

PHIRI

Population Health Information
Research Infrastructure

The future of European health (data) systems

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Health data

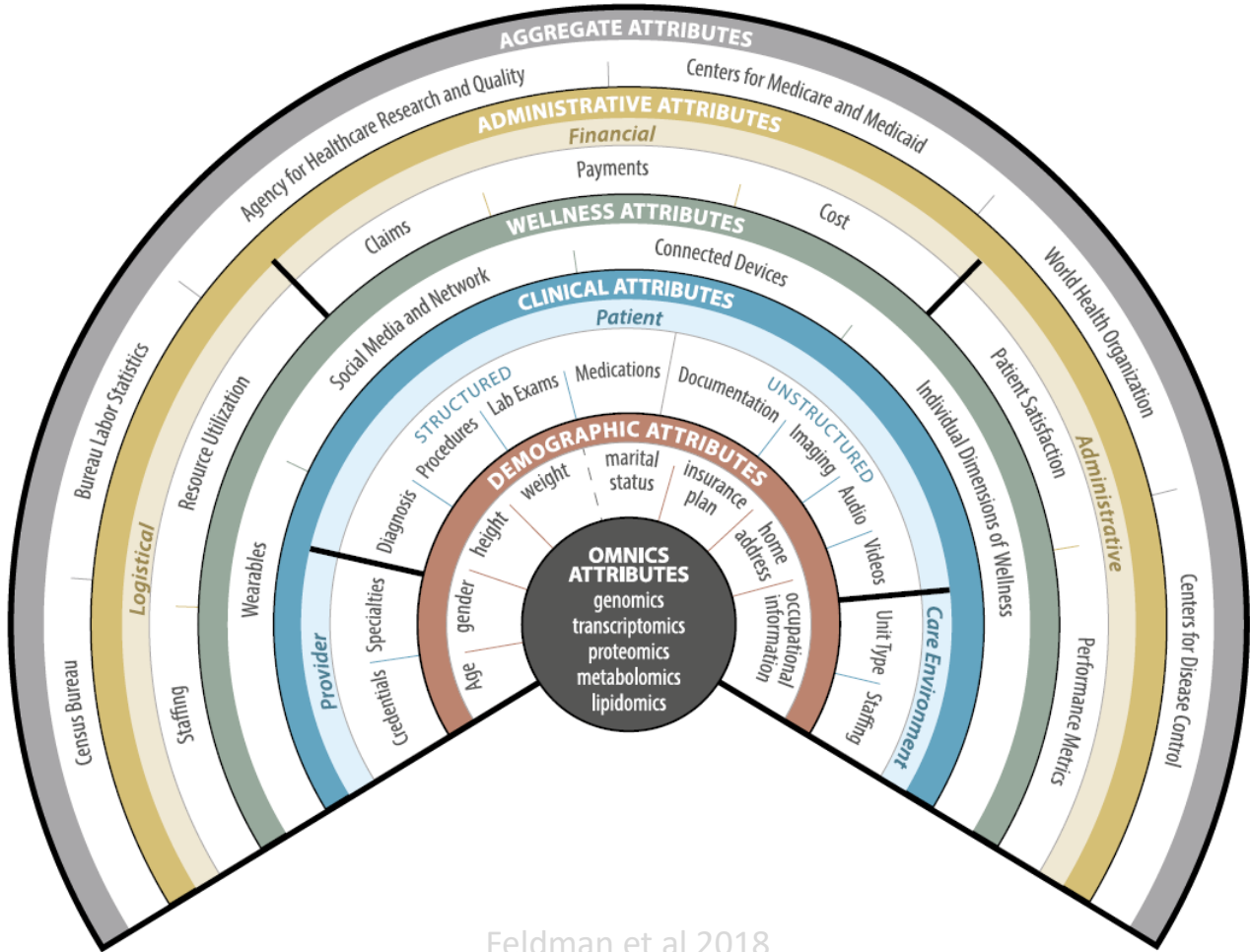
The EU's General Data Protection Regulation (GDPR) defines 'data concerning health' as

“any personal data related to the physical or mental health of a natural person, including the provision of health care services, which reveal information about his or her health status” (Recital 35)

