i~HD The European Institute for Innovation through Health Data
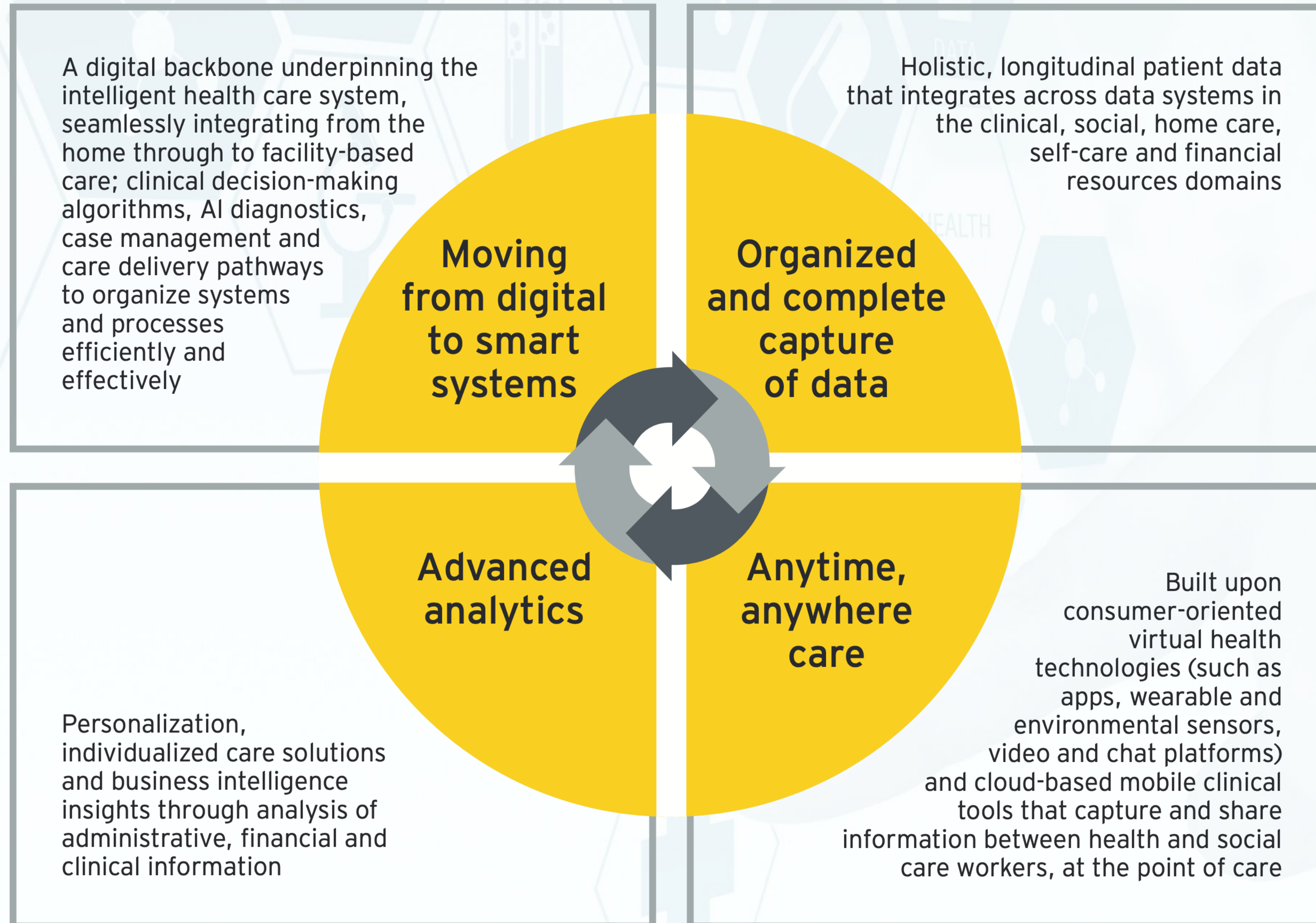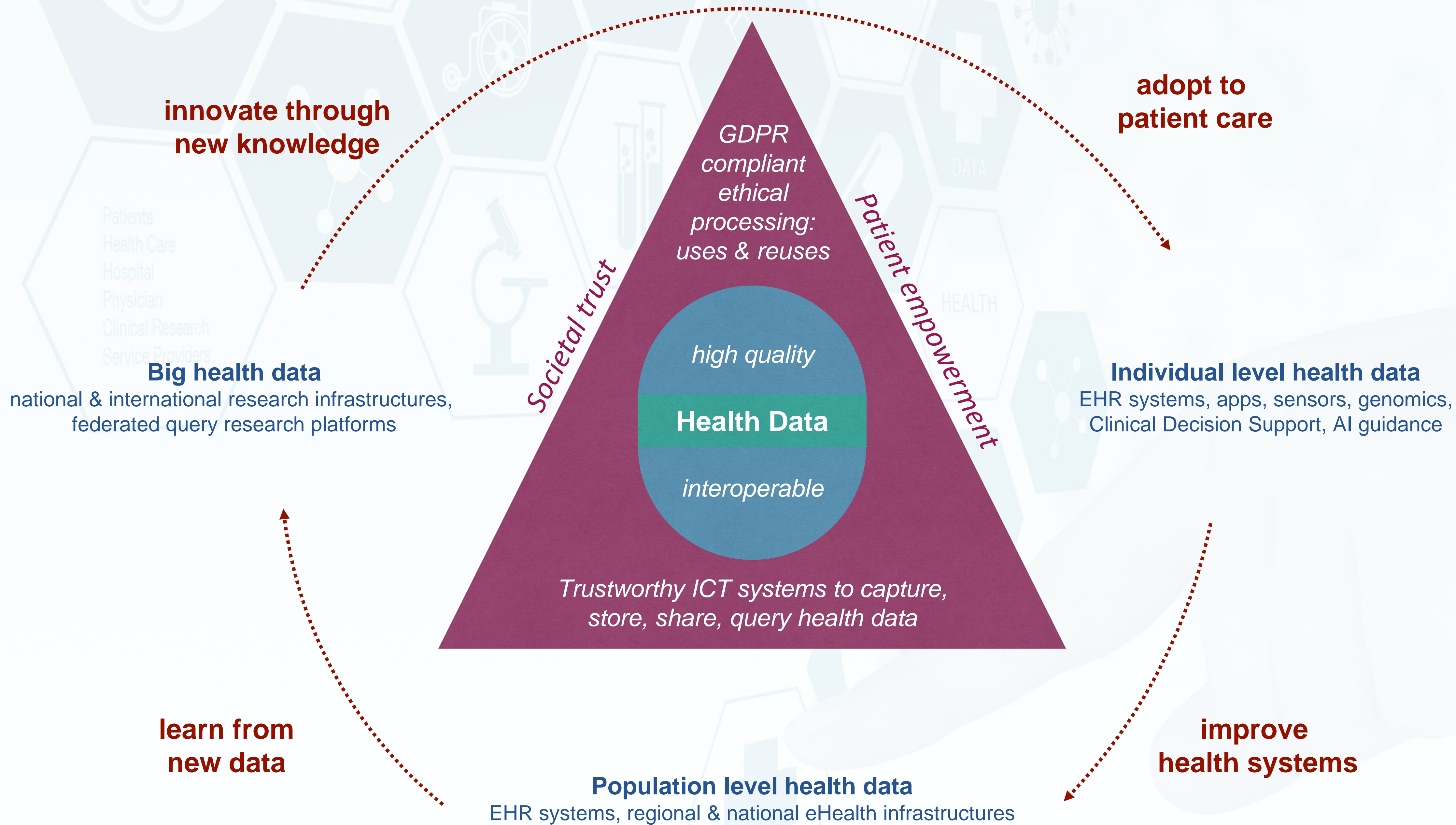
How Space can contribute to disruption and innovation in the health ecosystem
What disruptions do we need?

