Why *Open*... Matters

The Single Patient Record from an openEHR Perspective

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The Scene

1998 – Information for Health sets out interoperability and national standards as pillars of NHS digitisation.

2009 – "App-store" style toolkit announced (HC2009), echoing consumer tech but underestimating clinical data complexity.

2016 – Wachter Review: "Interoperability should be built in from the start" and nationally standardised—yet it must be modelled and governed.

Today – Shared care records exist, but semantics still fragment in the **middle**; we need a canonical core.

All of this has happened before, and it will all happen again."
– *Peter Pan*

Interoperability is not free.

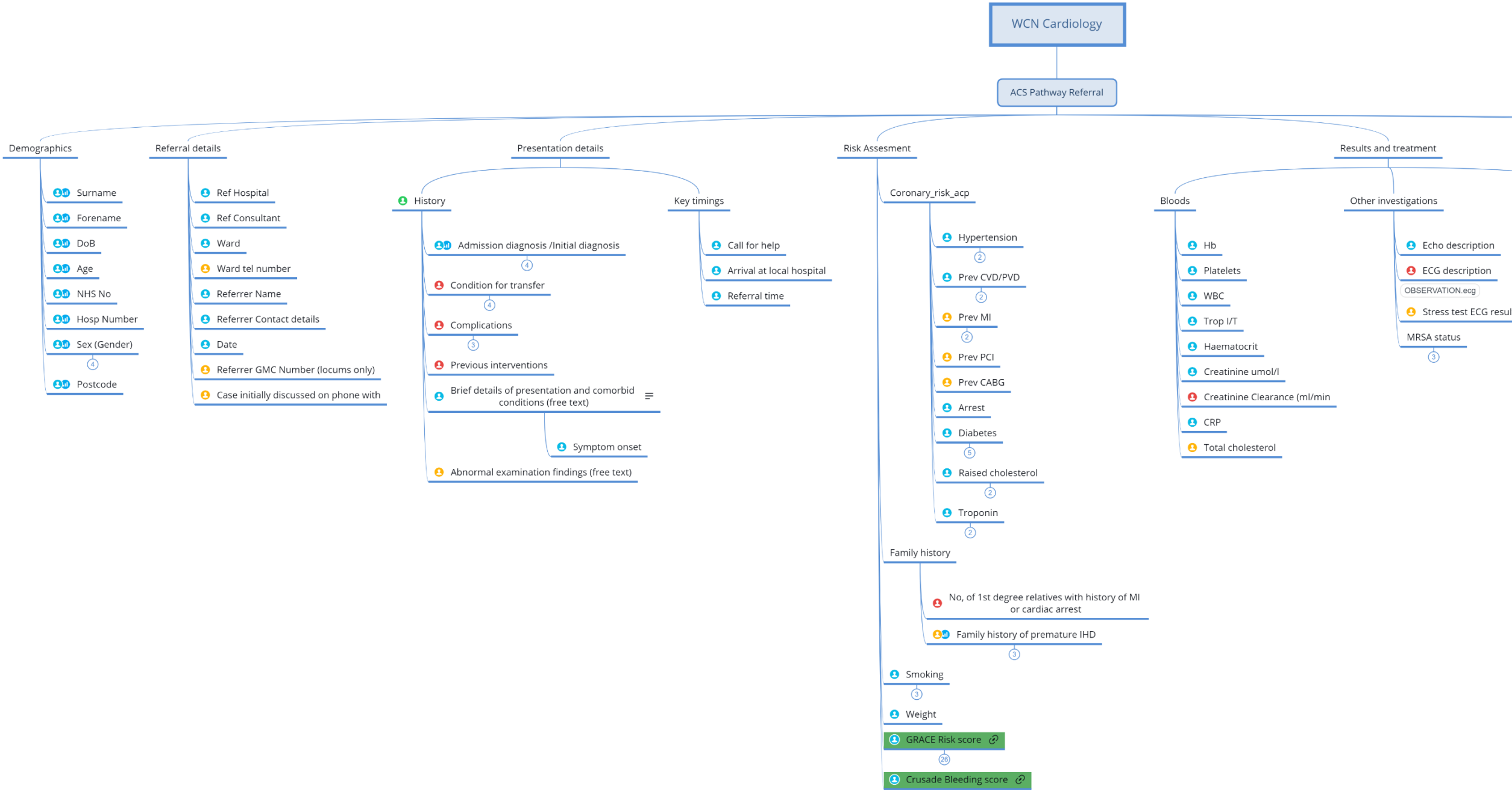
Rugby hooker called prostitute in Virgin Media Welsh translation gaffe