Concepts

- Special category of personal data acc. to GDPR Art 9
- Legal grounds for processing: consent, vital interests, or, in case of existing Union or Member State law: substantial public interest, healthcare, public health, scientific research (opening clauses)
- Personal vs non-personal data
- Anonymisation and pseudonymization

Health data - types



Feldman et al 2018

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Health data - changes

Developments changing the health data landscape

- New data collection points: medical devices (sensors, apps..), internet of (medical) things
 - Cheaper and faster availability of omics data
 - Digital health and digital care pathways
 - Imaging technology
 - Artificial intelligence (language recognition)
 - ...
- more data, more diverse data
- **Opportunity not only for healthcare, but also for public health and health policy:**
cf. discussions around precision public health, public health data science



Health data infrastructures

Health data infrastructures:

- Hospital information systems
- Laboratory software systems
- Radiology systems
- Health insurance claims management infrastructure
- Pharmaceutical information systems
- Clinical trials data infrastructures
- Public health registries and other registry data
- Private sector-held data (health apps)
- Etc.



Health data infrastructures

Challenges:

- Data availability (legal grounds for processing, etc)
- Data accessibility (interfaces, access rules)
- Data quality (missing data, bias, etc)
- Data linkage (legal grounds, institutional interests)
- Timeliness and responsiveness

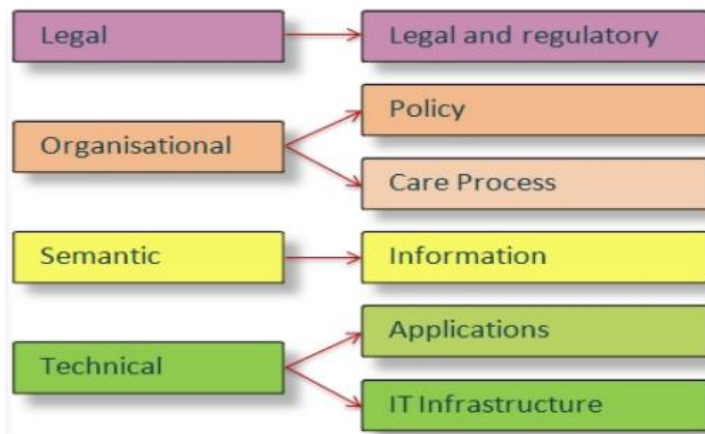
→ Interoperability along the care pathway, between healthcare sectors (inpatient-outpatient) and between healthcare and public health/health policy?

Health data - interoperability

European Interoperability Framework

Legal interoperability	e.g.: types of health data collected and processed in healthcare
Organisational interoperability	e.g. organization of care processes
Semantic interoperability	e.g. standards and terminologies (Snomed, ICD-10, etc.)
Technical interoperability	e.g. communication standards and IT infrastructure

