

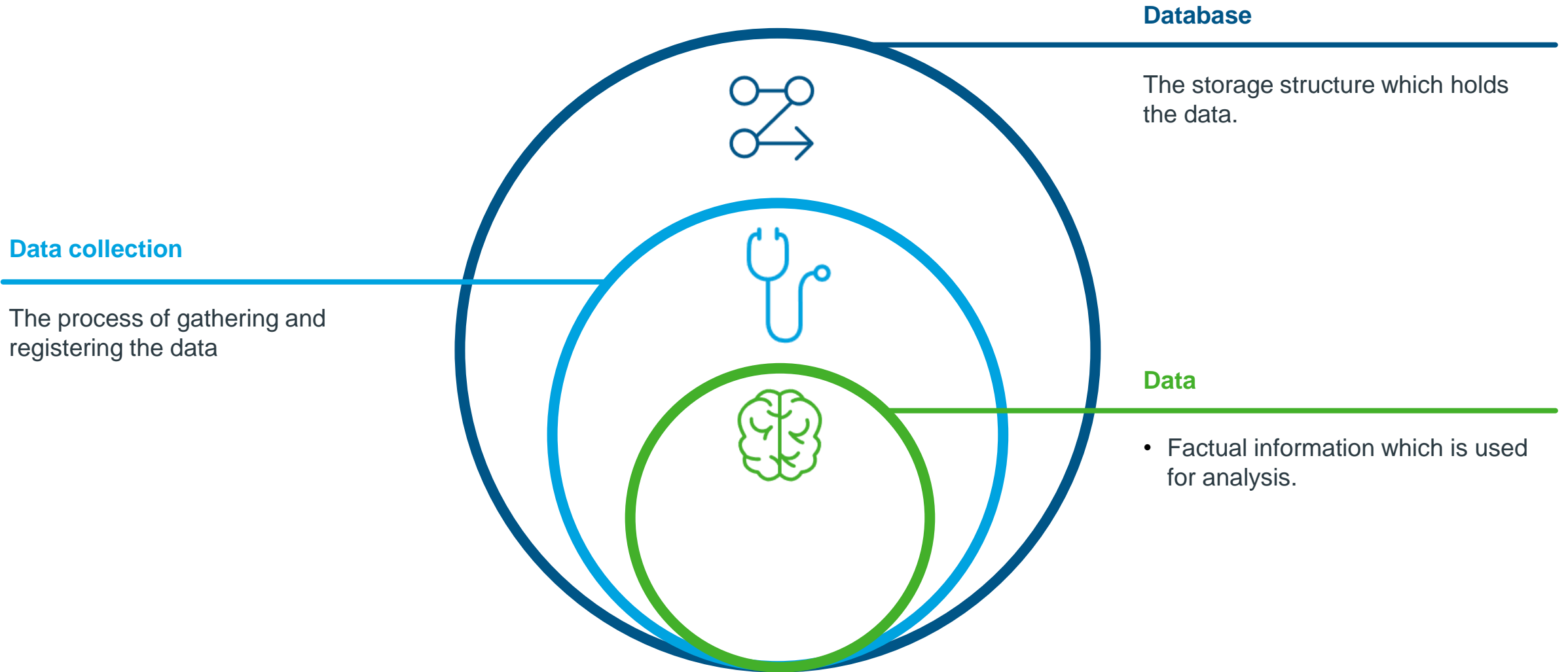
What is data quality, and how data types differ in terms of data quality?

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BBS/BES Seminar
Wednesday 15th March 2022 from 14:30-17:00 CET
Virtual meeting

