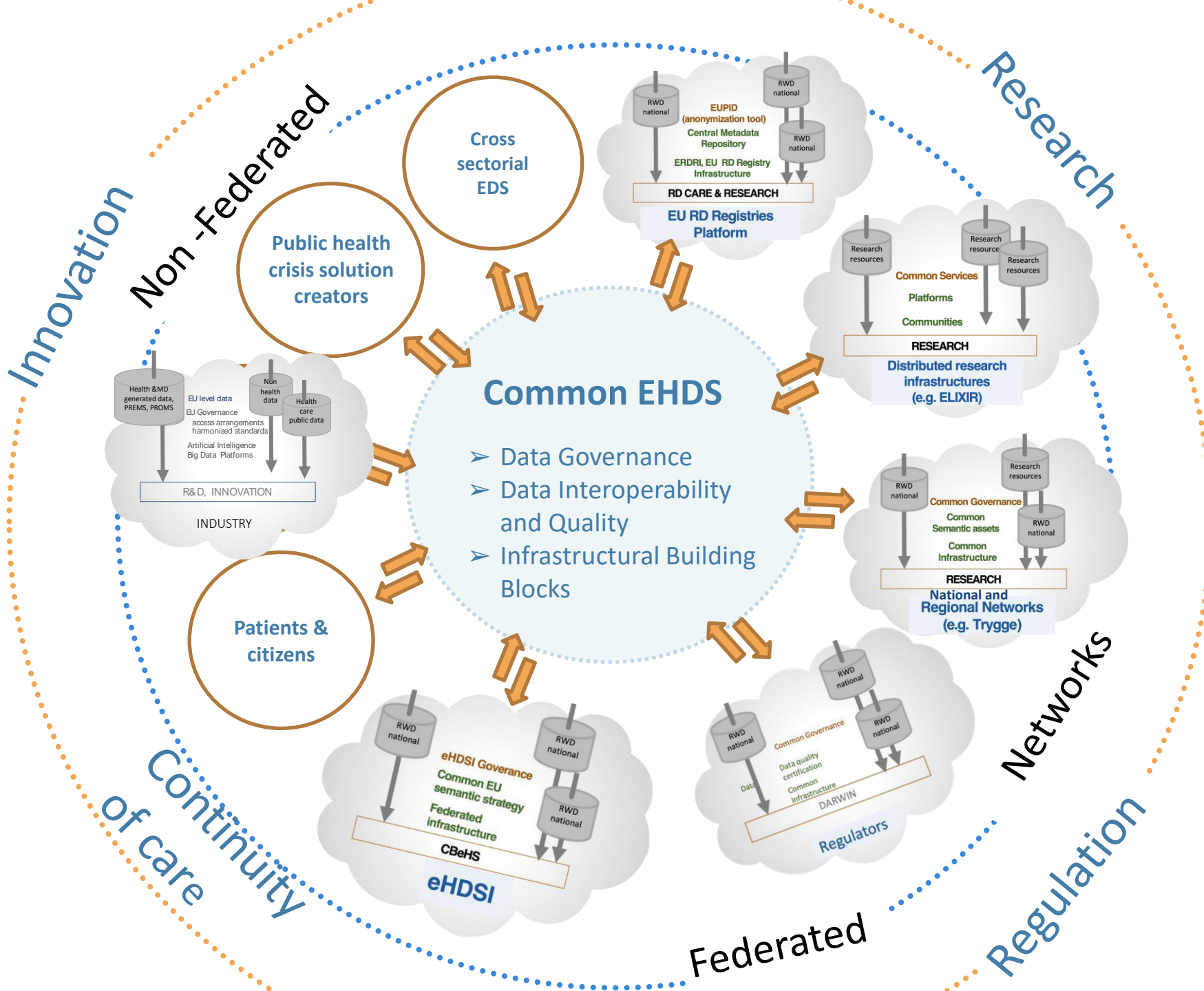
DigitalHealthEurope – some facts

▶ **Title**: Support to a Digital Health and Care Innovation initiative in the context of Digital Single Market strategy

▶ **Duration**: Jan ´19 – Sep ´21 (2 ½ years)

▶ **Instrument**: HORIZON 2020

▶ **Type**: Coordination & Support Action

▶ **Grant Agreement Number**: 826353

▶ **Acronym**: DigitalHealthEurope

▶ **Budget**: €3,999,993.75

▶ Carried out by 17 partners supported by a Board of 50+ Associated Experts

▶ Partners' members (EU & beyond) have >1,100 members, outreach to >20,000 orgs

DHE Stakeholder Consultations on EHDS

DHE CONSULTATIONS ON EHDS	
Consultation with Industry 26/05/2020	- 40 experts - Competitive ICT and service innovation industry (health IT, pharma, medical devices, etc.) - Networks and associations
Consultation with citizens, incl. patients 22/10/2020	- 17 citizens/patients - All regions of Europe - At least ten conditions - Sometimes in multi-morbid combinations

- Large EU citizen survey on health data sharing – 936 responses

- Two DHS & i~HD industry round tables, MyData Global, etc.