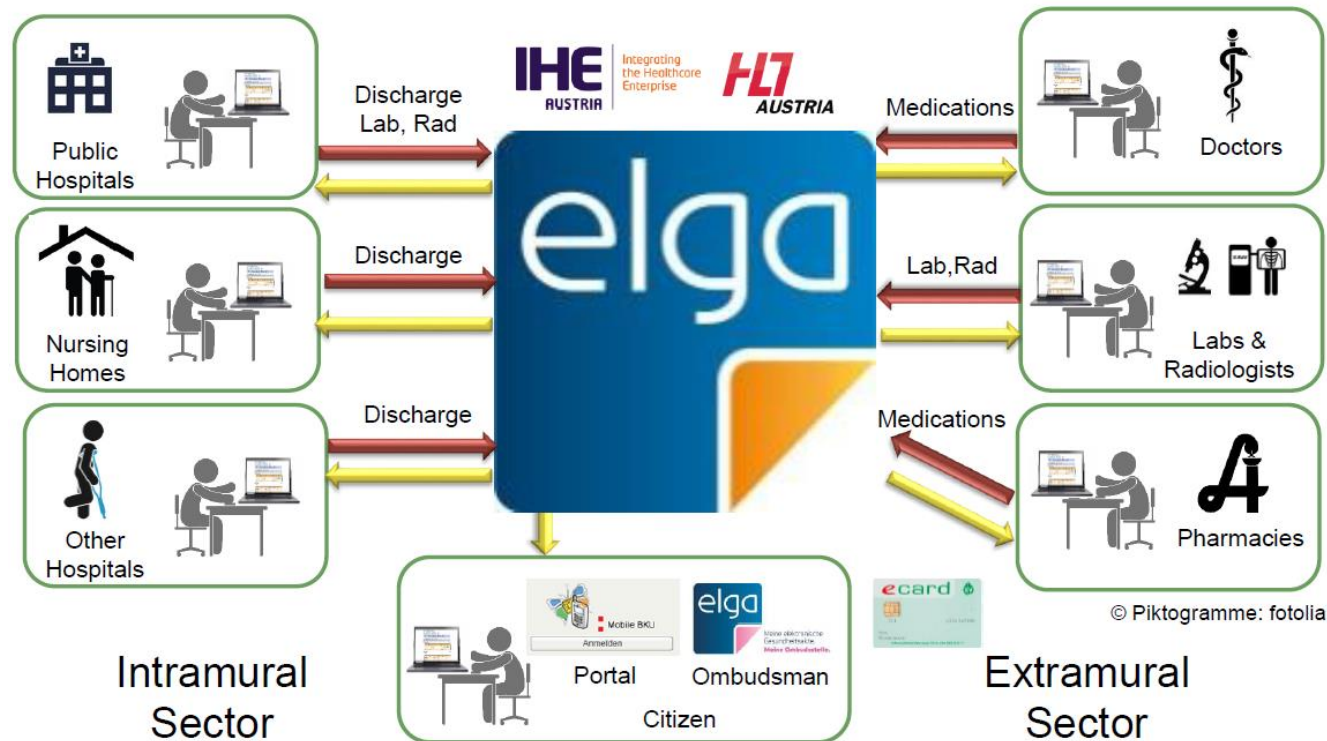
Refined eHealth European Interoperability Framework (eHealth Network 2015):



Case study: Austria

The Austrian health data infrastructure – two examples:

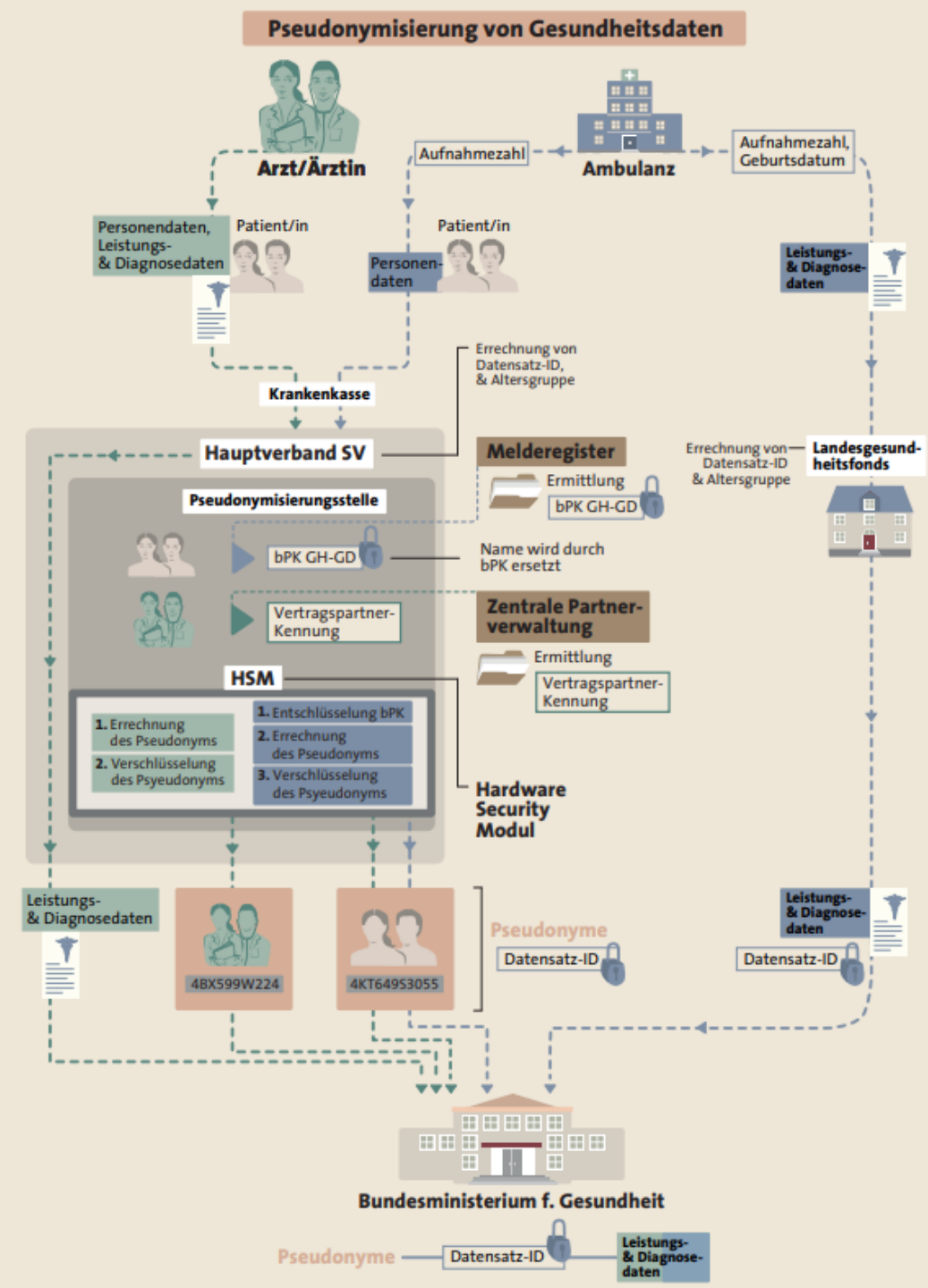
- National electronic health records through ELGA



Case study: Austria

The Austrian health data infrastructure – two examples:

- National electronic health records through ELGA
- Pseudonymisation of health data for systems planning



Health data as a policy problem

Policy challenge

Imagine the Austrian government is thinking about boosting health data sharing

Should Austrian health policy...

- support health data sharing.,
- In general
- For specific conditions (Covid-19), actors (university research) etc?
- limit/prohibit it,
- or do nothing about it?

If you were to decide on and design a policy response, how would you proceed? What steps are necessary?

Health data infrastructures

Functions of **health information systems** (WHO 2017); „[E]nsure the production, analysis, dissemination and use of reliable and timely data by decision-makers at all levels of the health system [...]“

