

# Health data drives innovation



## **Adult Immunization Board**

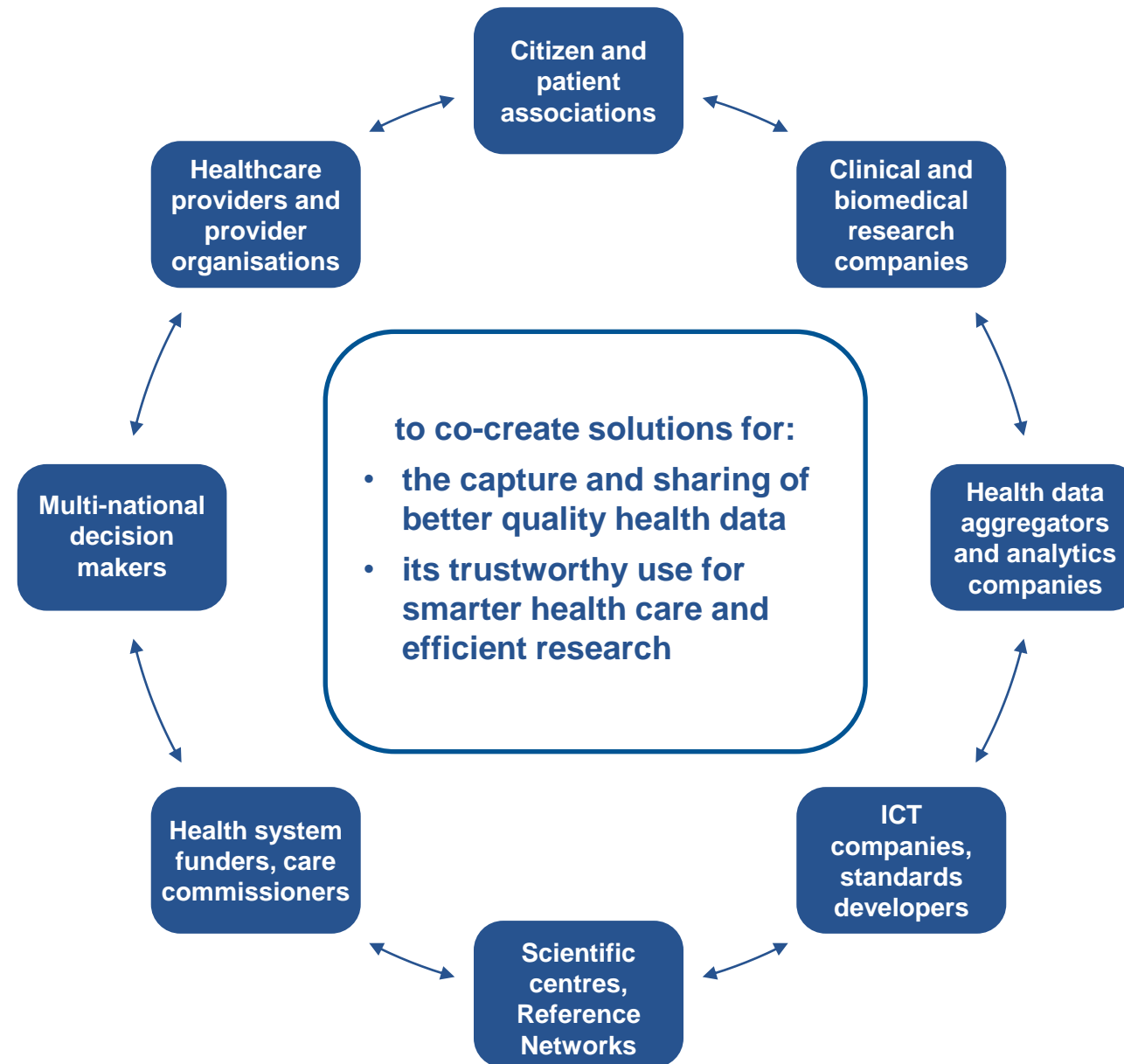
*Technical meeting - 20-21 April 2023*

European Health Data Space  
(EHDS):  
EU health data collection and  
data safety:  
impact on the estimation of  
burden of VPIs



*Dipak Kalra  
President*

# iHD is a neutral not for profit body, bringing stakeholders together



# The spectrum of data use: from care to research

## Individual level health data

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

### Used for:

- Health status monitoring
- Telehealth
- 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