Prof Dipak Kalra
President of i~HD

The new data-enabled ecosystem

A digital backbone underpinning the intelligent health care system, seamlessly integrating from the home through to facility-based care; clinical decision-making algorithms, AI diagnostics, case management and care delivery pathways to organize systems and processes efficiently and effectively

Holistic, longitudinal patient data that integrates across data systems in the clinical, social, home care, self-care and financial resources domains

Moving from digital to smart systems

Organized and complete capture of data

Advanced analytics

Anytime, anywhere care

Personalization, individualized care solutions and business intelligence insights through analysis of administrative, financial and clinical information

Built upon consumer-oriented virtual health technologies (such as apps, wearable and environmental sensors, video and chat platforms) and cloud-based mobile clinical tools that capture and share information between health and social care workers, at the point of care

Patients
Health Care
Hospital
Physician
Clinical Research
Service Providers

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
- 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
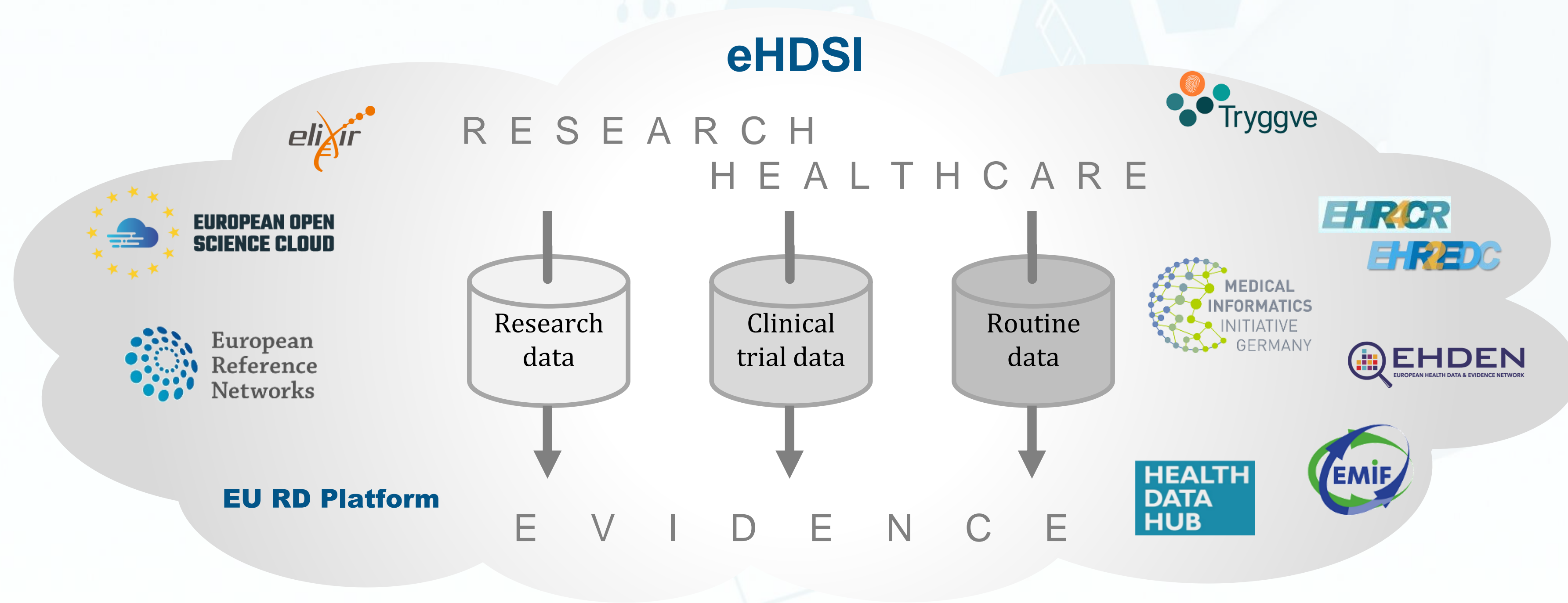- Health services and resource planning

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
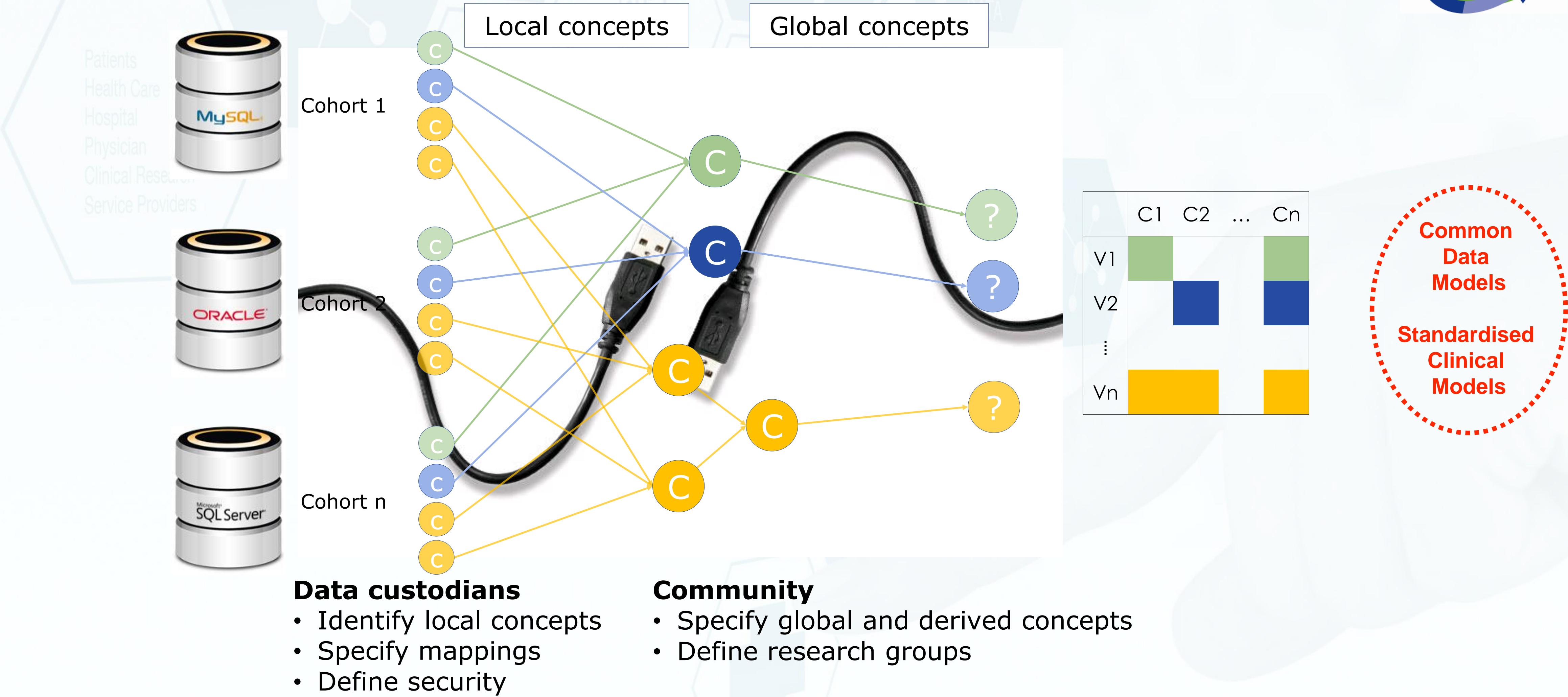- Disease understanding and stratification