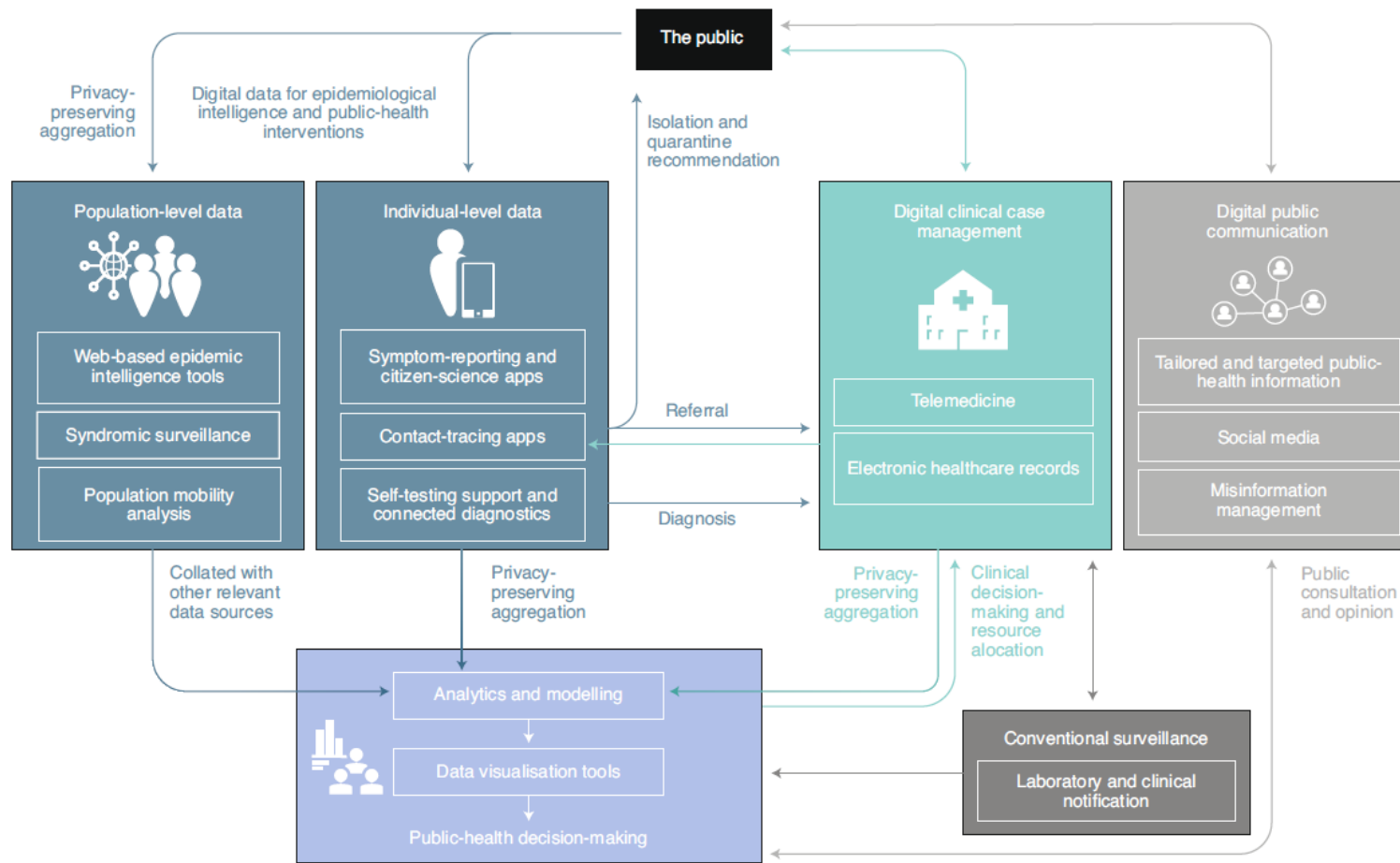
- Generate individual-level, facility-based and population-based data from multiple sources: public health surveillance platforms, medical records, civil registration data, household surveys, censuses, health service coverage and health system input data
- Detect, investigate, communicate and contain events that threaten public health security
- Synthesize information and apply this knowledge

„A good HIS improves both demand for and supply and use of data“ (ibid.)

→ Health data infrastructures as a precondition for functioning HIS

Examples: for surveillance (incl variant screening etc), contact tracing, quality assessment, accounting and planning, research (clinical trials), public health surveys, disease registries

The future



Budd et al. 2020

The future

New and improved

- Data collection opportunities
- Data transfer standards (HL7 FHIR, REST APIs etc.)
- Data infrastructure technologies (clouds, containerisation, distributed ledger systems, etc.)
- Analysis approaches (AI etc.)
- Governance mechanisms and access infrastructures

Health data: EU policy

Relevant EU legislation: GDPR, Data Governance Act (DGA), Cross-border Healthcare Directive, Open Data Directive

New project as part of the vision of a European Health Union and the EU's Data Strategy:

European Health Data Space

Regulation proposed and currently being negotiated

Primary use:

- right of patients to decide on the use of their health data (Art 33)
- novel sets of standardized health data (Art 5)