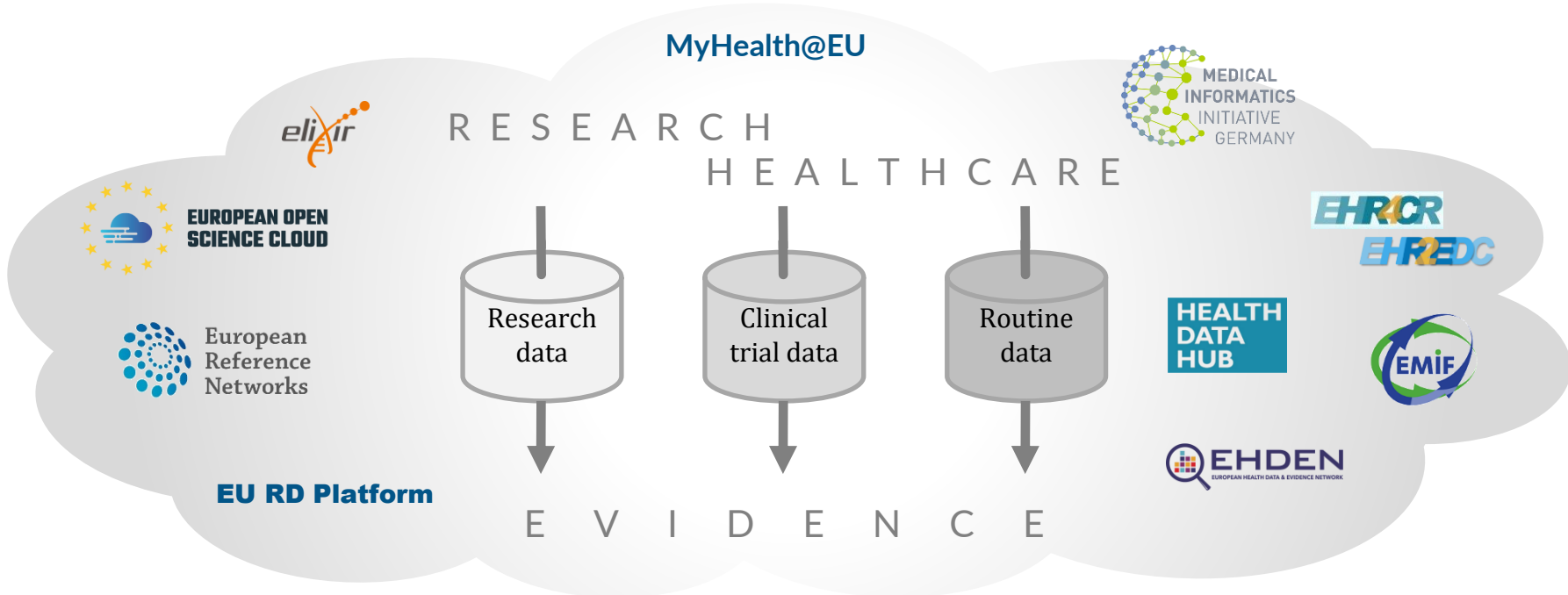
national & international research infrastructures, federated query platforms + cross-sectoral services

### Reused for:

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

# Big health data sharing initiatives

- 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



# Proposal for a Regulation on the European Health Data Space

It sets out rules, common standards, infrastructures and a governance framework for the use of electronic health data for healthcare, research, innovation and policy making

Empower individuals to access and control their personal health data



Ensure a consistent framework for the use of individuals' health data for research, innovation, policy-making and regulatory activities

Unleash the data economy by fostering a genuine single market for digital health services and products (EHR systems)