GETTY IMAGES

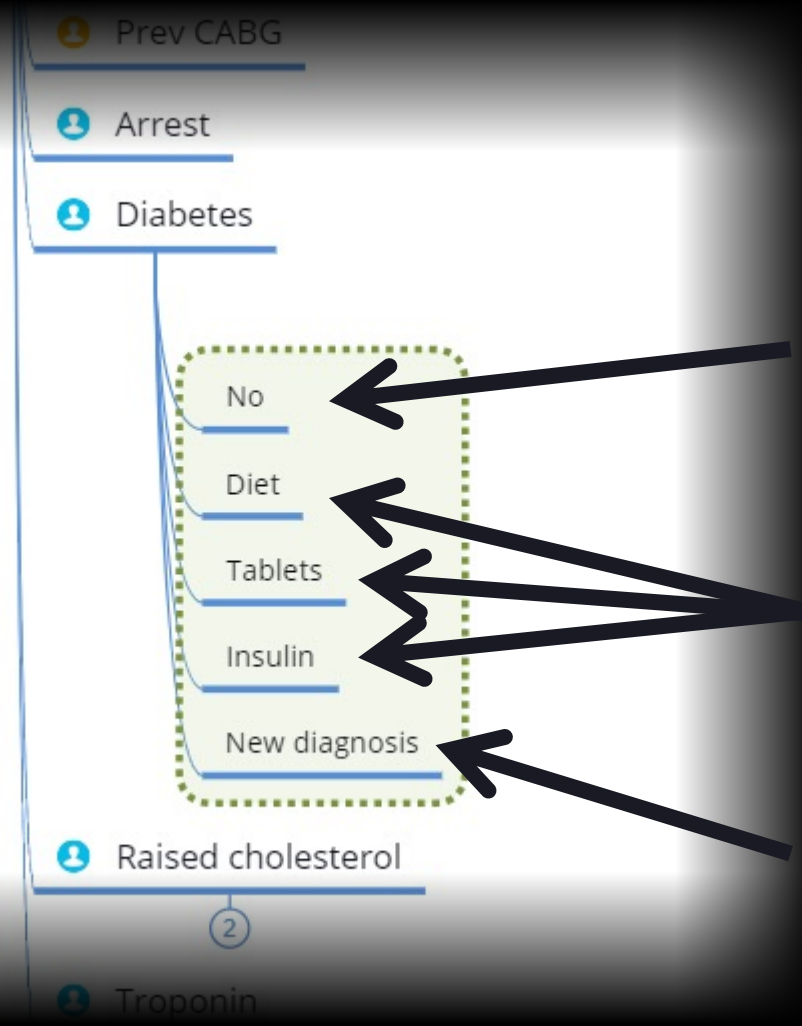
The language translation error occurred in TV listings about hooker Ryan Elias's appearance on a Welsh chat show next week

https://www.bbc.co.uk/news/articles/c620k0dzd18o

What must the SPR actually *do*?


