Health data drives innovation

Beyond loneliness to wholeness

8th December 2021

Maximising the value of health data

The European Institute for Innovation through Health Data

Dipak Kalra
President of i~HD

Health system sustainability and resilience

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:

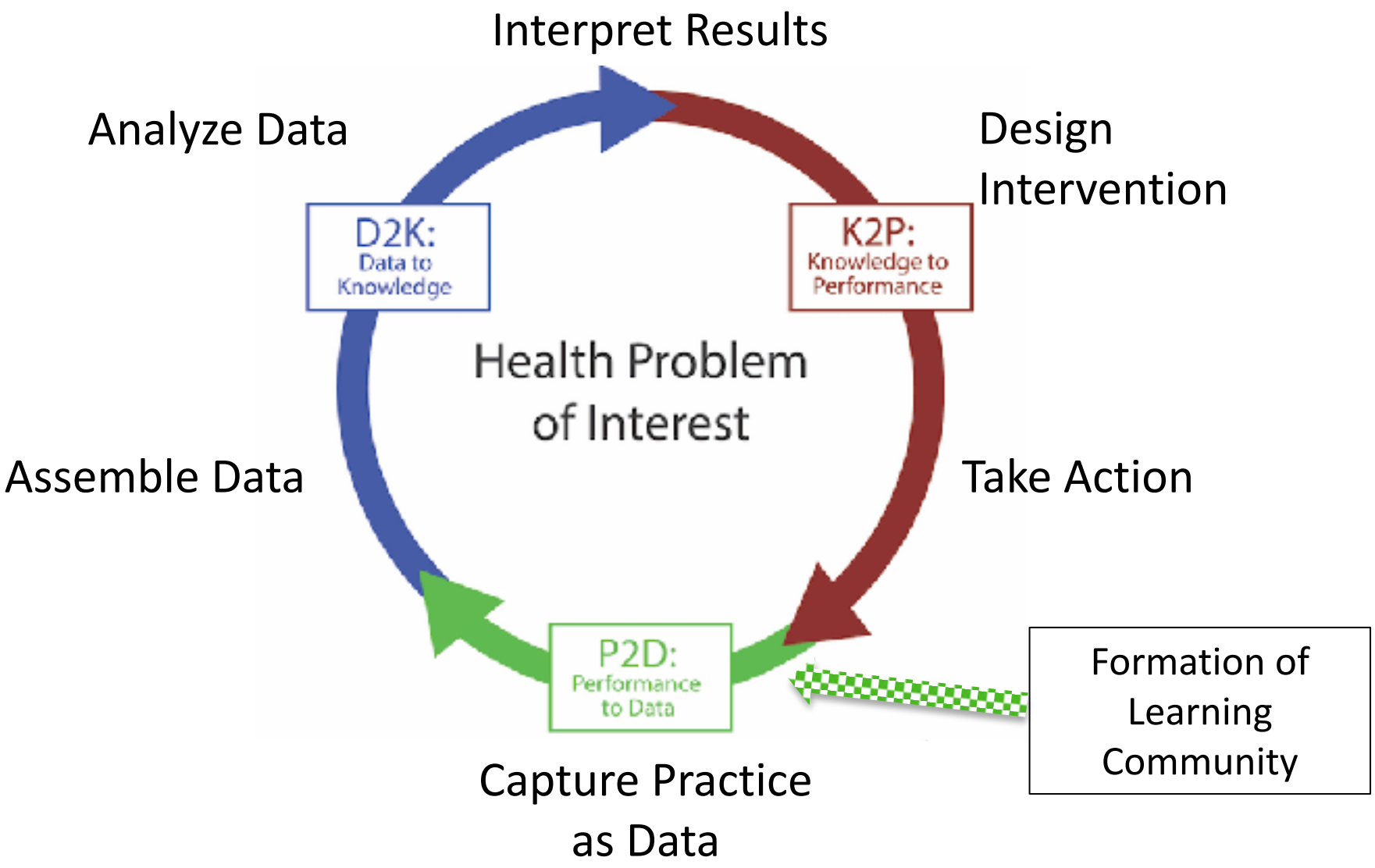
- Ageing and rising levels of chronic disease and comorbidity
- Public health problems and inequalities

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'

Slide courtesy of Daniel Furby, FIPRA International

The Learning Health System: "Virtuous Cycles" of Study and Change



How has “big” EHR data been used by health services?

- Demonstrated health improvements through using data in one **Learning Health System**

33% decrease in heart disease deaths

50% decrease in HIV deaths

50% decrease in septicaemia deaths

67% decrease in pressure ulcers

The LHS ambitions of many European healthcare provide

- Shift the focus of performance and reward from act… outcomes
- Optimise care pathways to maximise health o… whilst making best use of resources
- Respond to payer and public dema… ore integrated and person centred care
- Implement continuous lea… improvement cycles
- Enhance their cultur… pability to undertake research, for reputation and b… easons
- Collaborat… hospital networks, and across Europe, to share good practi… support each other with improvement

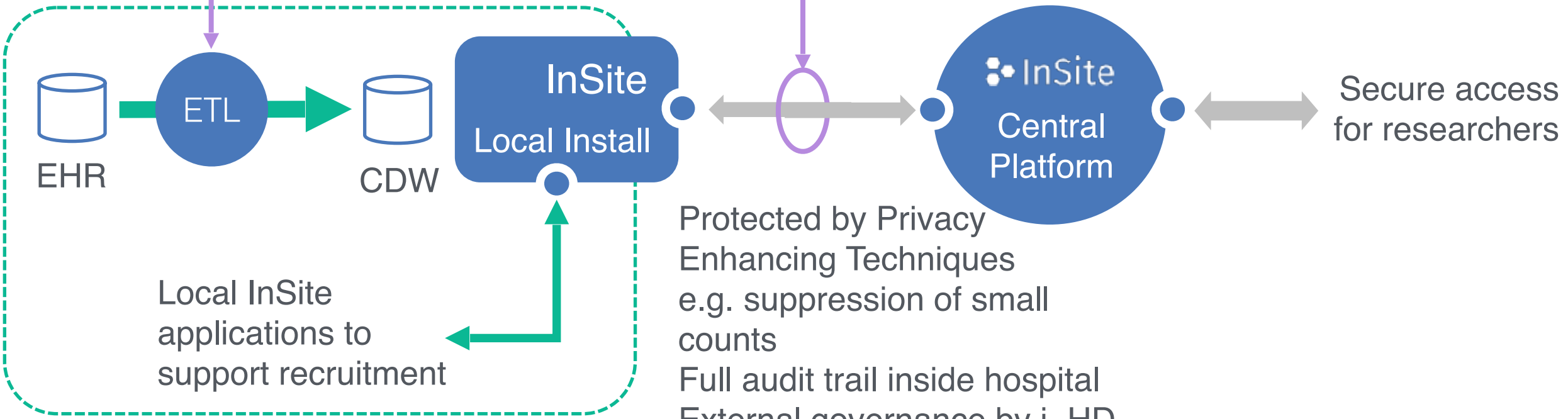
A connected EHR with reusable data is a critical success factor