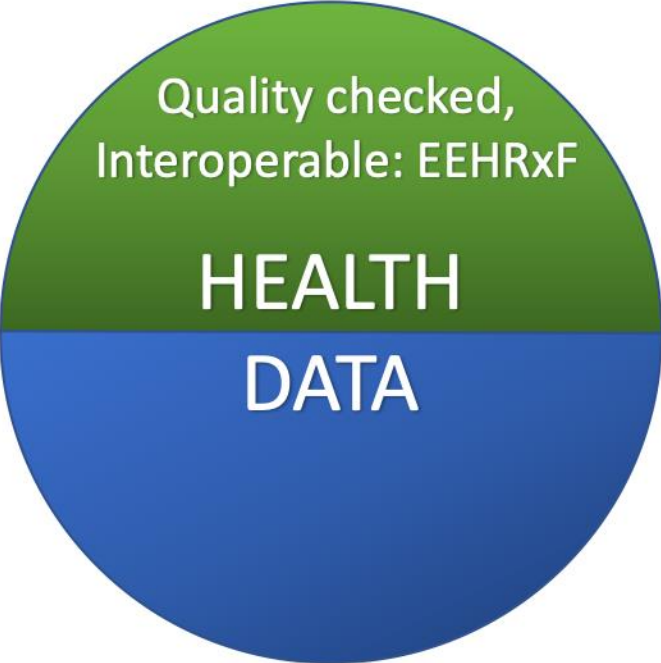


**Primary Use**  
For health, care, wellness



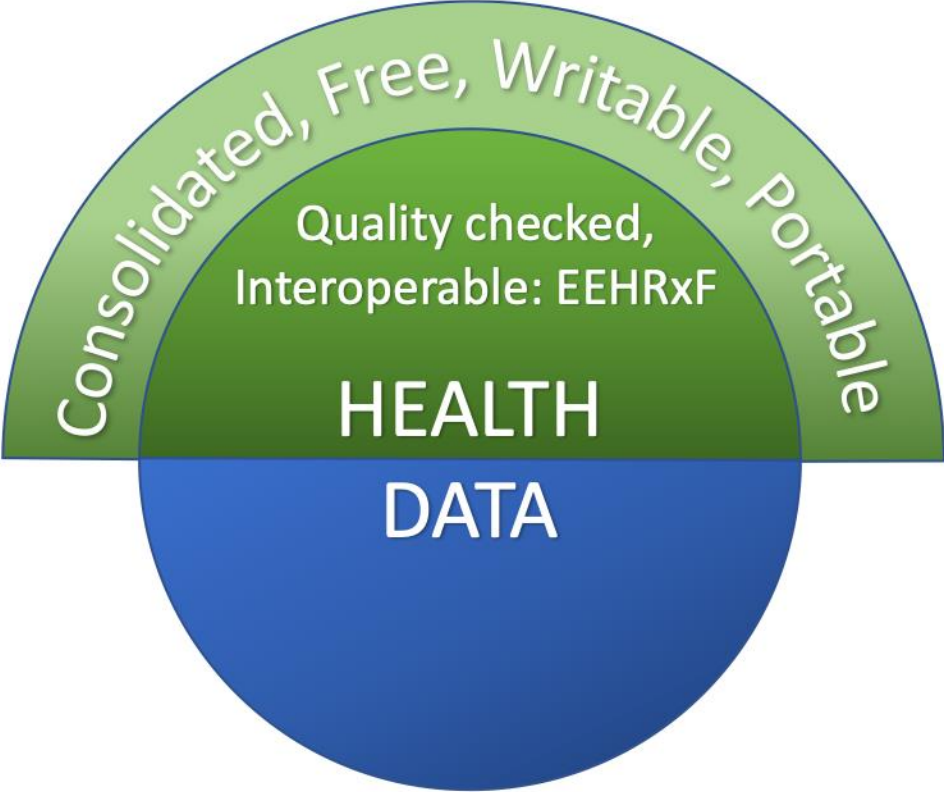
**Secondary Use**  
For research and strategy

**Primary Use**  
For health, care, wellness



**Secondary Use**  
For research and strategy

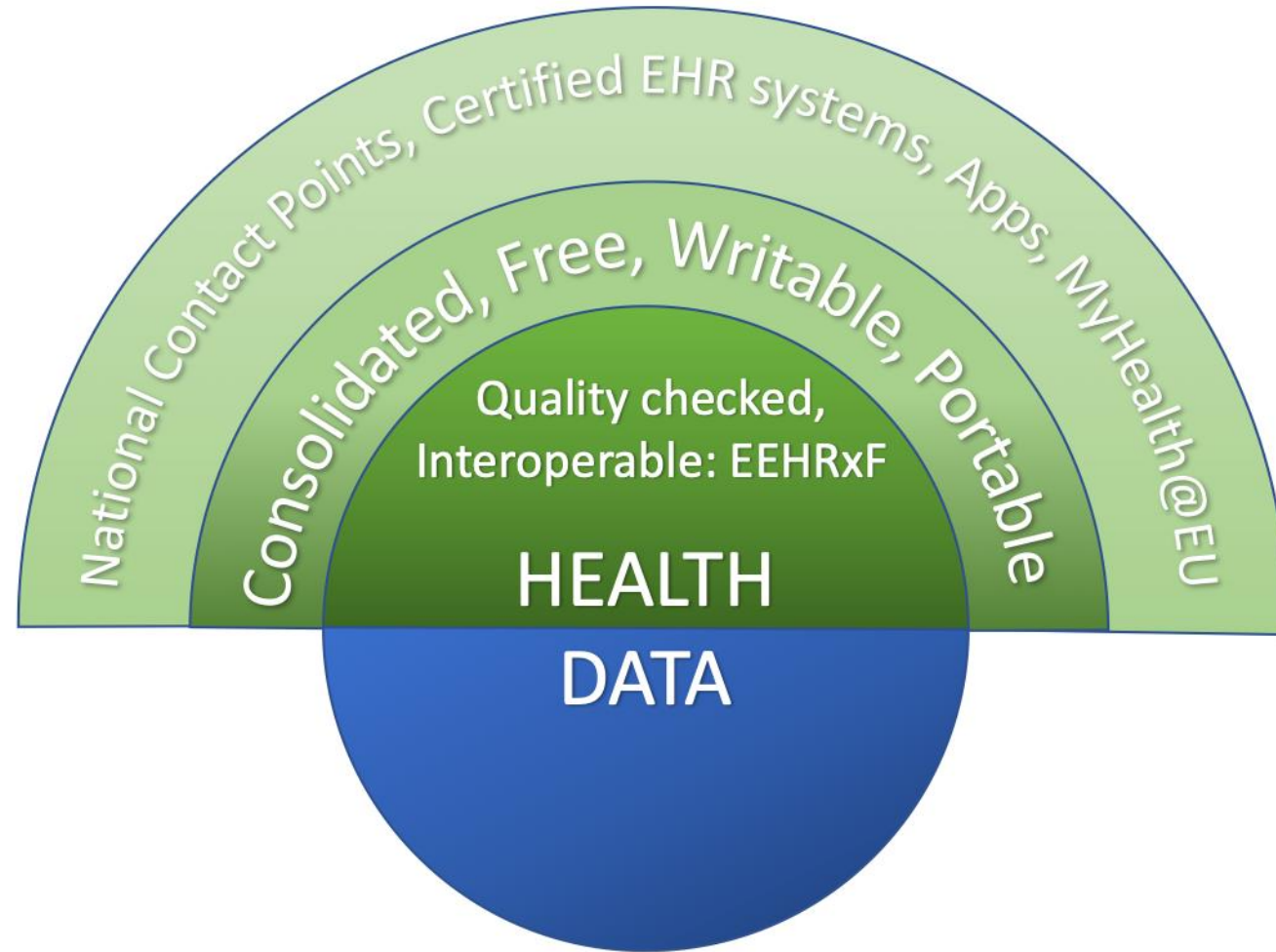
**Primary Use**  
For health, care, wellness