WCN Cardiology
ACS Pathway Referral
Demographics
Surname
Forename
DoB
Age
NHS No
Hosp Number
Sex (Gender)
4
Postcode
Referral details
Ref Hospital
Ref Consultant
Ward
Ward tel number
Referrer Name
Referrer Contact details
Date
Referrer GMC Number (locums only)
Case initially discussed on phone with
Presentation details
History
Admission diagnosis /Initial diagnosis
4
Condition for transfer
4
Complications
3
Previous interventions
Brief details of presentation and comorbid conditions (free text)
Symptom onset
Abnormal examination findings (free text)
Key timings
Call for help
Arrival at local hospital
Referral time
Risk Assesment
Coronary_risk_acp
Hypertension
2
Prev CVD/PVD
2
Prev MI
2
Prev PCI
Prev CABG
Arrest
Diabetes
5
Raised cholesterol
2
Troponin
2
Family history
No, of 1st degree relatives with history of MI or cardiac arrest
Family history of premature IHD
3
Smoking
3
Weight
GRACE Risk score
26
Crusade Bleeding score
Results and treatment
Bloods
Hb
Platelets
WBC
Trop I/T
Haematocrit
Creatinine umol/l
Creatinine Clearance (ml/min
CRP
Total cholesterol
Other investigations
Echo description
ECG description
OBSERVATION.ecg
Stress test ECG resul
MRSA status
3