Big health data sharing initiatives

- Myriad of initiatives to share health data across jurisdictional, institutional and domain borders:

    - Sharing data for cross-border care, e.g. eHDSI, ERN

    - Sharing data for research, e.g. EHDEN, French Health Data Hub, German MI Initiative

- Emerging paradigm for analysing personally-identifiable health data:

    - federated infrastructure model: network of repositories with an overarching governance and interoperability layer
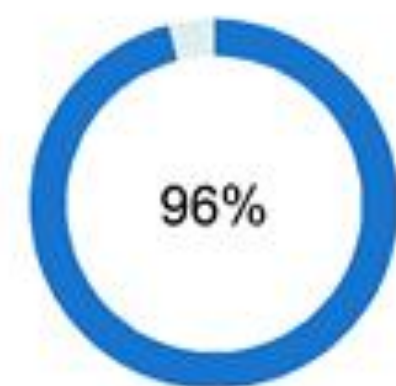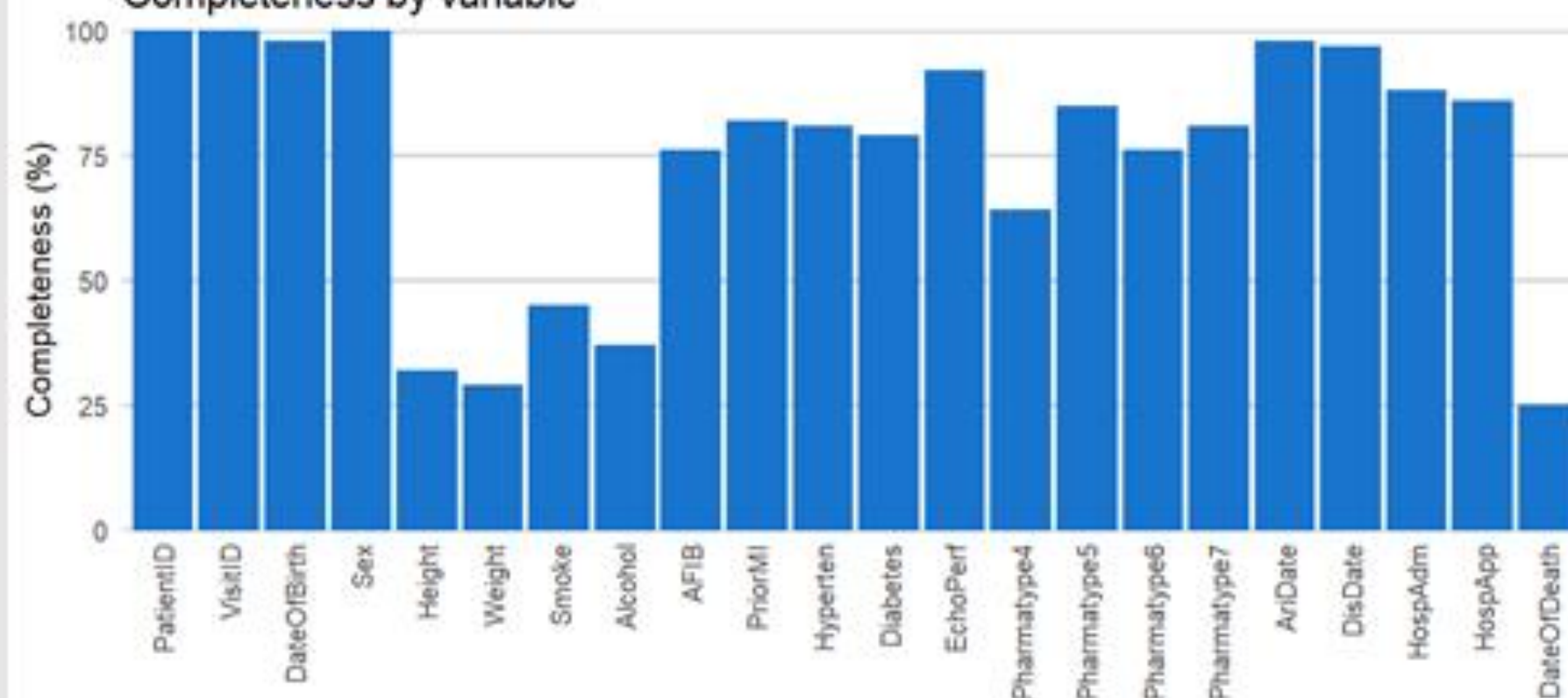
Data harmonisation