**Secondary Use**  
For research and strategy

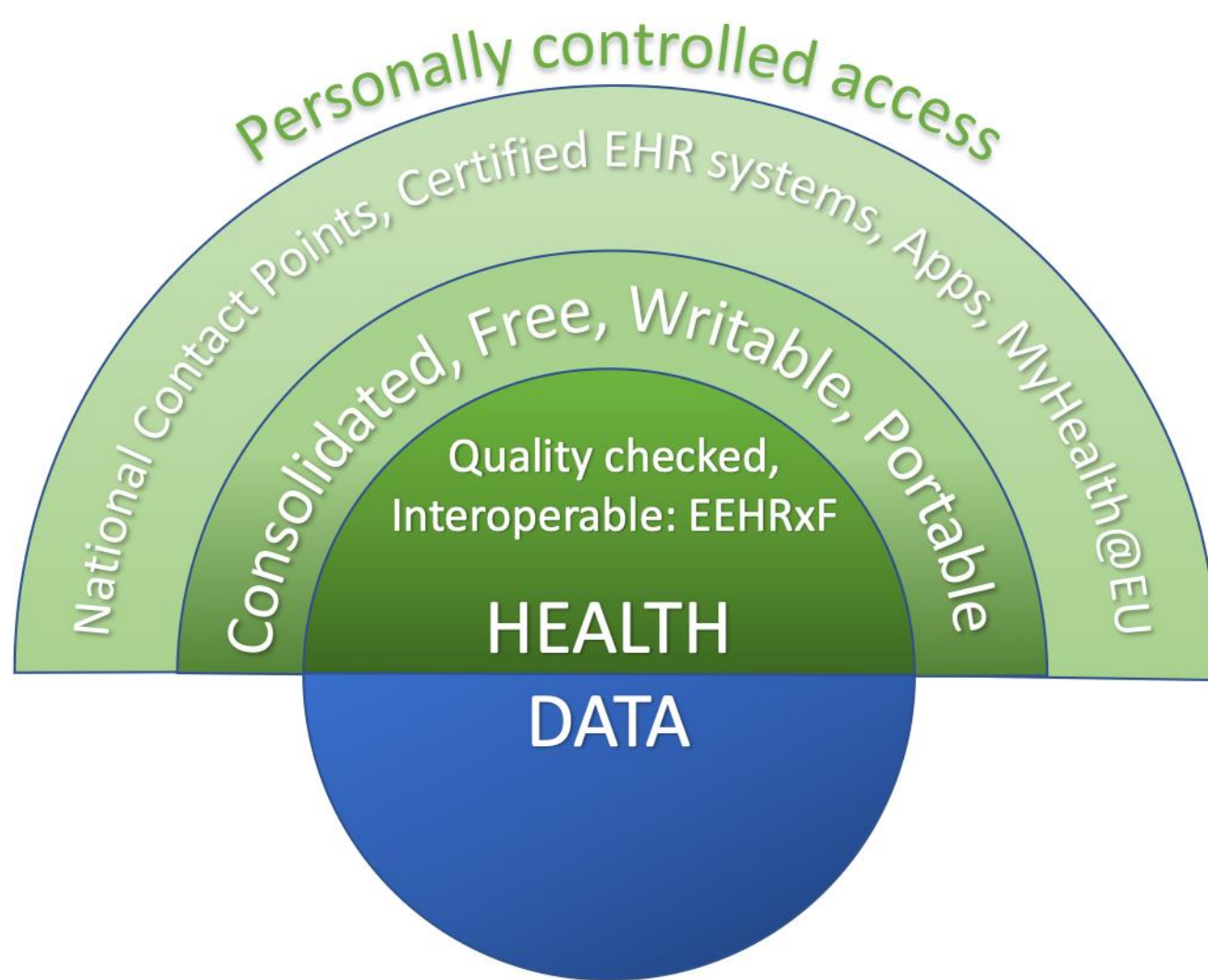


**Primary Use**  
For health, care, wellness



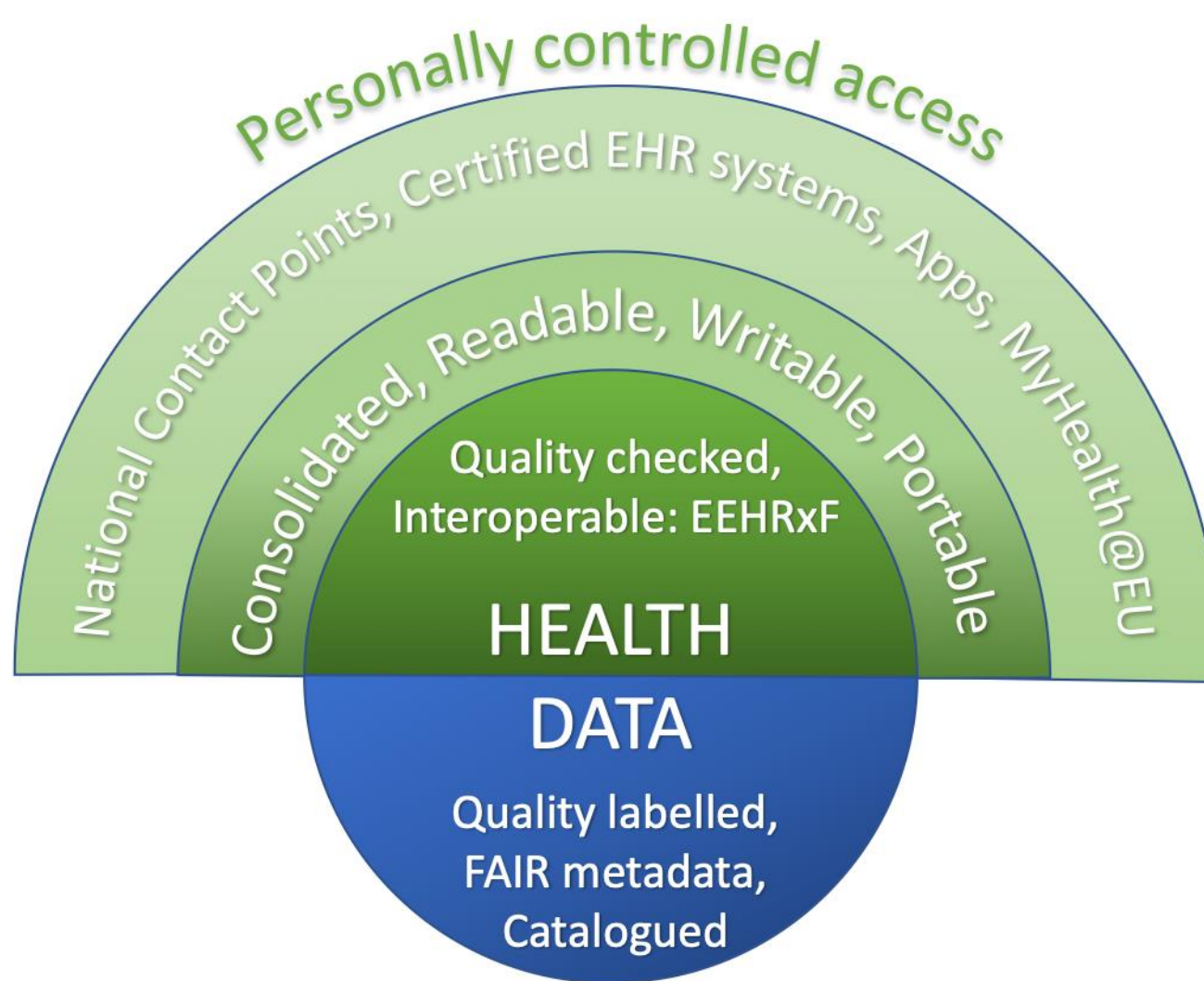