Modelling audit data



Query to the CDR/Problem List for absence of data

Treatment regimen

Date first diagnosed

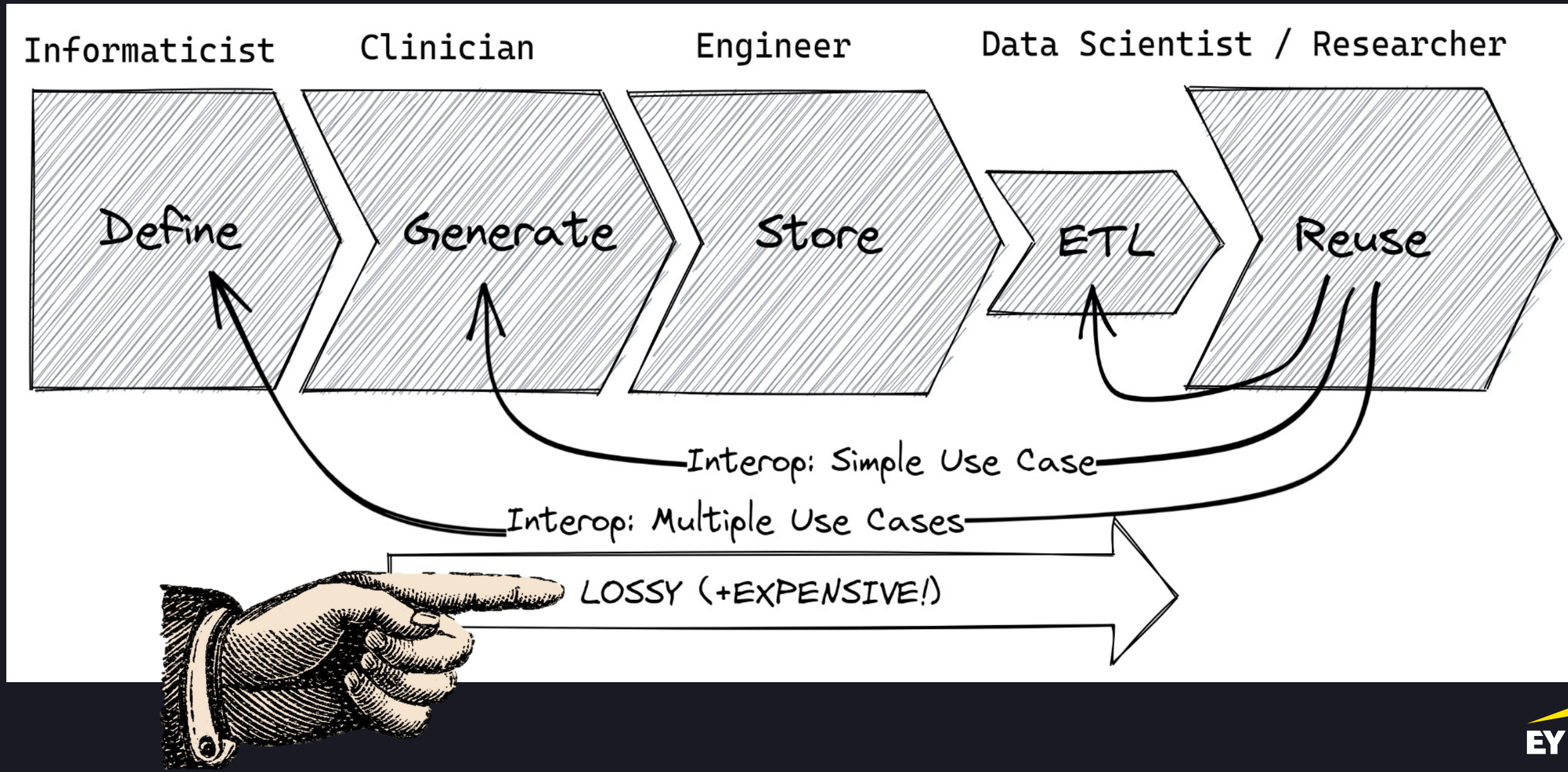

Photo by 傅甬 华 on Unsplash

Diabetes ≠ No

Data Transforms Destroy Semantics

- **Data Abstraction/Aggregation**:
  - Serves the new use case. This process can strip away context and granularity
  - Mismatched objectives
  - Data loss / lossy process
- **Standardisation and Coding**:
  - Health data often translated into standardised formats.
  - Loss of detail or misinterpretation of the data's original meaning
- **Privacy and Anonymisation**:
  - Identifiable information is removed or obscured.
  - Necessary; can remove context critical for understanding data.

- **Contextual Loss**:
  - Health data collected for primary use is deeply embedded in individual patient contexts;
    - personal history,
    - local healthcare practices,
    - treatment plans.
- **Data Quality and Consistency**:
  - Quality of data collected for primary care purposes can vary greatly,
  - Inconsistencies or errors in the data are often magnified.
  - Different healthcare providers might have different practices for recording information.


Informaticist
Clinician
Engineer
Data Scientist / Researcher
Define
Generate
Store
ETL
Reuse
Interop: Simple Use Case
Interop: Multiple Use Cases
LOSSY (+EXPENSIVE!)

The Trap: Architecture in the middle.

Why Open Matters

Open standards are publicly governed specifications that describe how data should be structured and exchanged, free of proprietary constraints.

E.g. HL7 FHIR, openEHR, SNOMED CT

The Open Platform is a technology stack whose data layer and APIs are published, royalty-free and governed by open standards.

Open platforms turn health data into a shared, trusted asset.