Local concepts

Global concepts

Cohort 1

Cohort 2

Cohort n

	C1	C2	...	Cn
V1				
V2				
⋮				
Vn				

Common Data Models

Standardised Clinical Models

Data custodians
- Identify local concepts
- Specify mappings
- Define security

Community
- Specify global and derived concepts
- Define research groups
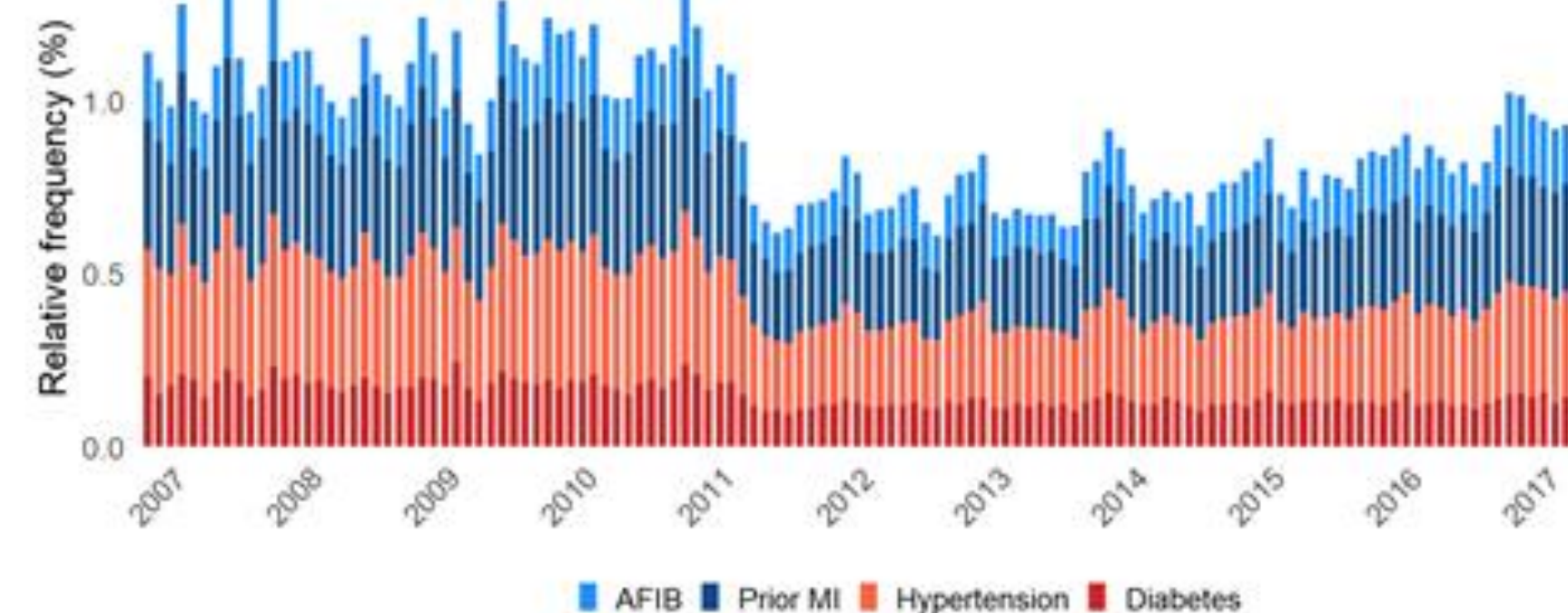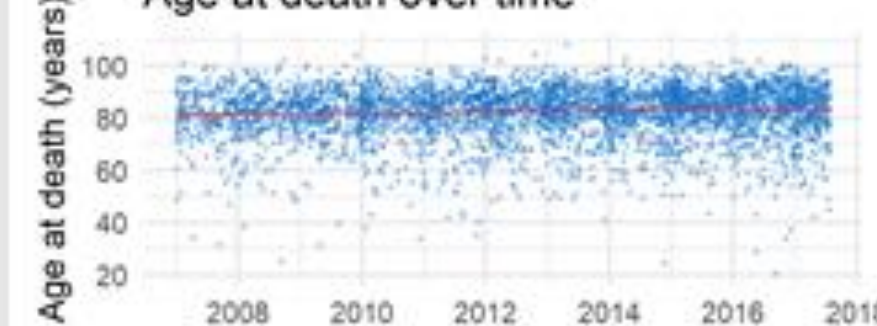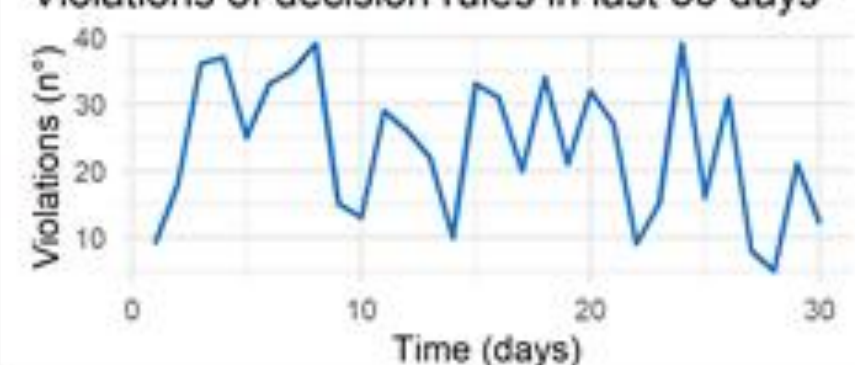