**Secondary Use**  
For research and strategy

**Primary Use**  
For health, care, wellness



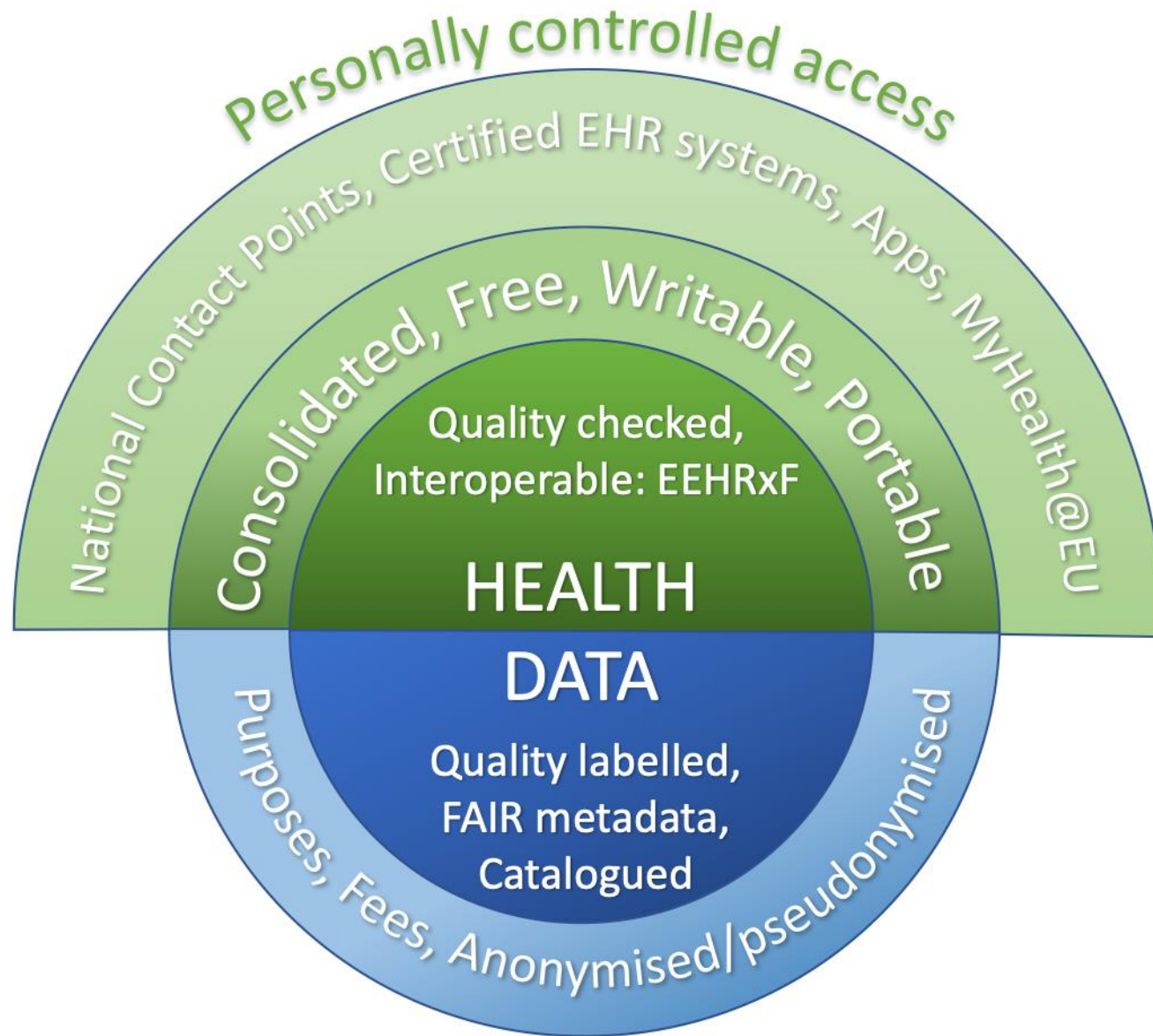
**Secondary Use**  
For research and strategy