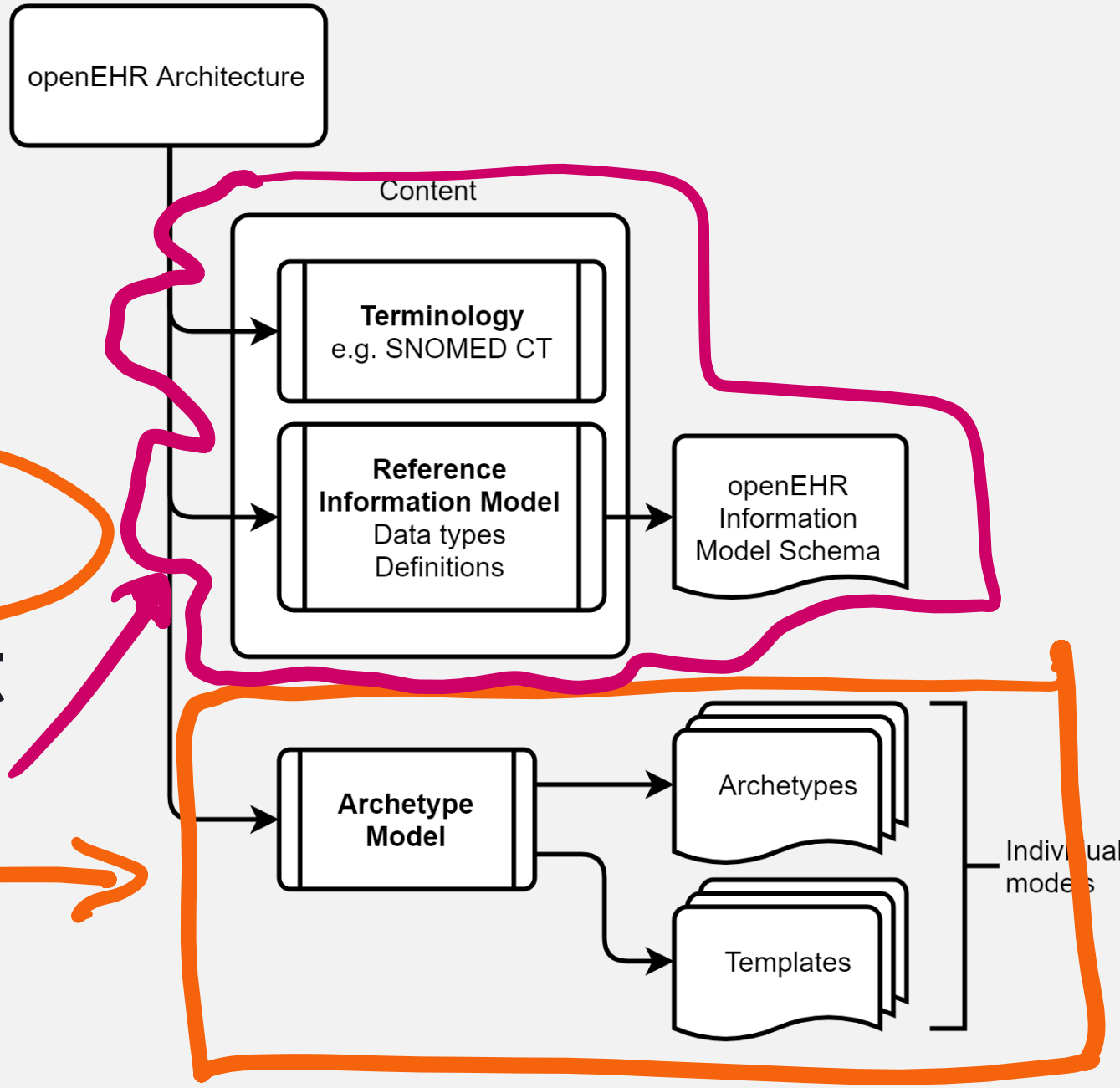
The Relationship

- **Standards are necessary but not sufficient.** You need them to ensure semantic consistency, yet on their own they don't deliver run-time services, scalability or security.
- **Open platforms operationalise open standards.** They turn data encapsulated within documents into live, governable services that can be extended safely.
- **Digital Care Record programmes should procure the platform, and endorse the standard.** Requirements should specify both compliance (standards) **and** openness of the platform (transparent APIs, modular architecture, fair licensing).