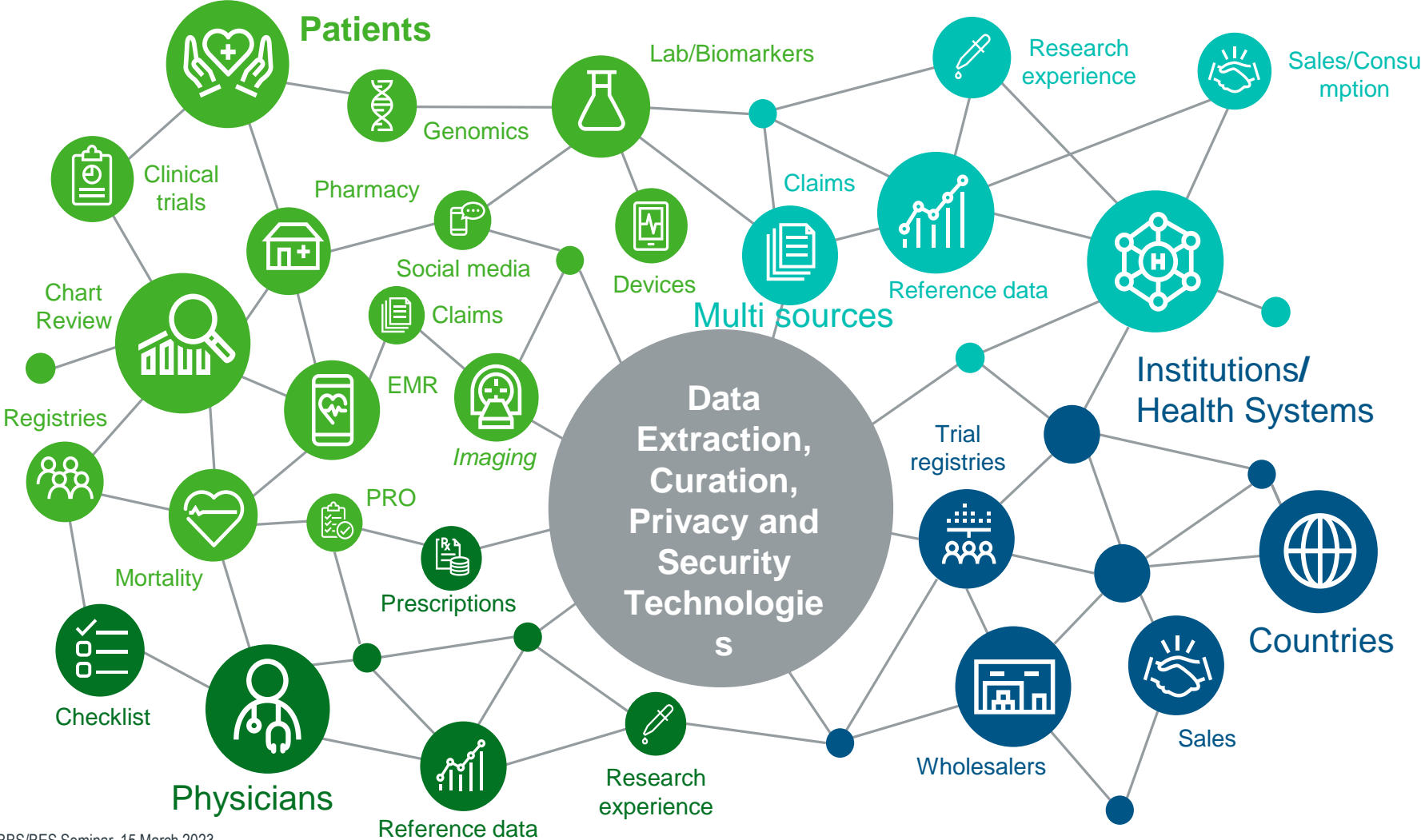
How well your data meets your needs?

Data quality can be measured at different levels



The FAIR principle

The ultimate objective of a database should be its re-usability.