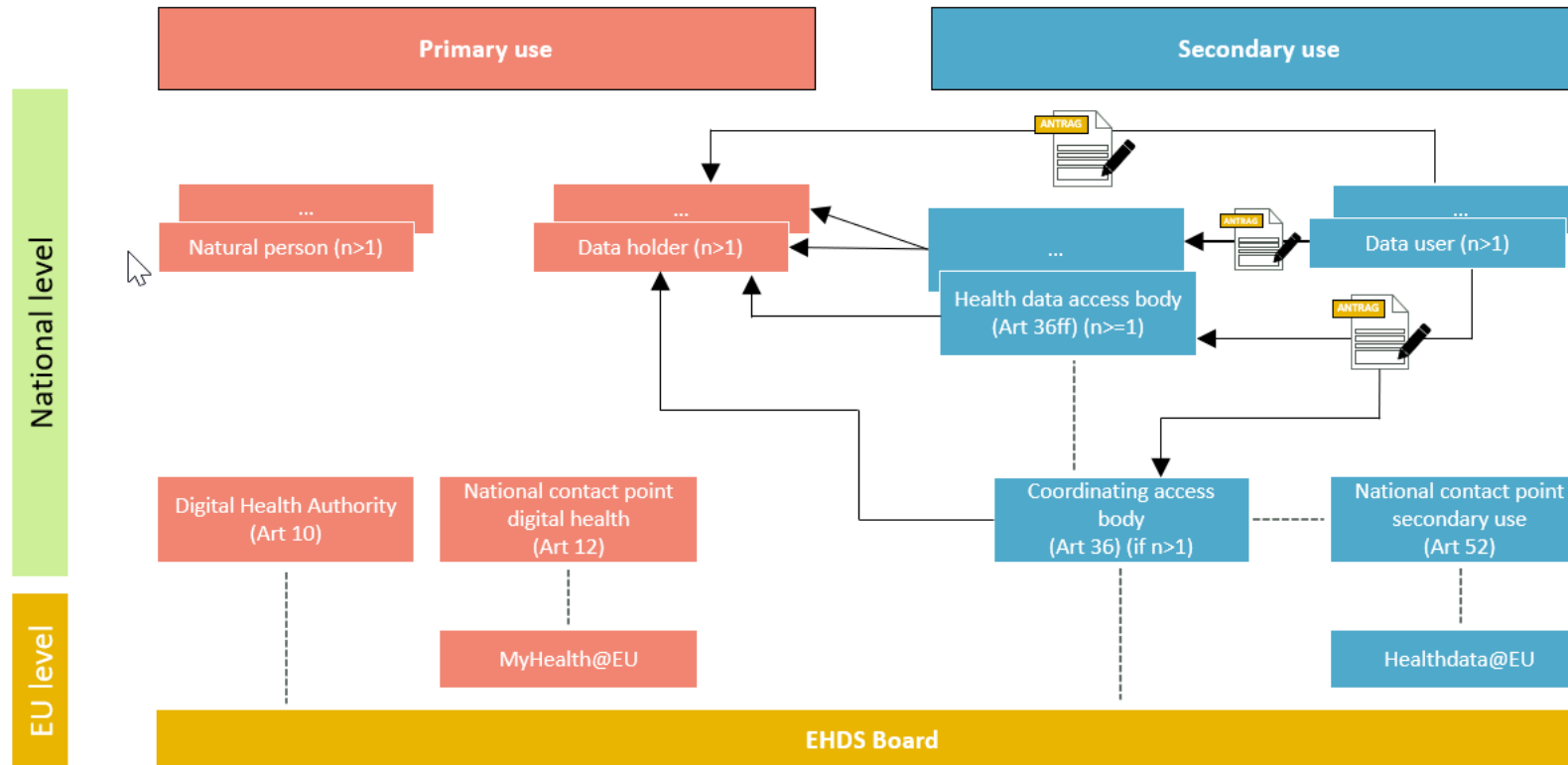
Secondary use: to be facilitated for

- Categories of health data (Art 33)
- Legitimate secondary use purposes (Art 34)

Current discussions: data protection (opt-out?), ensuring public value, role of the access bodies...

→ Your take?

The European Health Data Space





Wrap up

Designing health data infrastructures

- From reactive to proactive
- From case-by-case to modular, systemic and scalable
- From data duplication to automatised interfaces and on-demand availability
- Ensuring data protection and security
- Ethics, public value and accountability

EHDS as a stepping stone, but ,homework' to be done nationally



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Thank you!

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