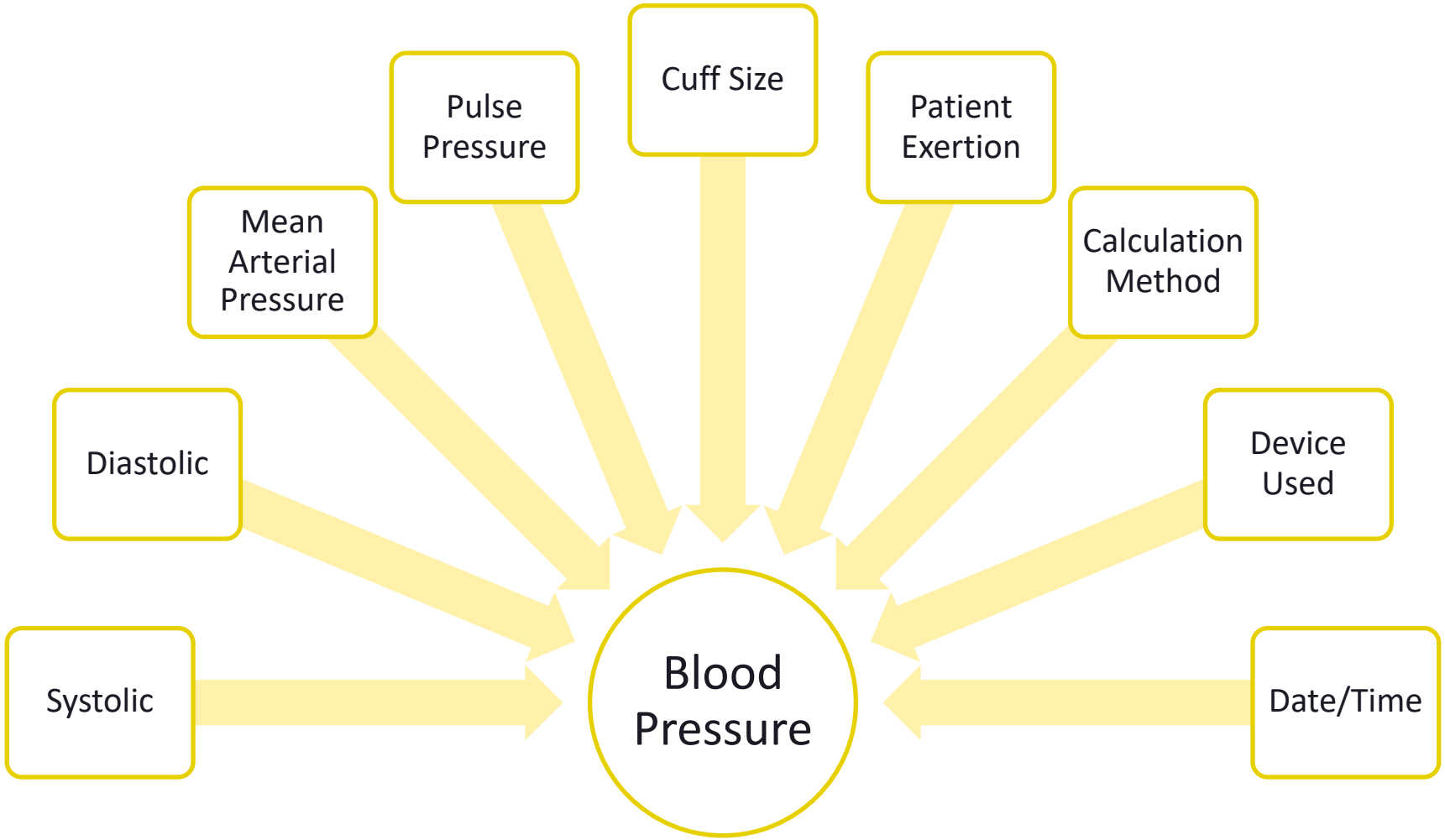
openEHR:

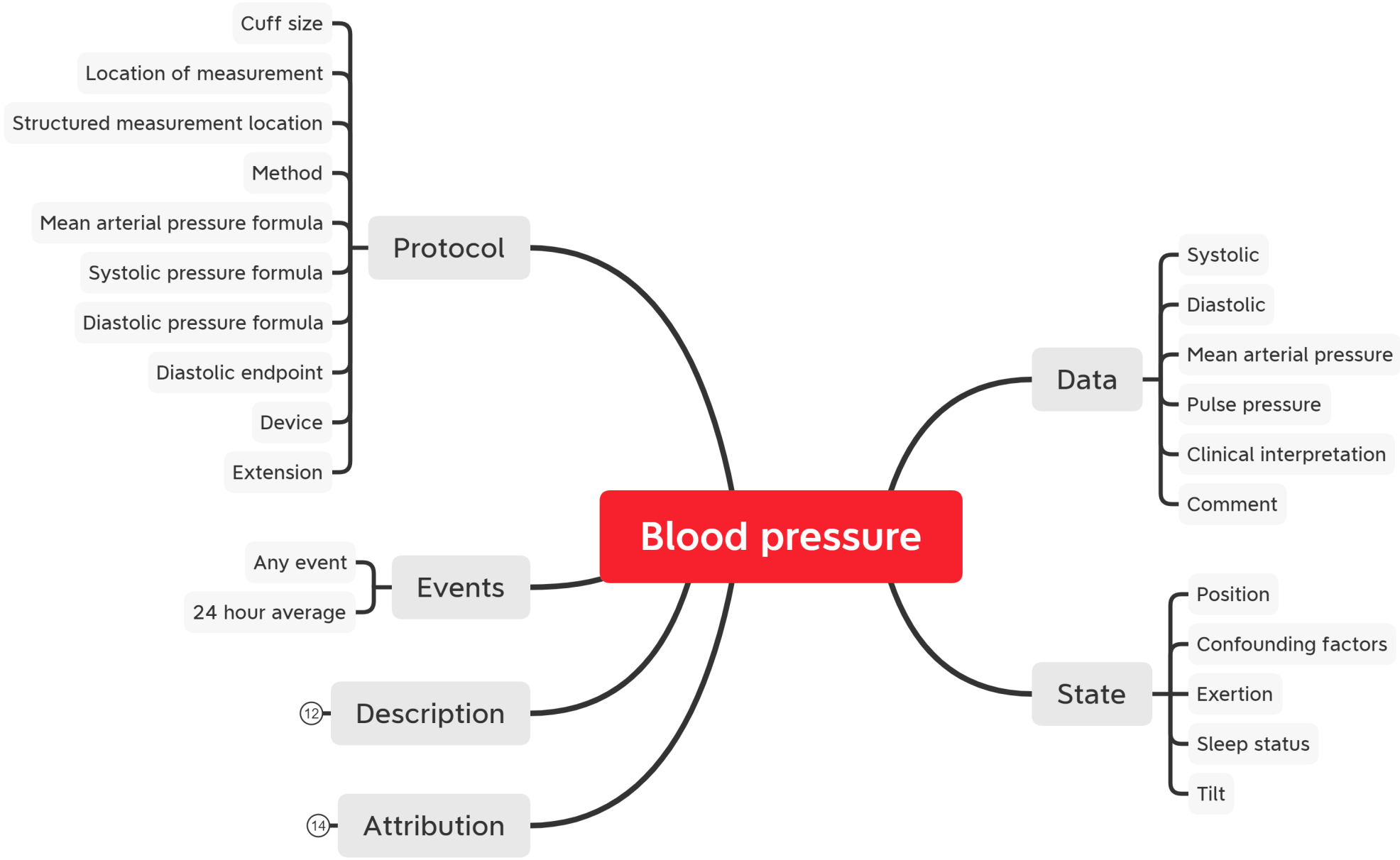
A specification comprising of;

- clinical models
- + the rules that govern them



How do you describe “blood pressure” as data?





openEHR-EHR-OBSERVATION.blood_pressure.v2

So what is a data standard?

Is HL7 FHIR a standard?

Is openEHR a standard?

Is SNOMED CT a standard?

- **FHIR and openEHR are not standards *themselves* – they are *standard-enabling frameworks*.**
- **SNOMED CT provides the words; FHIR and openEHR provide the grammar and syntax that let us create coherent, governed health data standards.**