F.A.I.R

Findable

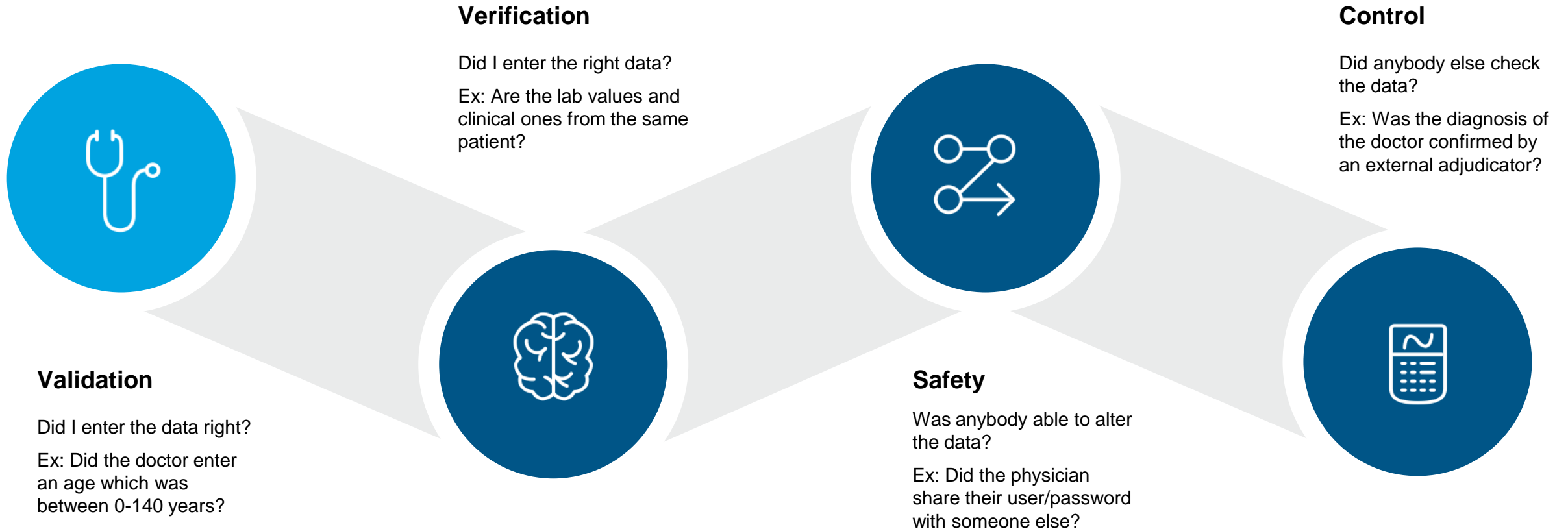
Accessible

Interoperable

Re Usable

Validation, verification, safety, control

Transparency and traceability allow the measurement of these elements.



Fitness for purpose

The most important element of fitness-for-purpose is relevance.

Relevance

Does it have the variables I need?

Completeness

Are all variables filled with values?

Accuracy

Does it have errors?

Linkability

Can I link it to other data sources?

Timeliness

Can I access the data within my deadlines?

Representativeness

Is the population similar to the one I want to study?

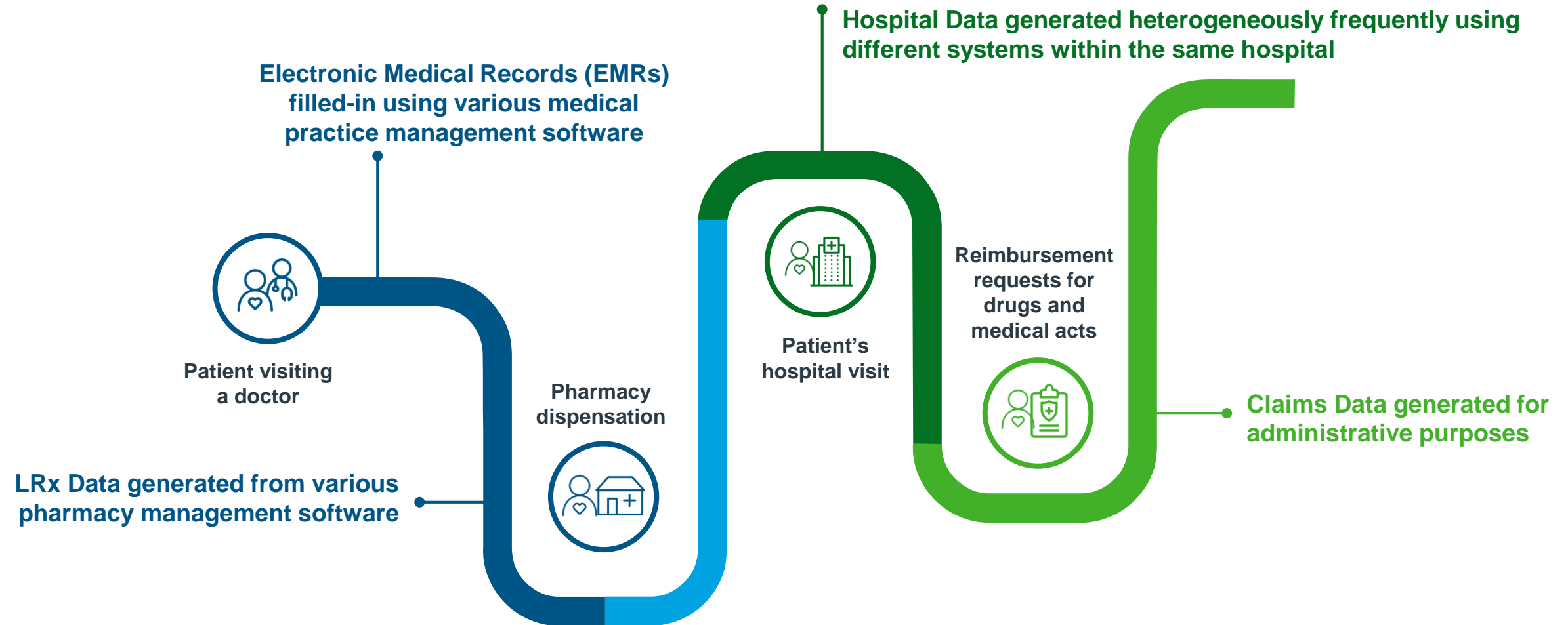
Accessibility

Can I access the data at all?