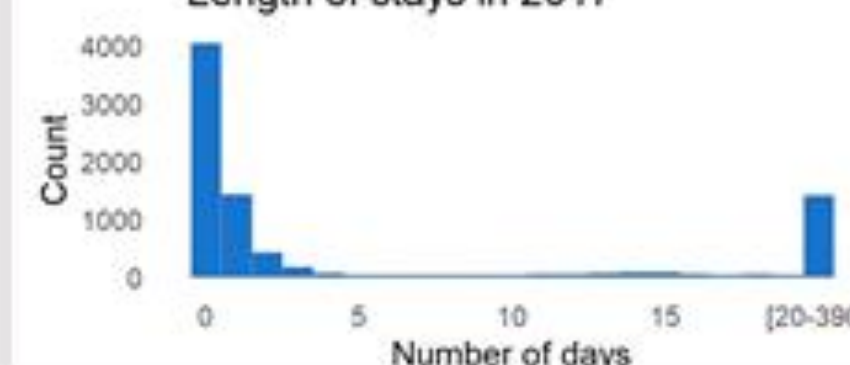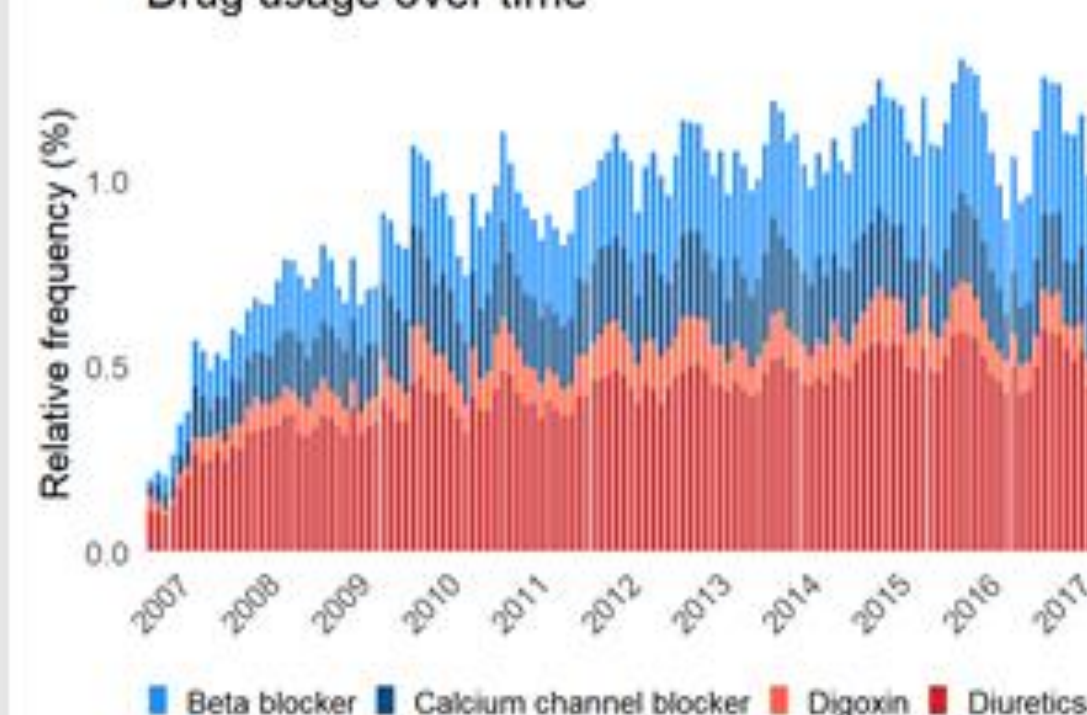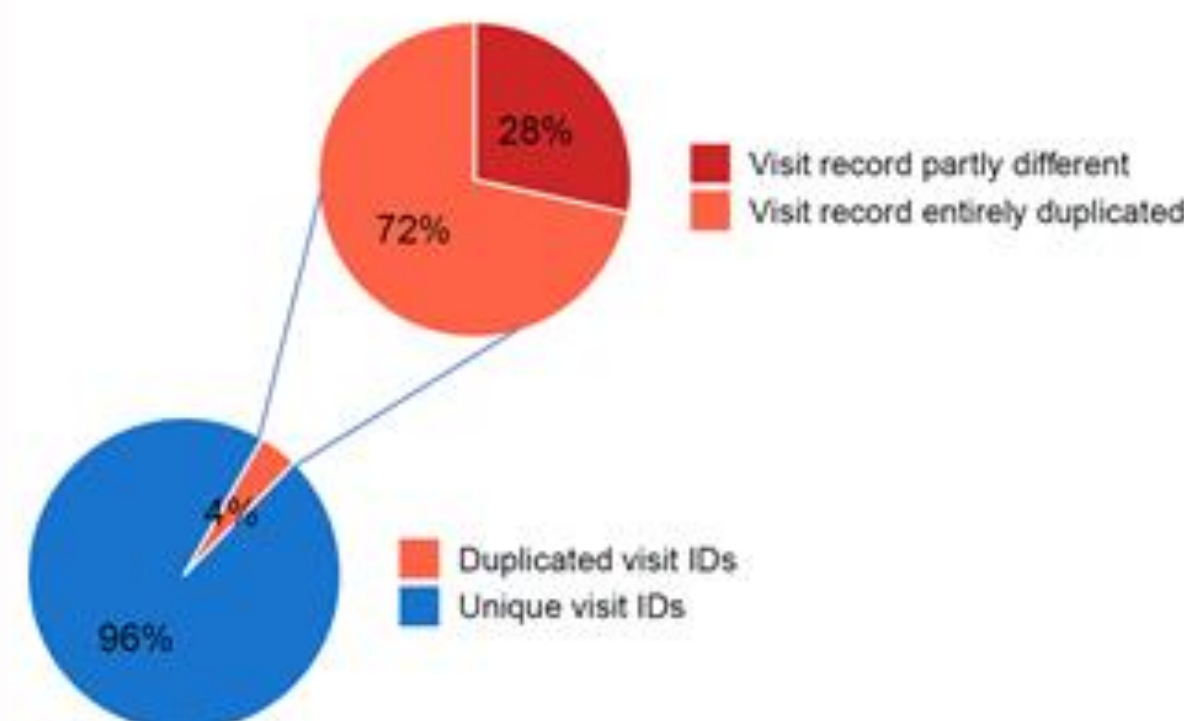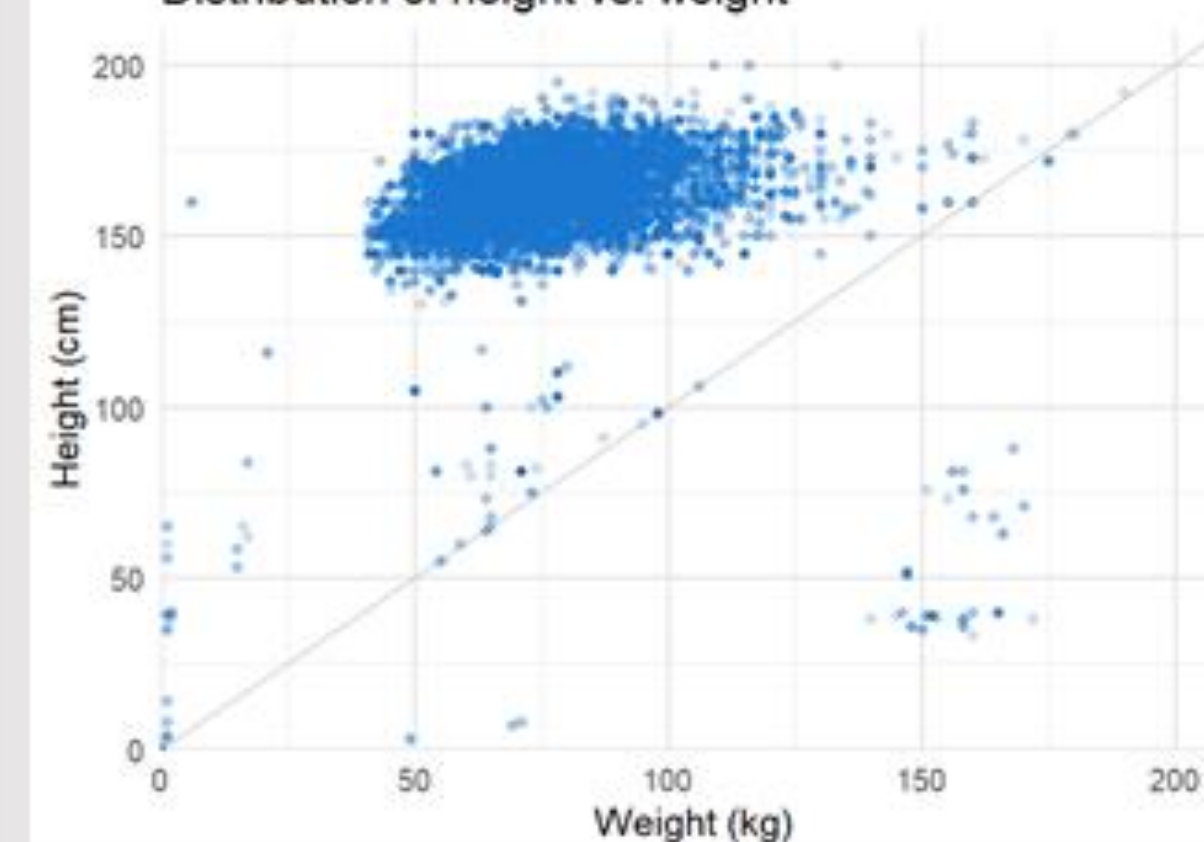
The challenge with gaining public acceptance of health data reuse