**Primary Use**  
For health, care, wellness



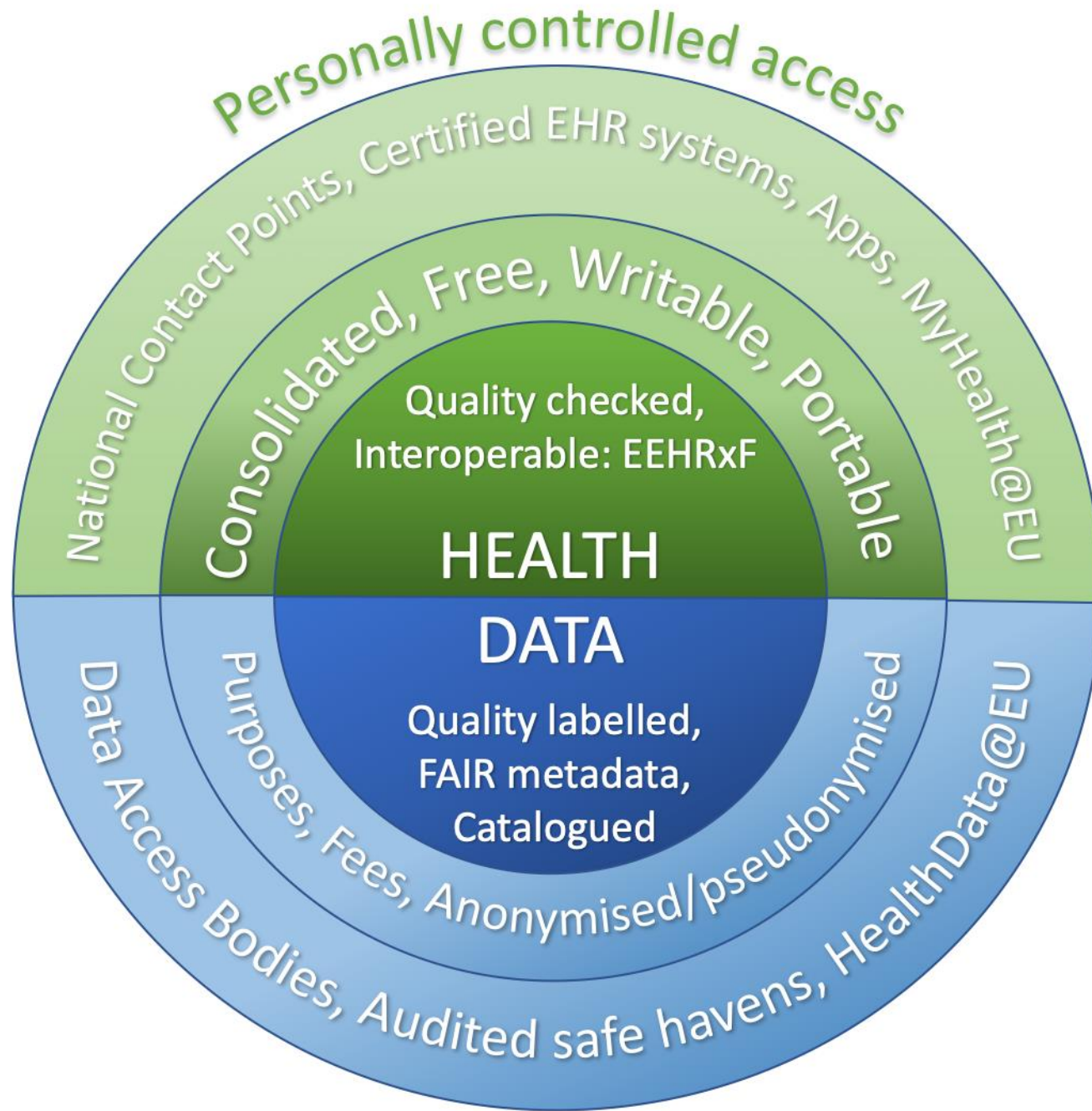
**Secondary Use**  
For research and strategy