Focus on main sources of secondary longitudinal patient data

Data is generated for administrative purposes not for analytical ones



Claims data

Initial purpose

- Economic management
- Reimbursement

Content

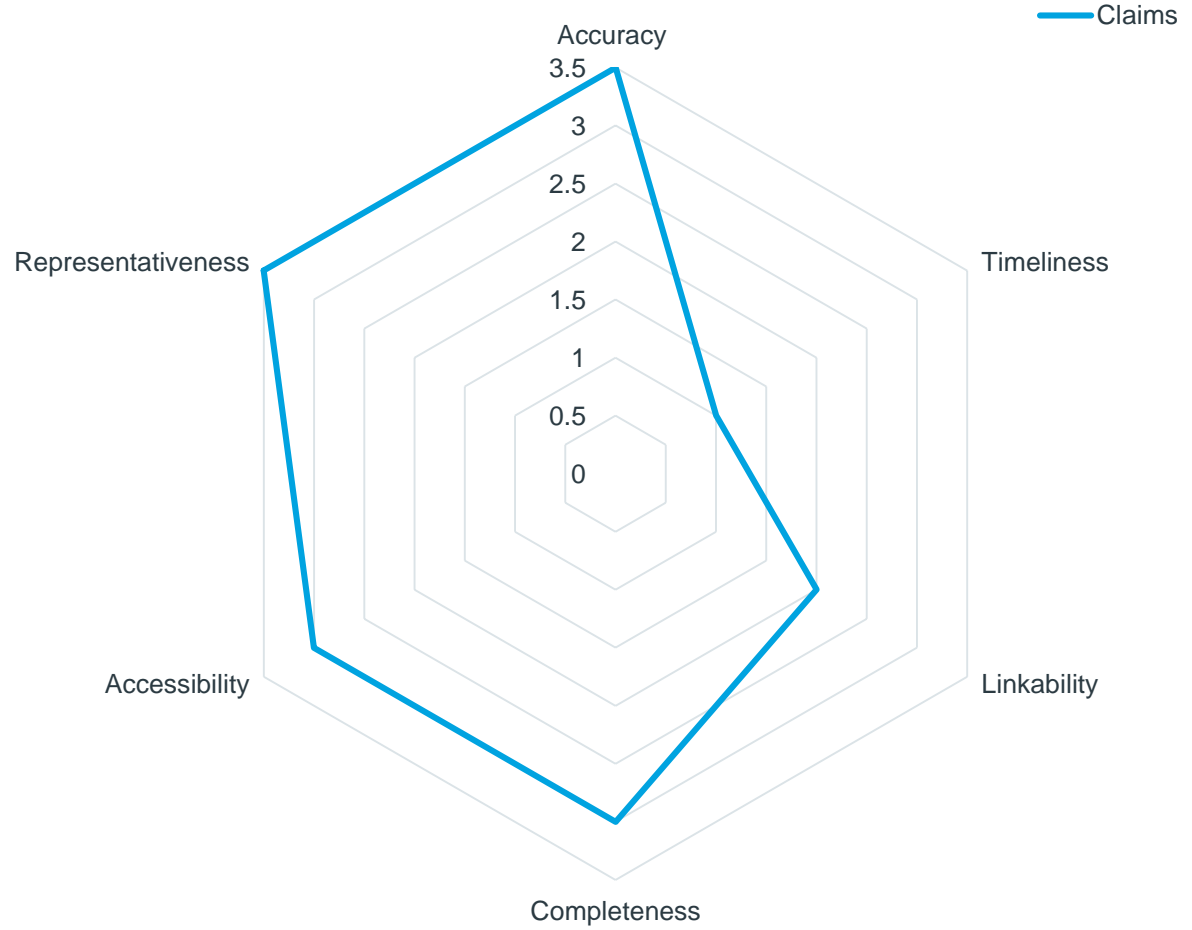
- Demographics
- Diagnoses
- Diagnostic related groups
- Procedures
- Reimbursed drugs/devices