InSite – Technical Overview, for Protocol feasibility

TriNetX

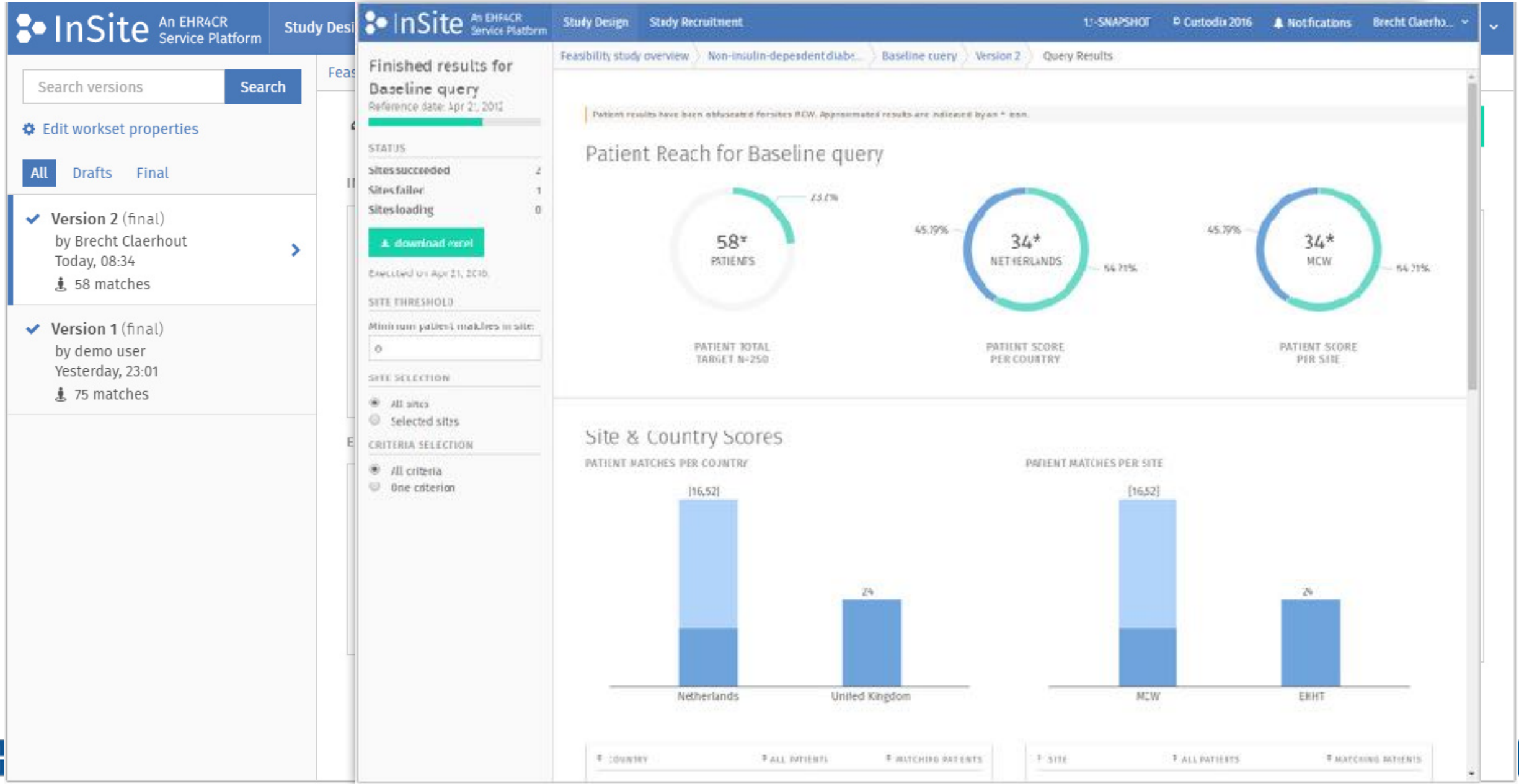
InSite provides expertise and tools to support local sites with mappings

Only aggregated data (patient counts) leave the hospital, only on approval



Protected by Privacy Enhancing Techniques
e.g. suppression of small counts
Full audit trail inside hospital
External governance by i~HD