**Primary Use**  
For health, care, wellness



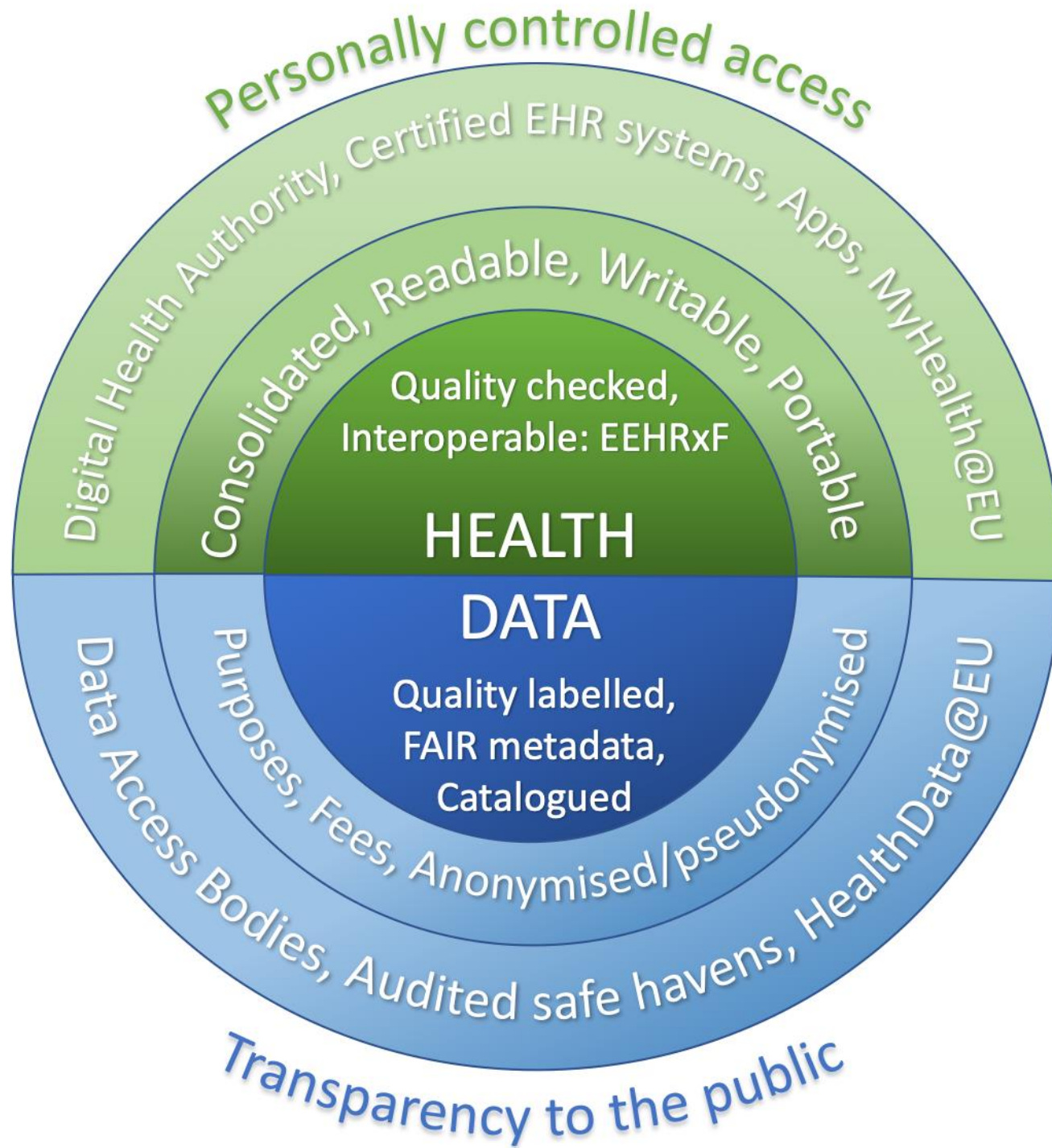
**Secondary Use**  
For research and strategy