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Big health data

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

Reused for:
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- Diagnostics development
- Drug development
- Disease understanding and stratification

Decreasing public understanding of why and how data are used

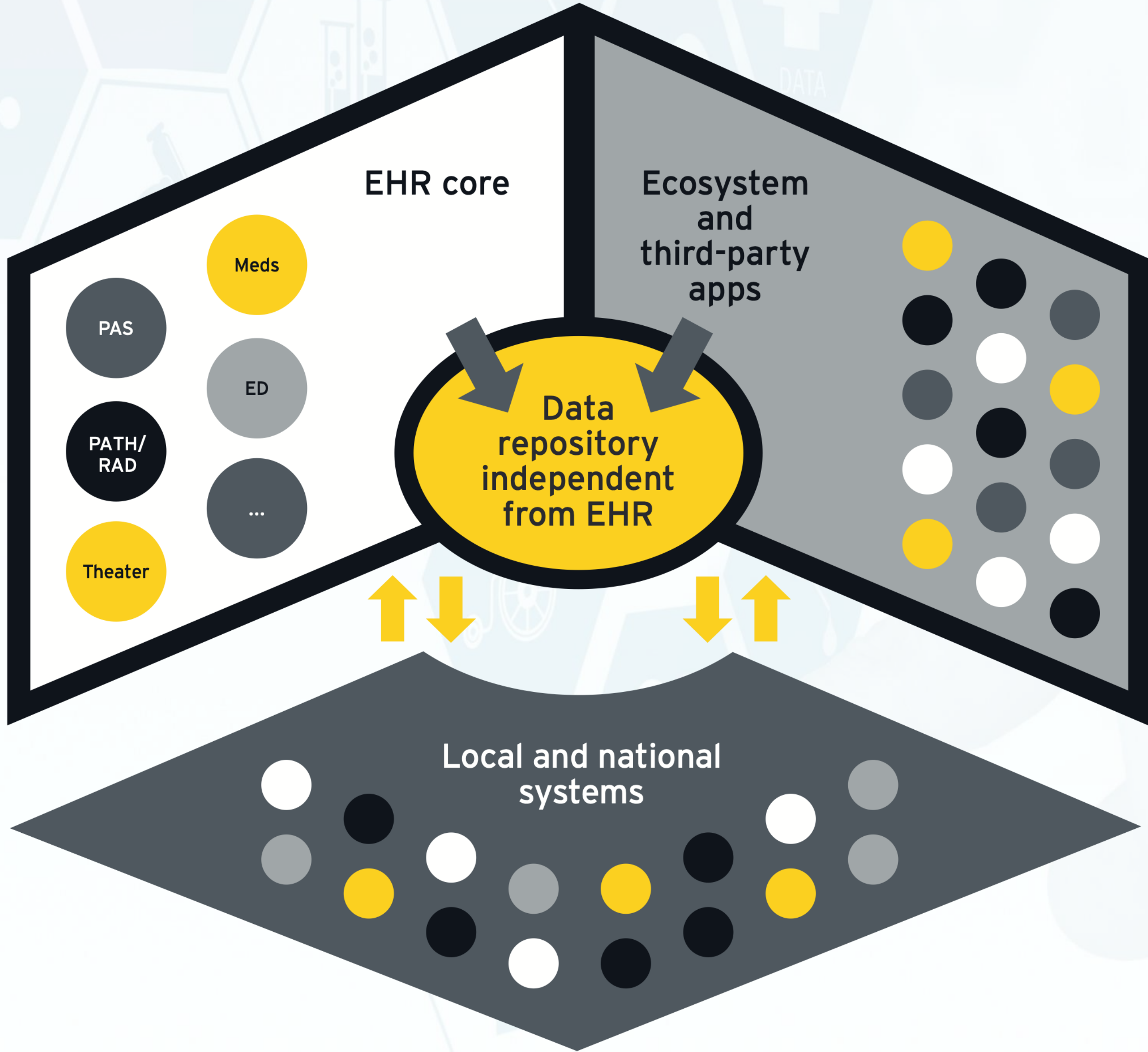Increasingly unfamiliar data users

Increasing distance of data results from the patient

Increasing time from data use to demonstrated value

Perceived lessening choice and greater cybersecurity risk = harder to trust

*i*HD

Open data platforms

EHR core

Meds

PAS

ED

PATH/ RAD

...

Theater

Data repository independent from EHR

Ecosystem and third-party apps

Local and national systems

Need to disrupt the value chains

Funders
- eHealth service providers
- Health care and health counseling organizations
- Insurance
- Crowd funding
- Direct funding
- industry

Providers
- EHR and Chronic Disease Management Platforms
- ICT and medical device industry
- Health care providers and care networks
- Health Professional organizations
- Patient advocacy organizations

Users
- Health Professionals
- Care Networks
- Patients
- Insurers
- Public Health organizations
- Regulatory Agencies
- Other business (e.g. Consultancies)

Beneficiaries
- Subjects of care (patients, population groups)
- Care providers
- Payers (insurance, patients, citizens)
- Society (social and economic agents)
- Research Community (academia, public health, Pharma)

Source: VALUeHEALTH