InSite – Protocol feasibility query



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

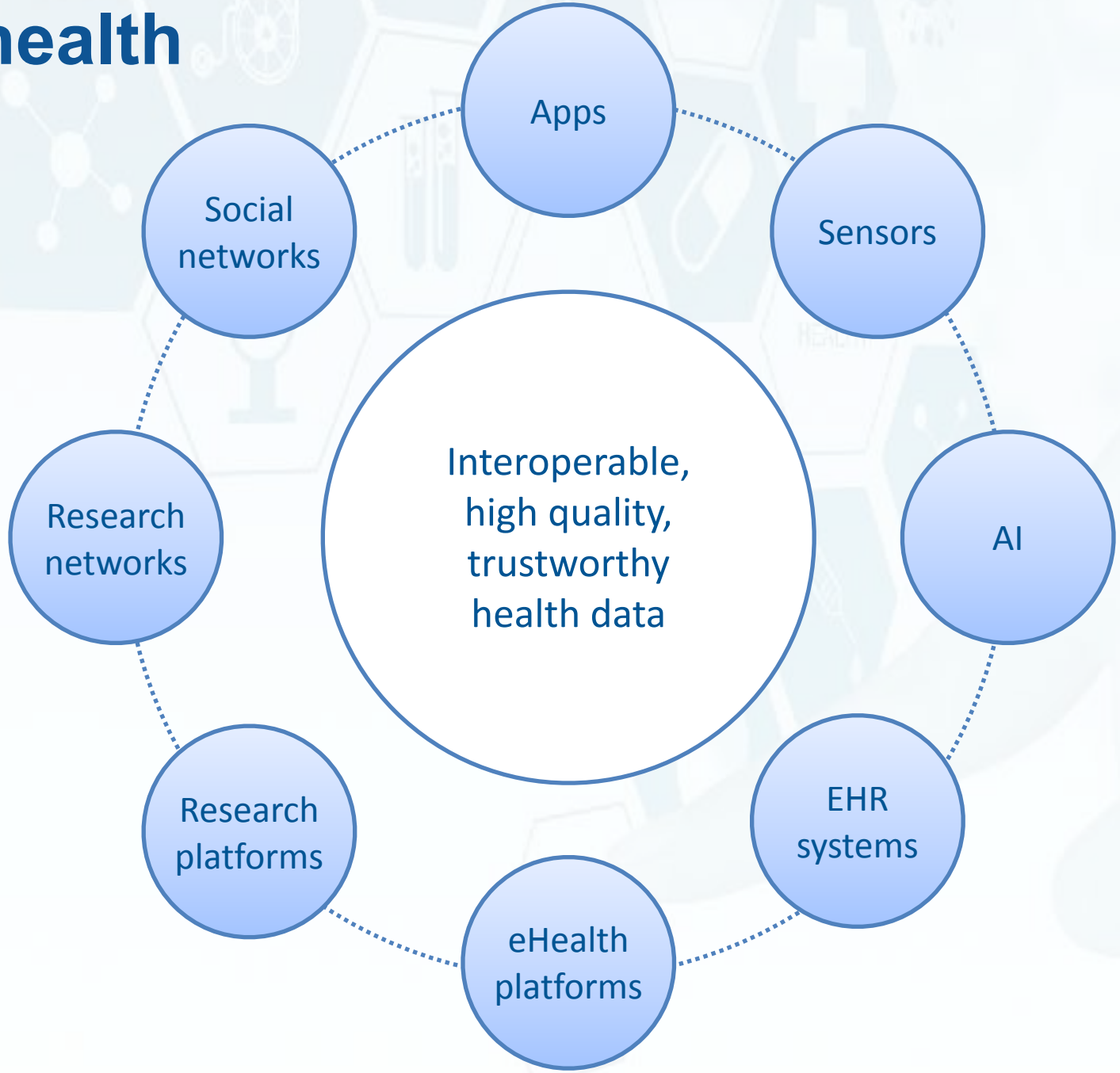
Big health data

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

The digital health toolbox



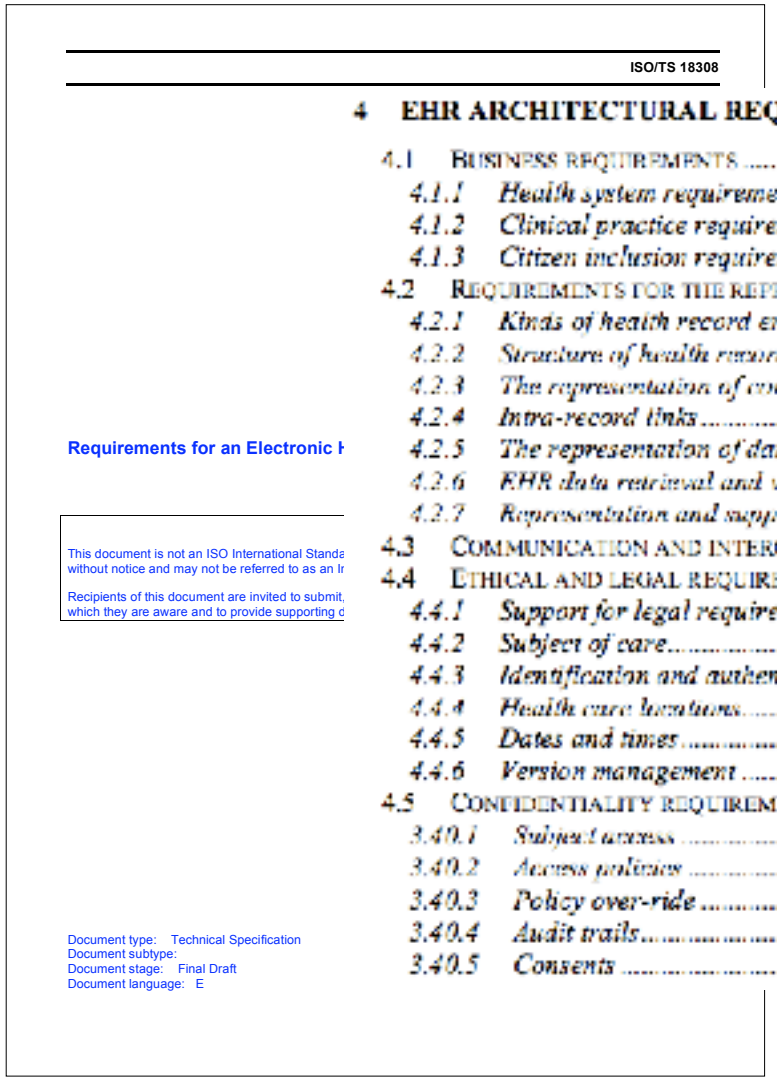
Essential needs for interoperability

- Guideline and decision support systems, notification and alerting components, and analytic tools need to process integrated health data drawn from multiple EHR systems in a consistent manner
- Intelligent personal health guidelines interoperating with PHRs and EHRs need to support the centring of care on patients
- Health services, insurers and public health bodies need fine grained activity and outcome data to inform service planning, commissioning and prevention/wellness programmes
- New generation personalised medicine needs to integrate EHRs with data from research: fundamental biomedical science, clinical and population health research, and clinical trials
- All data uses, communication, sharing and analysis must comply with data protection laws and be secure: to the same standard across countries

Example interoperability standards relevant to the EHR

Business requirements and functions	ISO 18308 EHR Architecture Requirements HL7 EHR Functional Model ISO EN 13940 Systems for Continuity of Care ISO EN 12967-1 HISA Enterprise Viewpoint
Information models	EHR Reference Model *open*EHR and EN ISO 13606-1 HL7 Clinical Document Architecture Clinical content model representation *open*EHR and EN ISO 13606-2 archetypes ISO 21090 Healthcare Datatypes ISO EN 12967-2 HISA Information Viewpoint
Clinical knowledge and content models	Terminologies: SNOMED CT, LOINC, etc. Clinical models: Archetypes, Templates, etc. Ontology standards… Genomic standards… Metabolic standards….
Computational services and message models	EHR Communication Interface Specification ISO/EN 13606-5 ISO EN 12967-3 HISA Computational Viewpoint HL7 SOA Retrieve, Locate, and Update Service DSTU HL7 FHIR
Privacy and security	EHR Communication Security ISO/EN 13606-4 ISO 22600 Privilege Management and Access Control ISO 14265 Classification of Purposes of Use of Personal Health Information ISO 27789 EHR Audit Trails

ISO 18308 EHR architecture requirements



ISO/TS 18308

4 EHR ARCHITECTURAL REQUIREMENTS

4.1 BUSINESS REQUIREMENTS

4.1.1 Health system requirements

4.1.2 Clinical practice requirements

4.1.3 Citizen inclusion requirements

4.2 REQUIREMENTS FOR THE REPRESENTATION OF CLINICAL INT

4.2.1 Kinds of health record entries

4.2.2 Structure of health record entries

4.2.3 The representation of context within health record ent

4.2.4 Intra-record links

4.2.5 The representation of data values within health record

4.2.6 EHR data retrieval and views

4.2.7 Representation and support of clinical process and wo

4.3 COMMUNICATION AND INTEROPERABILITY REQUIREMENTS

4.4 ETHICAL AND LEGAL REQUIREMENTS

4.4.1 Support for legal requirements

4.4.2 Subject of care

4.4.3 Identification and authentication

4.4.4 Health care locations

4.4.5 Dates and times

4.4.6 Version management

4.5 CONFIDENTIALITY REQUIREMENTS

3.40.1 Subject access

3.40.2 Access policies

3.40.3 Policy over-ride

3.40.4 Audit trails

3.40.5 Consents

Requirements for an Electronic H

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The EHR shall preserve any explicitly defined relationships between different parts of the record, such as links between treatments and subsequent complications and outcomes.

The EHR shall preserve the original data values within an EHR entry including code systems and measurement units used at the time the data were originally committed to an EHR system.

The EHR shall be able to include the values of reference ranges used to interpret particular data values.

The EHR shall be able to represent or reference the calculations, and/or formula(e) by which data have been derived.

The EHR architecture shall enable the retrieval of part or all of the information in the EHR that was present at any particular historic date and time.

The EHR shall enable the maintenance of an audit trail of the creation of, amendment of, and access to health record entries.

A diagnostic code for COPD might be entered in an EHR as:

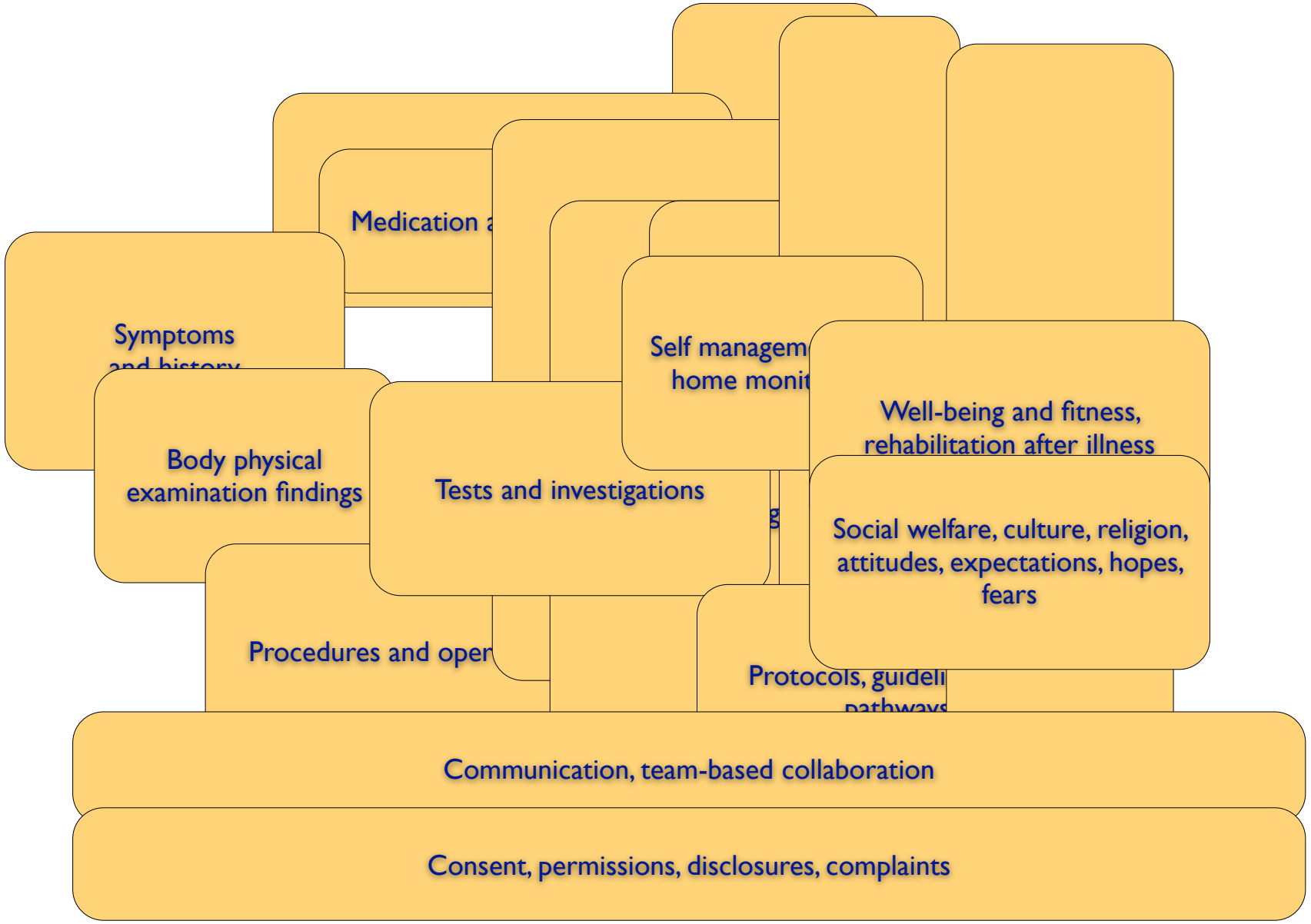
- a new diagnosis confirmed today as a result of lung function tests
- a diagnosis suspected today on the basis of a possible history
- one of a number of differential diagnoses being considered
- the query diagnosis written on an order for lung function tests
- a diagnosis excluded today on the basis of the tests
- an incorrect diagnosis made by an inexperienced junior clinician
- the indication for a flu vaccine
- the condition from which the patient's mother suffers
- a risk because of family history or lifestyle
- a worry the patient has
- because it has a higher reimbursement than asthma
- a data entry error that has been corrected