**Primary Use**  
For health, care, wellness



**Secondary Use**  
For research and strategy

**Primary Use**  
For health, care, wellness



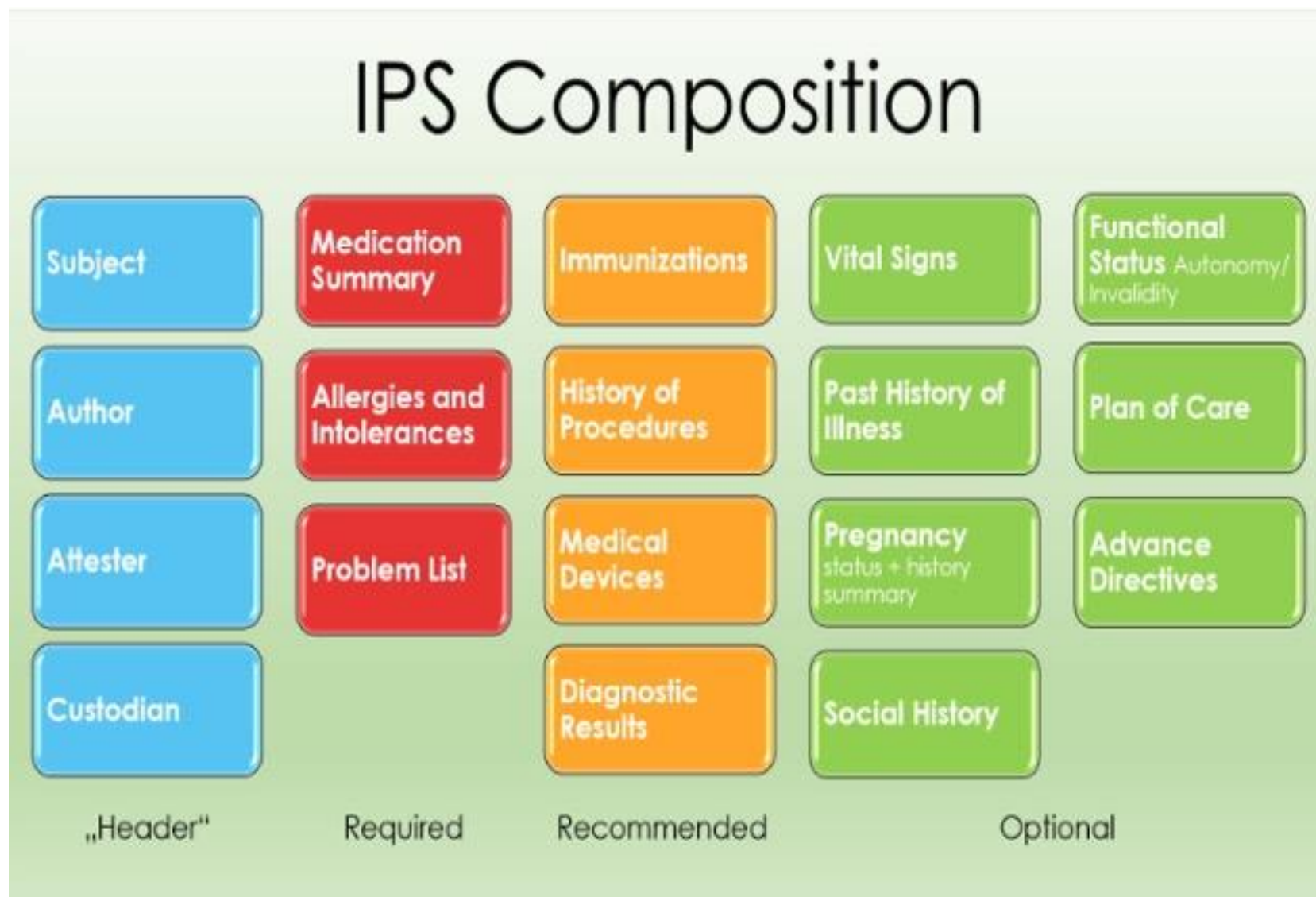
**Secondary Use**  
For research and strategy

# The European EHR Exchange Format

- Patient summary - closely related to the International Patient Summary (IPS)
- Electronic prescriptions
- Electronic dispensations
- Medical images and image reports
- Laboratory results
- Discharge reports

Adopted in the EHDS Regulation  
Implemented through MyHealth@EU

# Main content of the International Patient Summary





# Immunisation Information Systems: Making interoperable data systems for vaccination a reality in Europe

2022 RECOMMENDATIONS BASED ON  
CALLS TO ACTION ON HEALTH DATA  
ECOSYSTEMS



# The ten functional capabilities used as variables to generate the heat map and scorecard



The presence of a vaccine register or equivalent



Whether there is a cancer register



Whether HPV vaccination was included in the register



Whether vaccination related information was included in the cancer registry data set



The level of interest in using ICT (EHR systems etc.) within healthcare provider organisations



Whether there is an integrated national approach to managing vaccination information



The level of interest in developing registers



The extent to which best practices are being replicated



Whether there is a cancer screening register



The frequency with which reporting data is generated



YOUR VISION.REALISED.

Country	Weighted score
Denmark	99%
Finland	96%
Netherlands	94%
England	92%
Sweden	92%
Wales	90%
Ireland	86%
Scotland	86%
Northern Ireland	85%
Latvia	81%
Malta	81%
Slovenia	76%
Belgium	75%
Portugal	74%
France	73%
Spain	72%
Germany	70%
Romania	66%
Estonia	65%
Italy	64%
Hungary	60%
Slovakia	59%
Luxembourg	58%
Lithuania	48%
Austria	44%
Czech Republic	40%
Croatia	38%
Greece	36%
Cyprus	36%
Poland	34%
Bulgaria	33%



- Vaccination record access to individuals and families
- Continuity of care across borders
- Tracking complications and adverse events: individuals and populations
- Linking vaccination coverage to disease burden
- Linking outbreaks to vaccination coverage gaps
- Linking campaigns to vaccination uptake
- Academic and industry research
- Comparisons of vaccination programmes and delivery models



### Person specific

- vaccination administration record
- vaccination schedules & future appointments, as they would apply to an individual
- post-vaccination health issues
- personal disease screening results and disease occurrence
  - International Patient Summary (which includes vaccination information)



### Population level

- customer relationship management (e.g., scheduling, reminding, informing, targeted education, personalised Q&A ...)
- vaccination schedules, per vaccine and for different sub-populations
- population level disease screening and disease incidence/prevalence information including geographic and demographic distribution



### Programme specific

- vaccination supply chain
- structure and delivery of immunisation programmes
- health education campaigns targeting different groups
- location and tracking of outbreaks
  - factors influencing vaccination hesitancy