- Joining the dots: Ensuring better data for person-centred health and care, optimised research and Learning Health Systems

- >5 workshop sessions
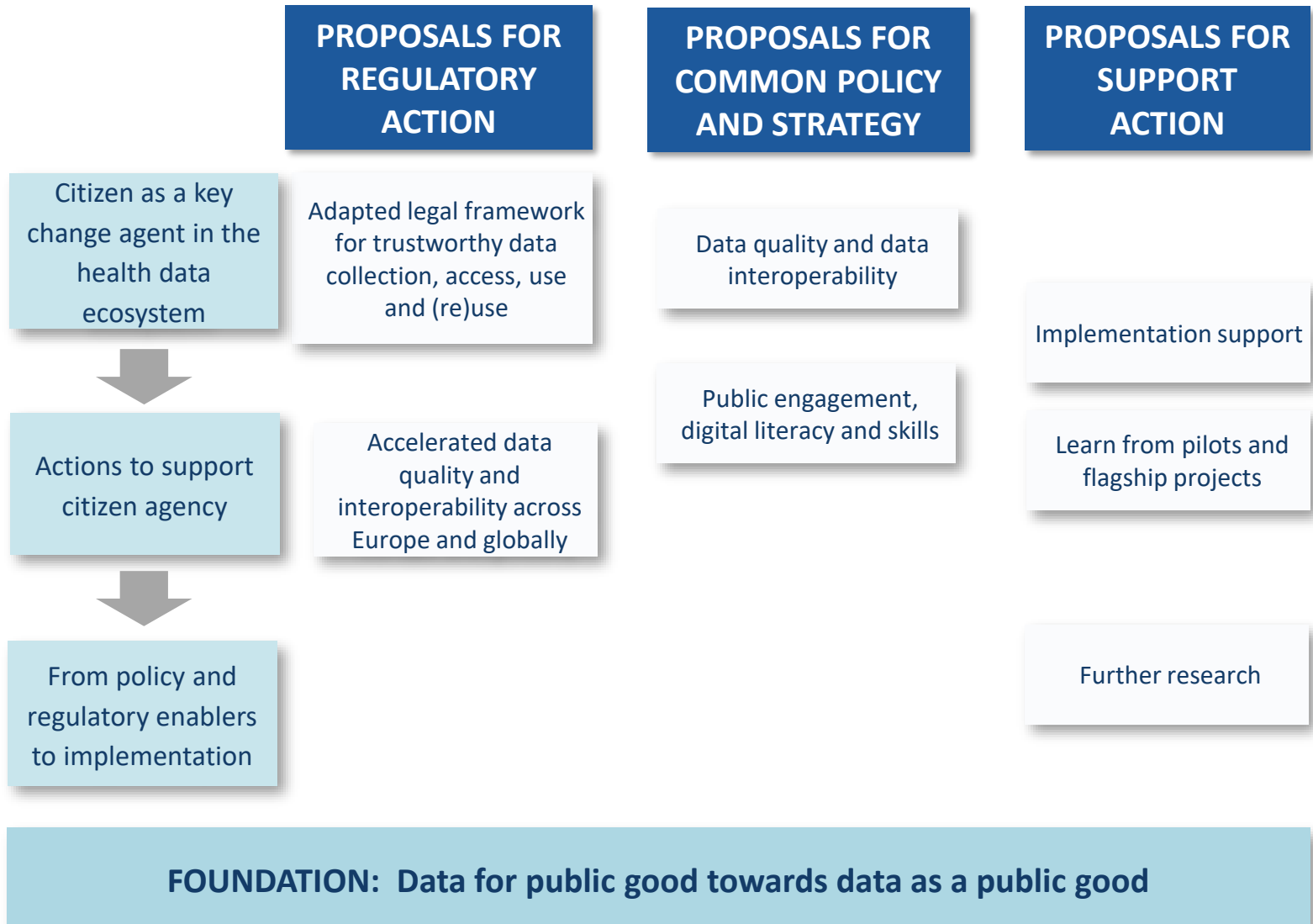
Roundtables (RTs) exploring cross-cutting issues

▶ RT 1: Legal Challenges in Health Data Use

▶ RT 2: Interoperability and Health Data Standards

▶ RT 3: Cloud Technology in Health Data Use

➡ 158 draft recommendations related to health data

Structure of DHE Recommendations

Digital Health Europe

| PROPOSALS FOR REGULATORY ACTION | PROPOSALS FOR COMMON POLICY AND STRATEGY | PROPOSALS FOR SUPPORT ACTION |

Citizen as a key change agent in the health data ecosystem

Adapted legal framework for trustworthy data collection, access, use and (re)use

Data quality and data interoperability

↓

Actions to support citizen agency

Accelerated data quality and interoperability across Europe and globally

Public engagement, digital literacy and skills

Implementation support

Learn from pilots and flagship projects

↓

From policy and regulatory enablers to implementation

Further research

FOUNDATION: Data for public good towards data as a public good

Thank you for your attention!

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