To trust data in a shared record environment we also need to know:

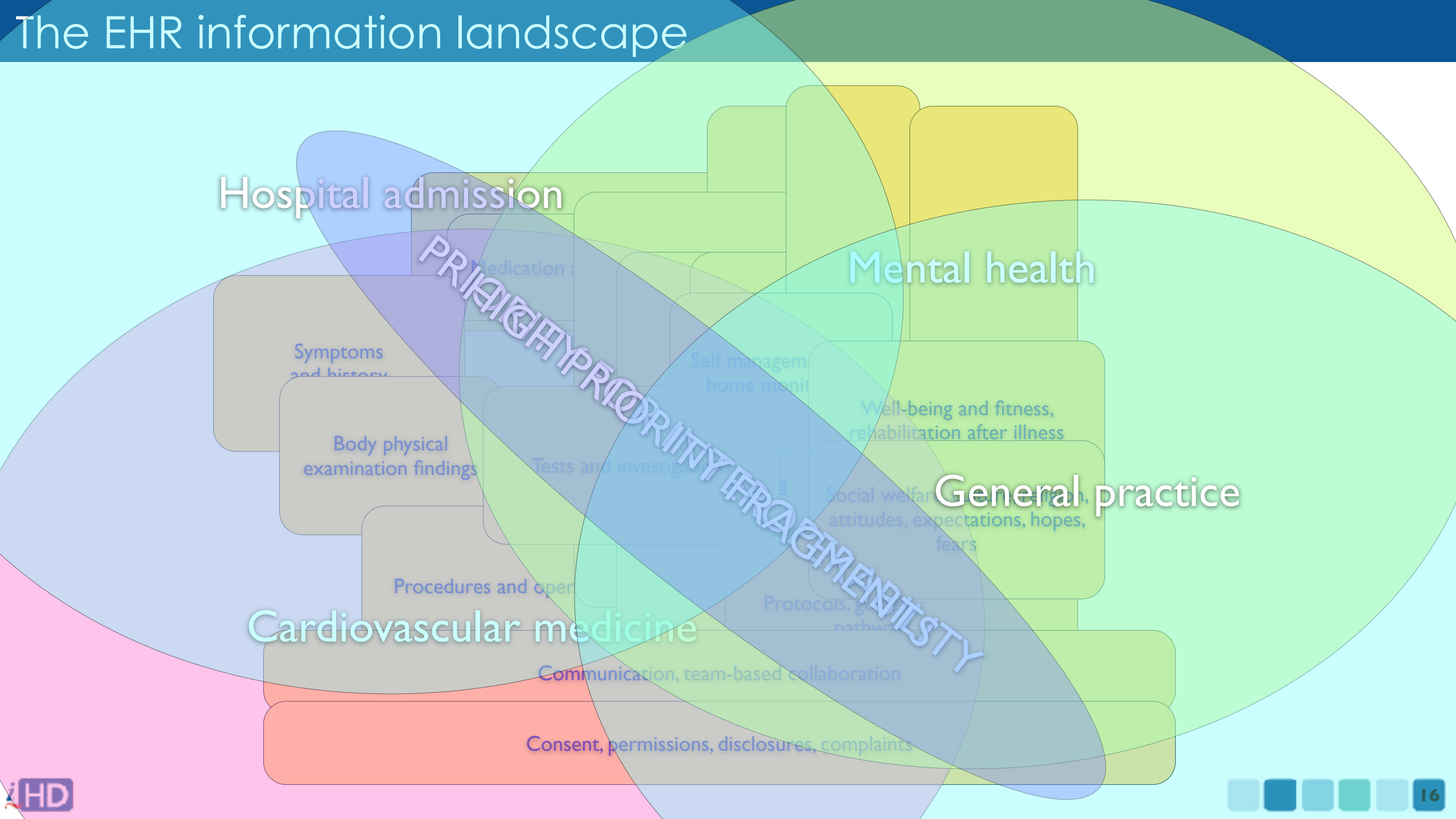
- Provenance
  - robust patient identification, handling duplicates, reliable cross-provider linkage
  - authorship and author credentials
  - date and time, date formats and time zone
  - data integrity: units of measurement, term lists and terminology systems, drugs databases…
- Traceability
  - version history: confirming the latest version
  - reasons for changing records: typo correction, update, change of clinical opinion, disproved…
  - system, sub-system and repository history, system updates, roll back
- Security
  - access controls
  - indelible audit trail
  - adequate protection and backup