The takeaway…

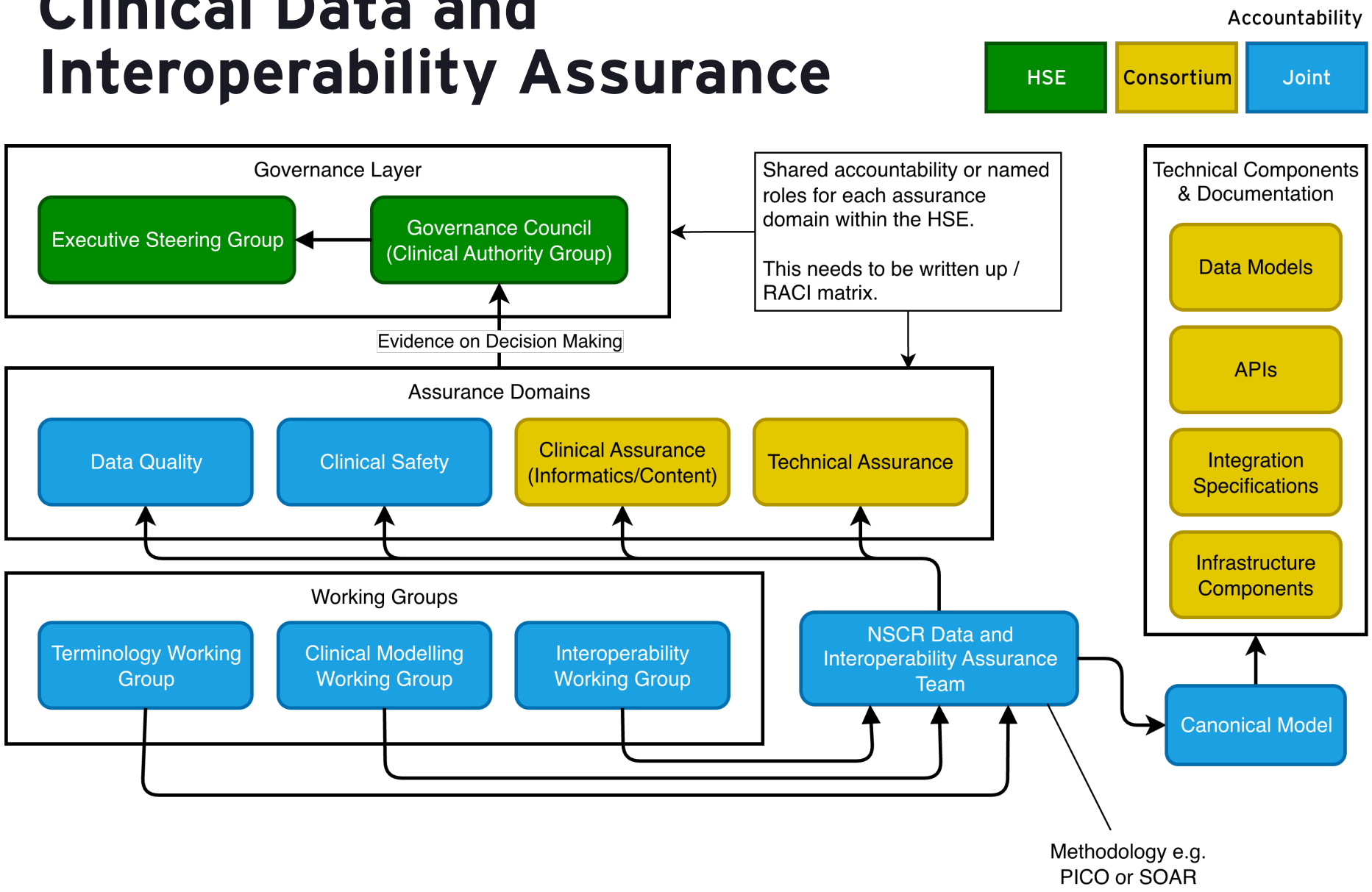
Layer	Function	"Ready-to-use?"	Why / Why not
SNOMED CT	Vocabulary (meaning)	✅ Yes	You can code data directly with concept IDs.
FHIR	Exchange grammar	⚠️ Not yet	Needs profiling to constrain optionality and vocabulary.
openEHR	Persistence grammar	⚠️ Not yet	Needs archetypes/templates to express domain semantics.

Converge or Collide?

"Both openEHR and HL7 FHIR are community-driven standards, developed and enabled by dedicated global communities with diverse stakeholders including clinicians, informaticians, developers, and vendors. This shared foundation provides a powerful springboard for joint efforts to enable better healthcare delivery, foster innovation and accelerate vital research and development worldwide."

Joint Statement openEHR and HL7 FHIR
June 3rd 2025

Clinical Data and Interoperability Assurance



1. **Structural Semantic Capability**: The theoretical semantic richness of the data structure (e.g., schema design).
2. **Implementation Realisation**: The practical fidelity and completeness of the semantic structure as implemented in real-world deployments.
3. **The Principle of Canonical Model Alignment**: The ease and safety with which incoming data can be accurately mapped into canonical data structures such as openEHR archetypes and templates

The SPR from an openEHR Perspective...

A governed, patient-centred canonical record; persist the meaning once, then project it everywhere.