Trustworthy data is needed for trusted use

The EHR information landscape



The EHR information landscape



Scaling up International Patient Summaries

Security preferences

Identification

Vaccinations

Encounters

Procedures

Treatment plan

Health problems

Allergies

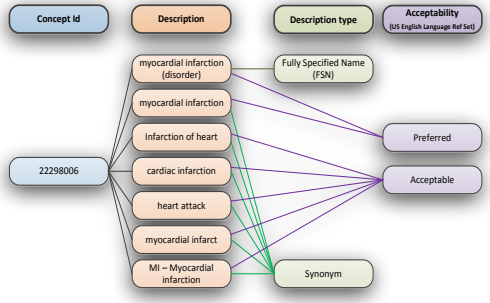
Medications

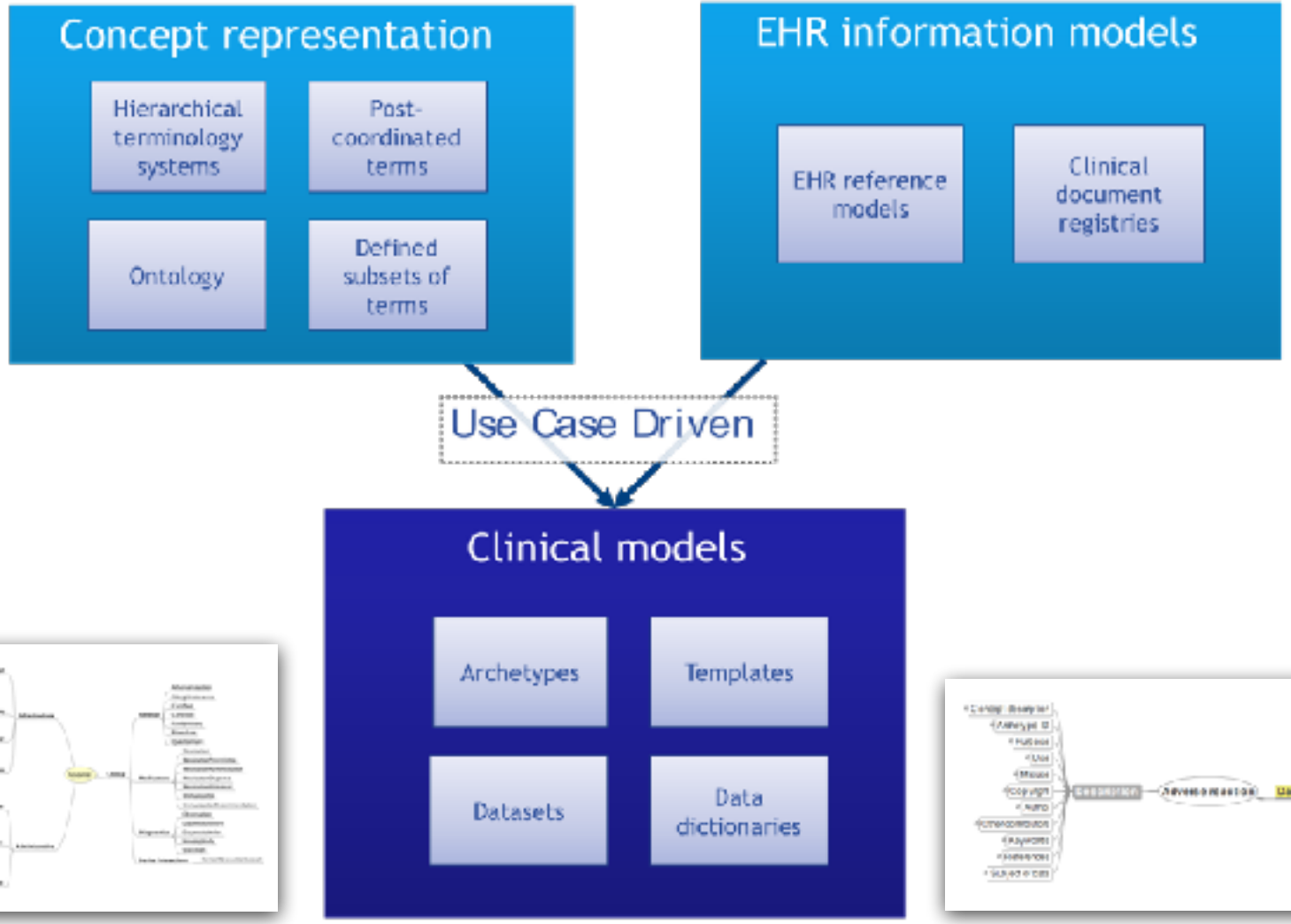
Implantable devices

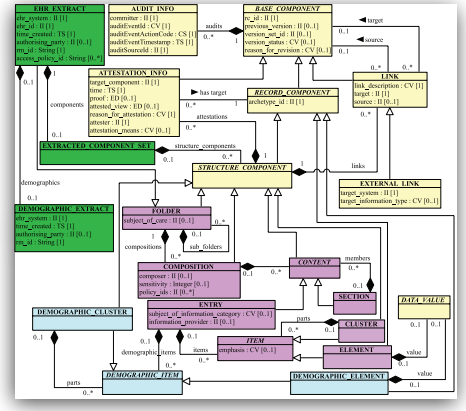
Care team

Great potential for care co-ordination and for learning health systems

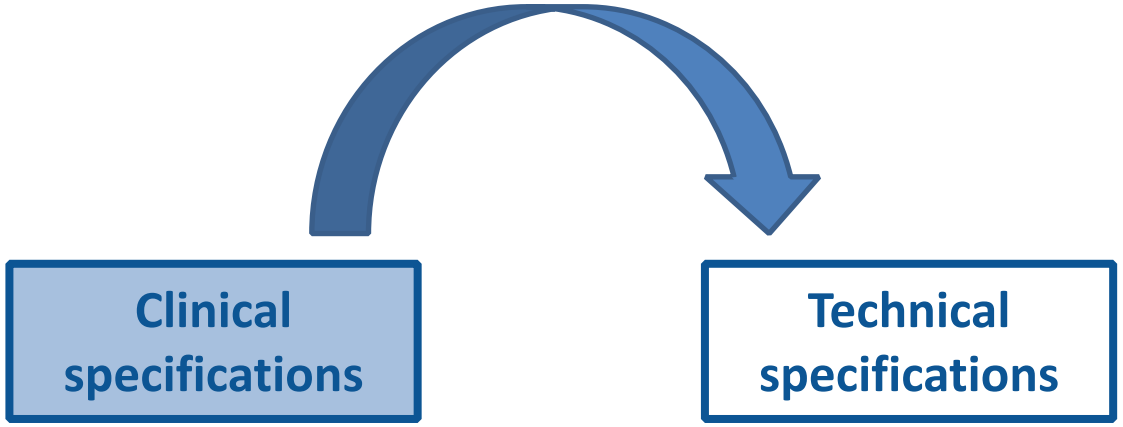
Overview of assets used to represent clinical meaning







An iterative, interactive standards development process is needed



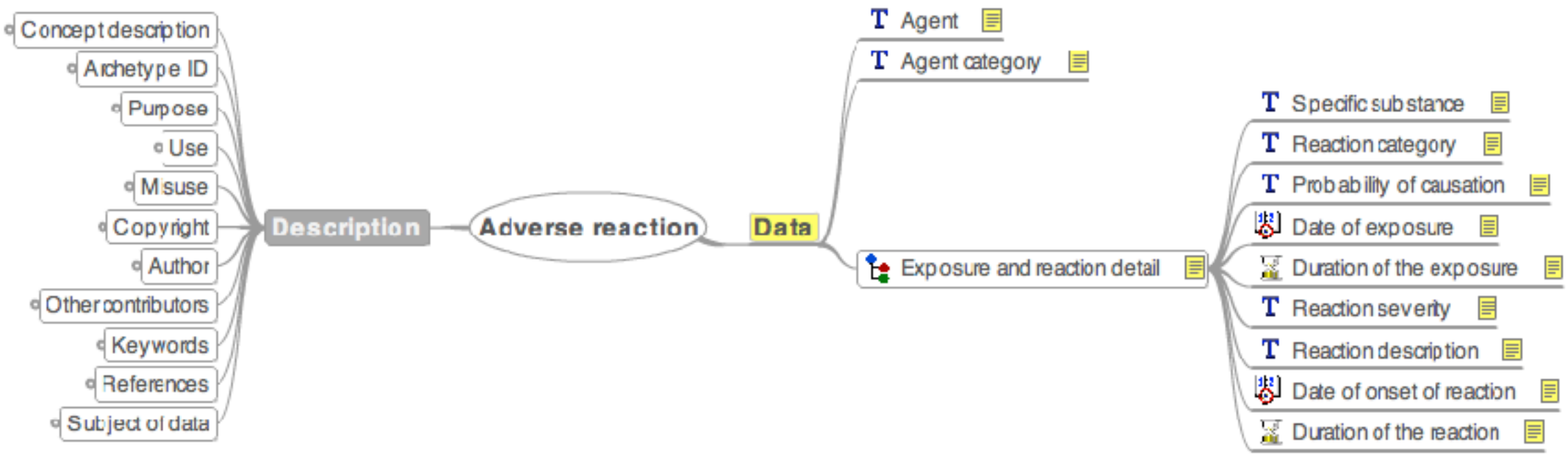
Clinician and patient involvement

Research and public health involvement

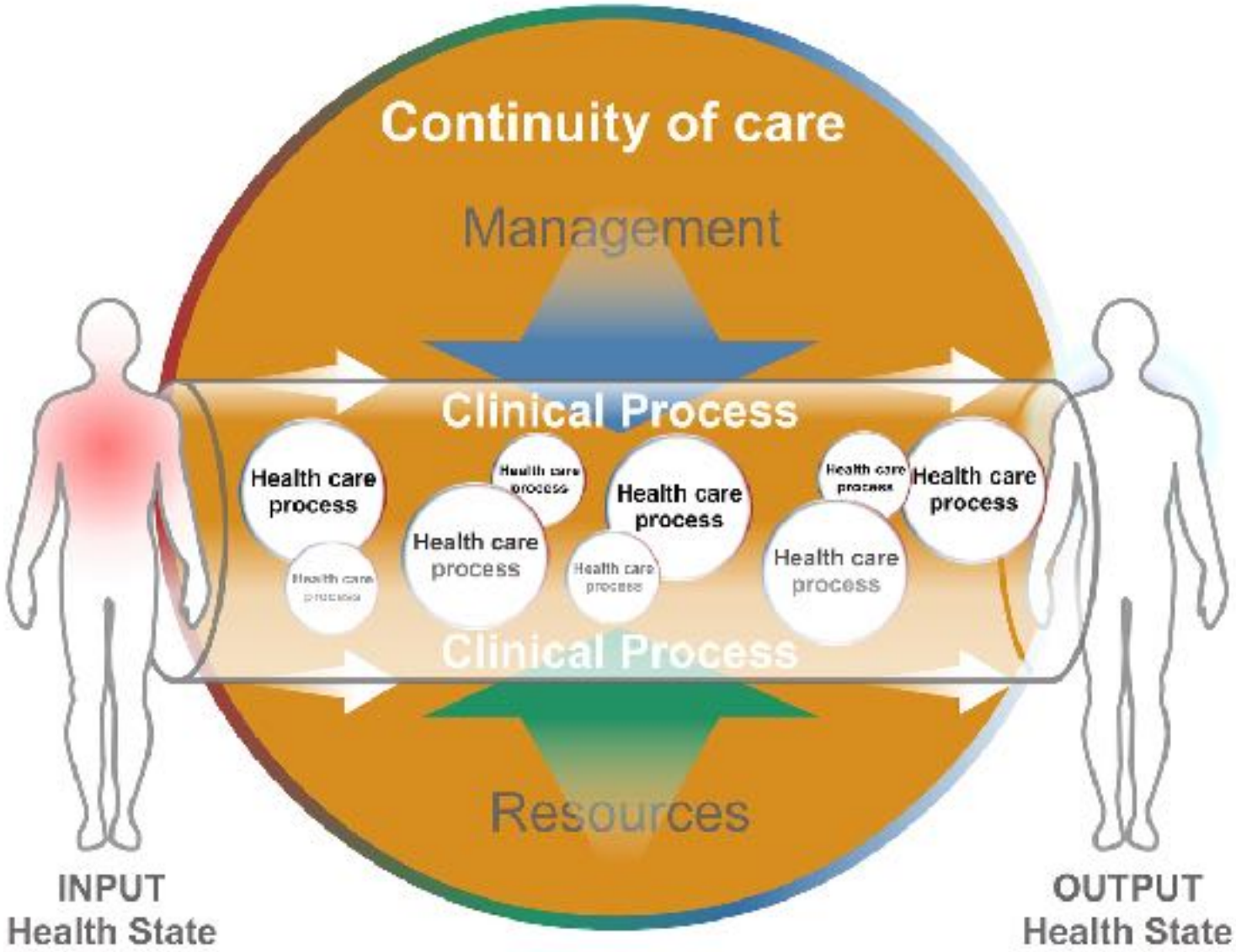
combine modelling, terminology, ontology & workflow representations to produce harmonised semantic resources

Slide courtesy of Robert Vander Stichele

Adverse reaction archetype



ISO 13940 System of concepts to support continuity of care (2015)



Perverse incentives do not favour interoperability

- Decision/policy makers
- Public/private payers

Funders of health and care, orchestrate the data flows

optimise reimbursement

- Industry/EHR vendors, SDOs
- ICT purchasers

Providers and purchasers of health ICT solutions

optimise business efficiency

- Health and care professionals
- Research sector (public/private)

Users of health ICT, creators of health data

optimise workload

- Patients
- Citizens
- Carers

Supposedly the beneficiaries of health ICT

New business models and business plans need to:

- Decision/policy makers
- Public/private payers

Financially incentivise integrated person centred care

optimise outcomes

- Industry/EHR vendors, SDOs
- ICT purchasers

Provide and purchase collaborative ICT solutions

optimise effectiveness

- Health and care professionals
- Research sector (public/private)

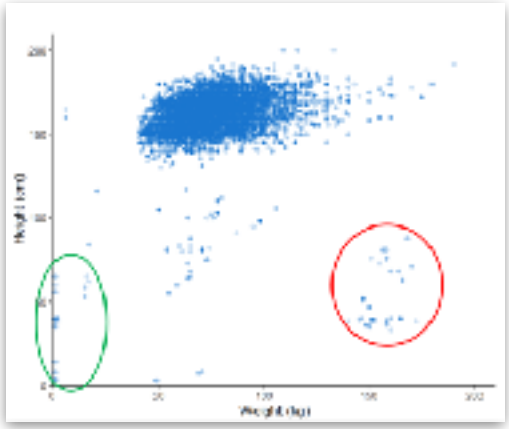
Improve quality through patient-centred ICT solutions

optimise health

- Patients
- Citizens
- Carers

Use health ICT to co-create health and partner HCPs

Example data quality issues from hospitals



34% of weight errors led to medication-dosing errors
48% of these patients required additional monitoring, examination or treatment

Data Item	Site 1	Site 2	Site 3	Site 4	Site 5	Site 6	Site 7
Gender	100,00%	100,00%	100,00%	100,00%	100,00%	100%	100%
Case Status	99,87%	100,00%	60,00%	100,00%	100,00%	100,00%	100%
Date of Birth	100,00%	100,00%	99,00%	NA	100,00%	100%	100%
Admission date	100,00%	100,00%	100,00%	NA	100,00%	99,53%	58%
Diagnosis Text	50,46%	84,02%	100,00%	100,00%	98,05%	100,00%	14%
Diagnosis Code	50,46%	84,02%	100,00%	100,00%	98,05%	100,00%	14%
Discharge date	100,00%	100,00%	100,00%	NA	100,00%	100,00%	58%
Diagnosis Date	50,46%	84,02%	100,00%	100,00%	100,00%	NA	13%
Potassium in serum	52,38%	28,27%	100,00%	NA	100,00%	100%	49%
Sodium in Serum	52,38%	27,70%	100,00%	NA	100,00%	100%	45%
Platelets Blood	52,78%	33,14%	63,73%	NA	100,00%	100%	45%
SGPT (ALT) in serum	33,61%	22,29%	100,00%	NA	100,00%	100%	47%
Total Protein in serum	52,37%	14,96%	86,53%	NA	100,00%	100%	47%
Total Bilirubin in serum	33,03%	16,99%	100,00%	NA	100,00%	100%	47%

Data quality variation across example EU hospitals - the data most needed for clinical research (partial table)

- Most RWD is captured by busy junior staff, using various EHR systems
- Staff have no access to training in data quality
- Patients also have no training! (but their data is becoming increasingly important)

Data Quality Monitoring Dashboard

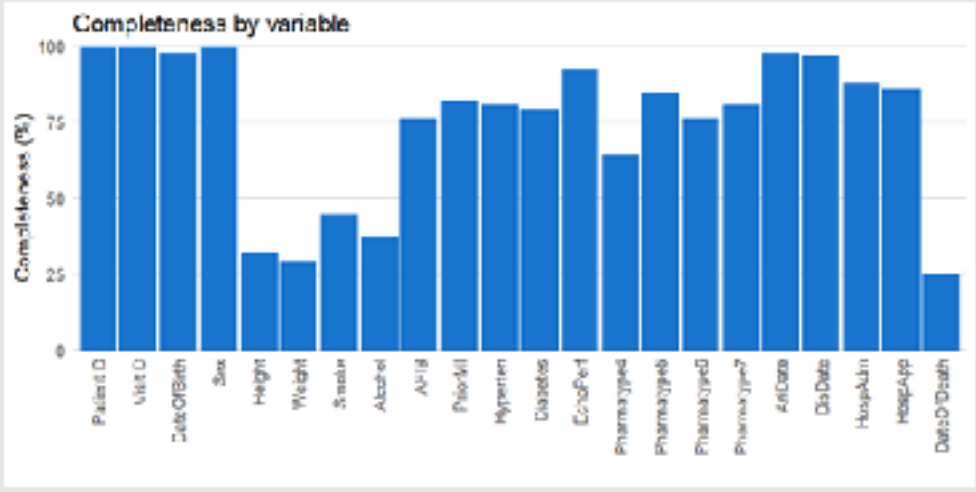
Completeness 75%

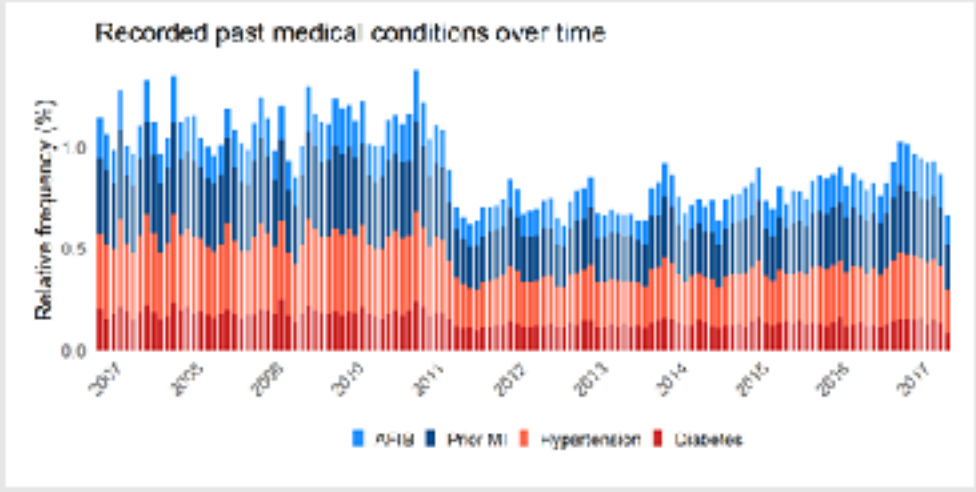
Consistency 77%

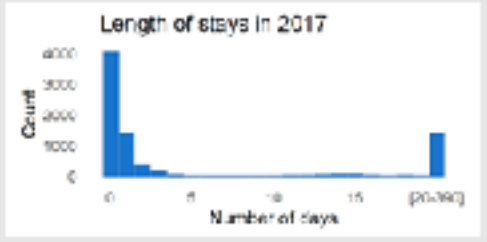
Correctness 82%

Uniqueness 96%

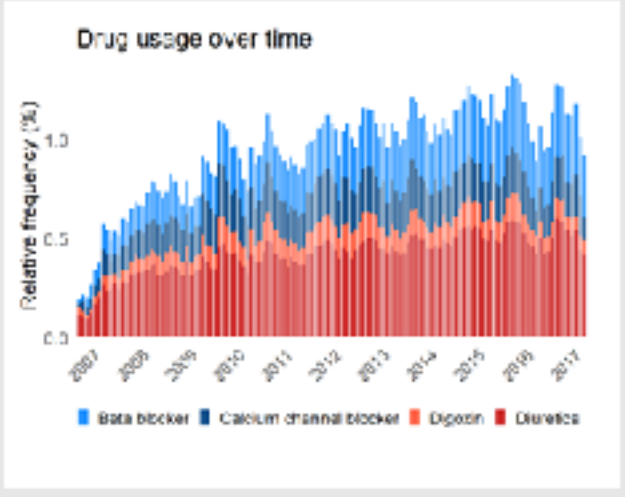
Stability 73%

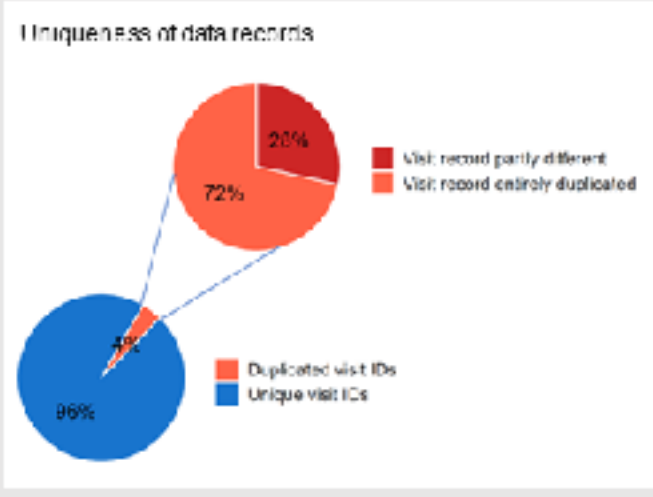


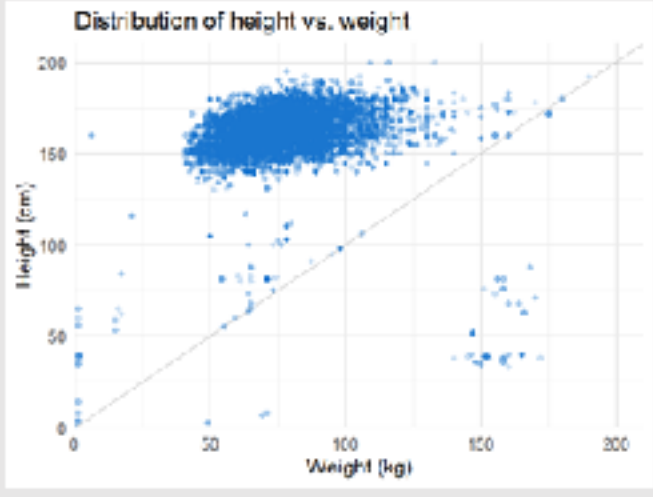




The European Institute for Innovation through Health Data







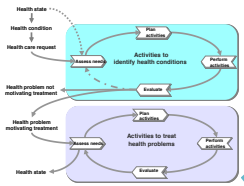
Incentivisation / Strategies for DQI

- Monitoring, Benchmarking, and Feedback
- Implementation through:
  - Software tools / apps and data quality dashboard
    - Regular checks for DQ dimensions and individual or institutional performances
  - Positive user experience
    - Improvements in software lead to DQI
  - Appointing a Data Quality Manager
    - Praise and commendation from immediate managers, individual feedback
    - Improved research opportunities
  - Allowing patient's access to EHR data
    - Creation of transparency
    - Stimulus for doctors to increase their attention to DQ and avoid missing information

90% of the data in the world today has been created in the last 2 years

Population registries, Clinical trials databases

Care pathways, decision support, trends and alerts



There will soon be almost as many personal assistant bots on the planet as people

Genomic data

The Digital Citizen

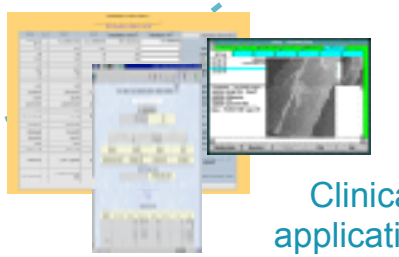
Environmental data

Mobile devices

Bio-sensors

Personal sensor data is expected to grow to 90% of all stored information within the next decade

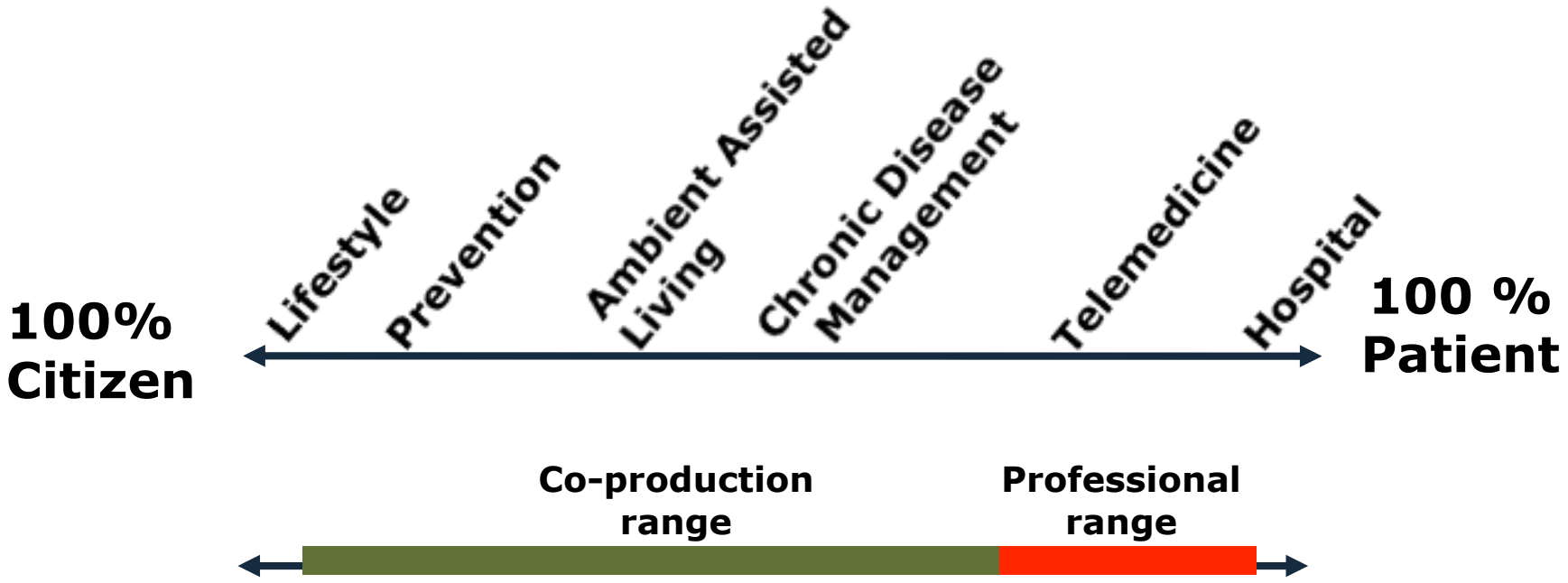
Social networks



Clinical applications

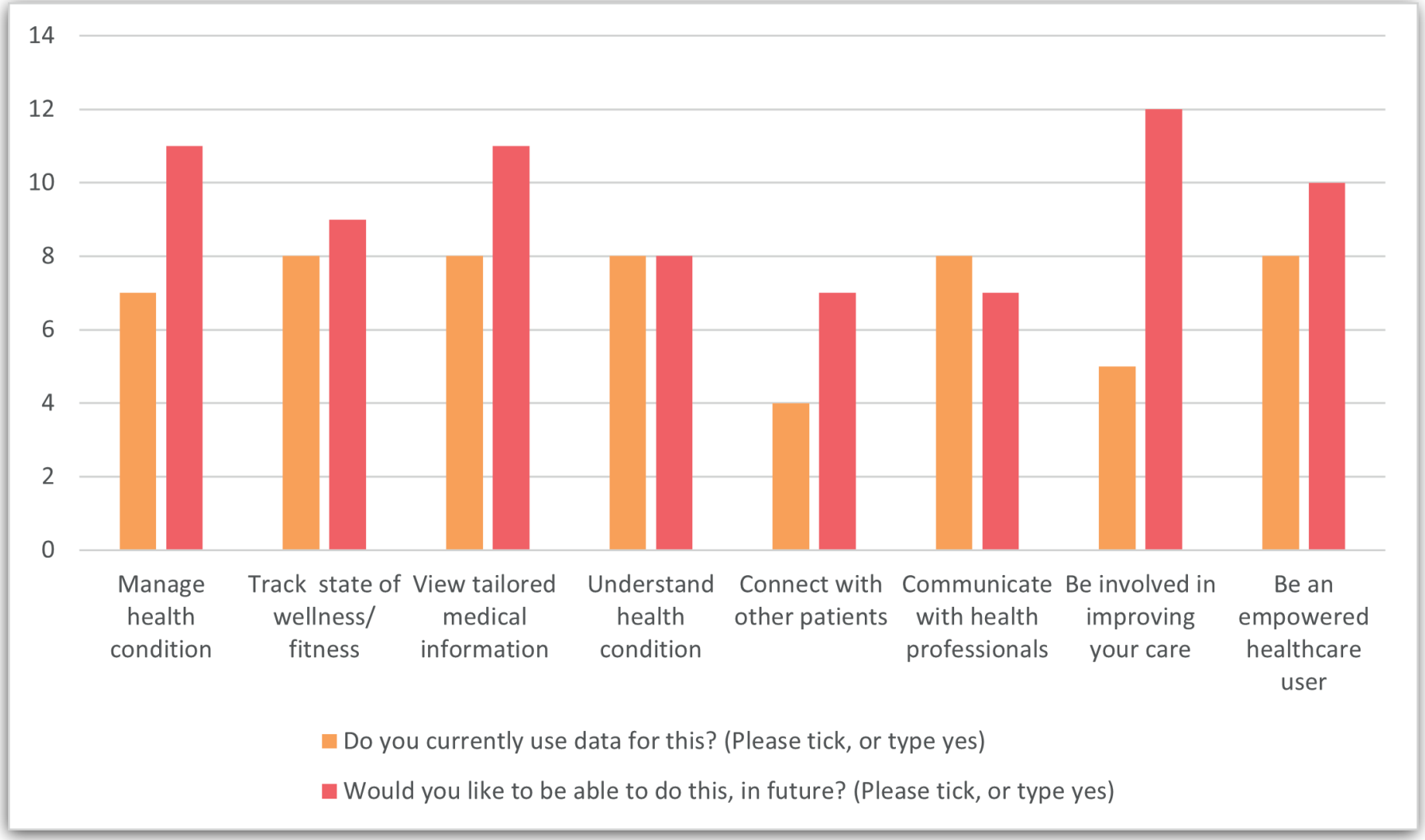
> 1 billion people have access to mobile broadband internet

The Digital Health Continuum



Slide courtesy of Niels Boye

Why do patients want to make more use of their own health data?



How do patients use digital health today?

Track health state

Learn about health conditions, treatment options

Compare with others

Set personal goals

Track progress towards targets

Track bodily function

Adjust dosage to fit lifestyle

Monitor symptoms

Prevention and wellbeing

Assess impact of treatment

Better able to share decision making

Activity, sleep, diet

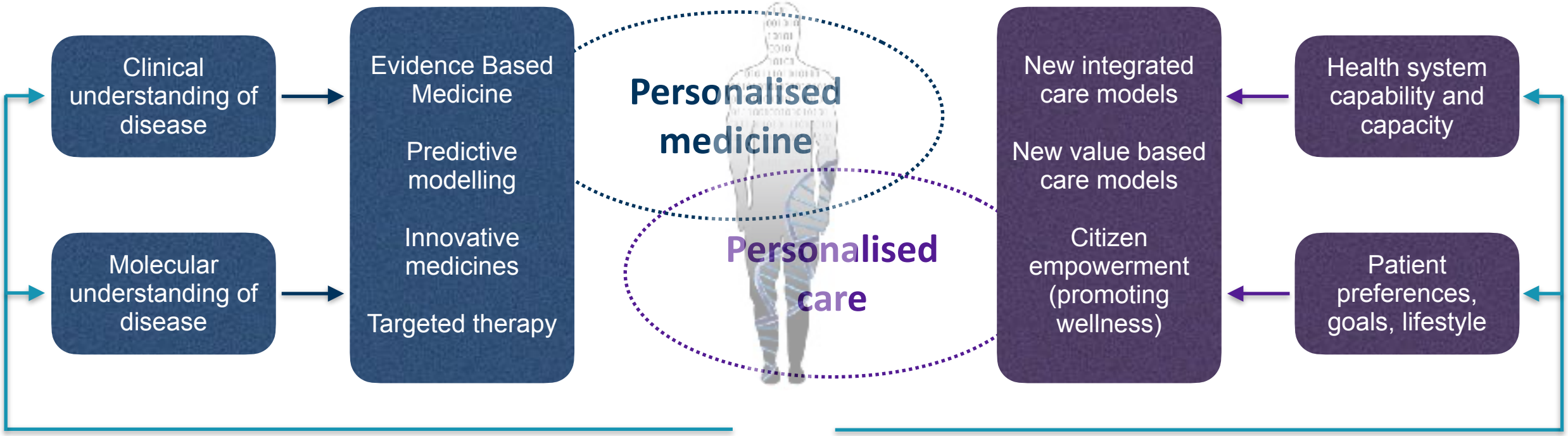
Document side effects

Contribute their own collected data to research

Know what to discuss with clinical team

Allow their clinical data to be used for research

Personalised Health and Learning Health Systems…



…need all stakeholders to collaborate, to maximise the insights we can gain from health data