Settings

- Mainly Hospitals
- Increasingly linked to outpatient claims

Good for

- Economic and resource utilization
- Epidemiology
- Healthcare system



EMR data

Initial purpose

- Clinical management
- Patient follow up

Content

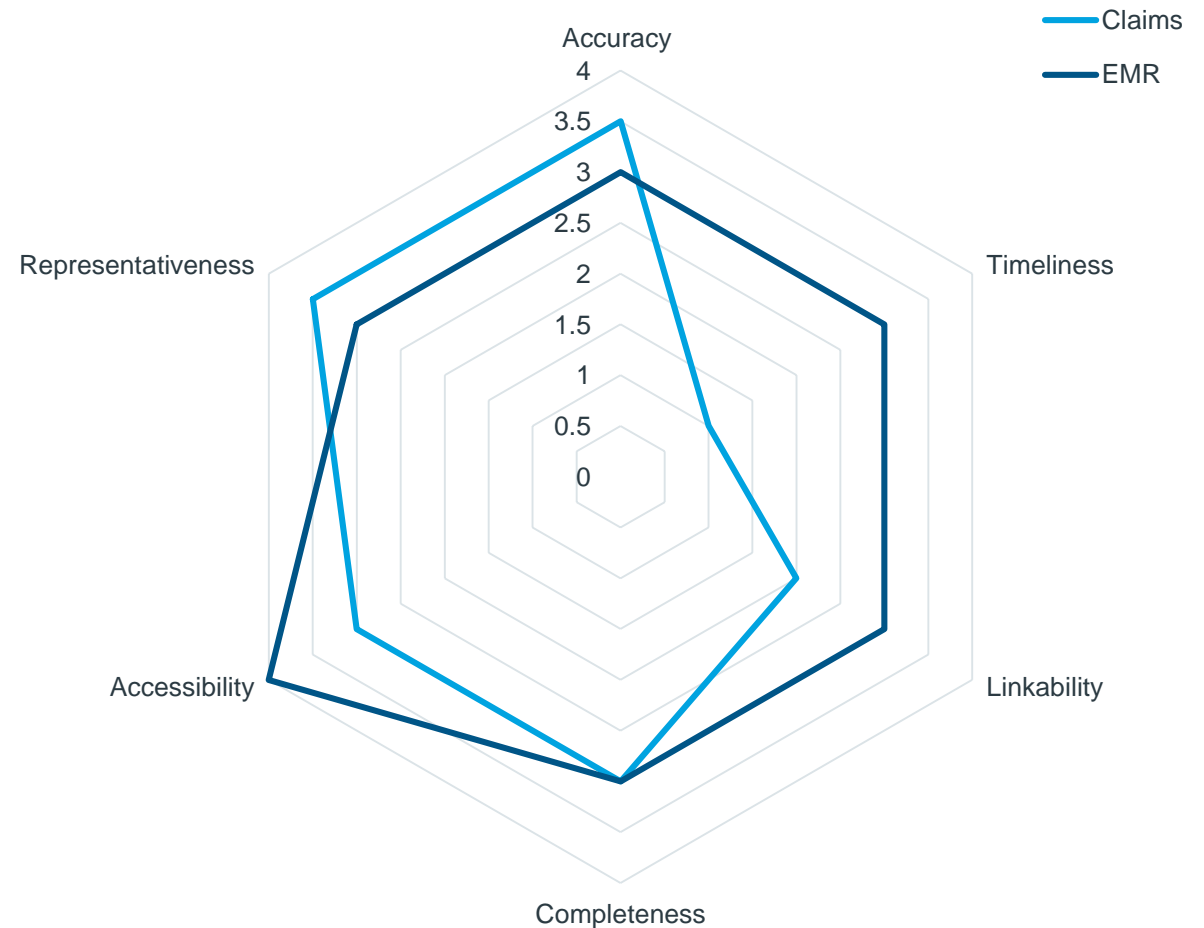
- Demographics
- Diagnoses
- Signs and symptoms, allergies, smoking
- Lab values
- Drugs and to a less extent procedures

Settings

- Mainly primary care
- Increasingly secondary care and hospitals

Good for

- Exposure evaluation
- Drug utilization
- Disease epidemiology
- Benefit-risk assessment
- Unmet needs, burden, adherence



Pharmacy records/sales data

Initial purpose

- Sales management
- Benchmarking

Content

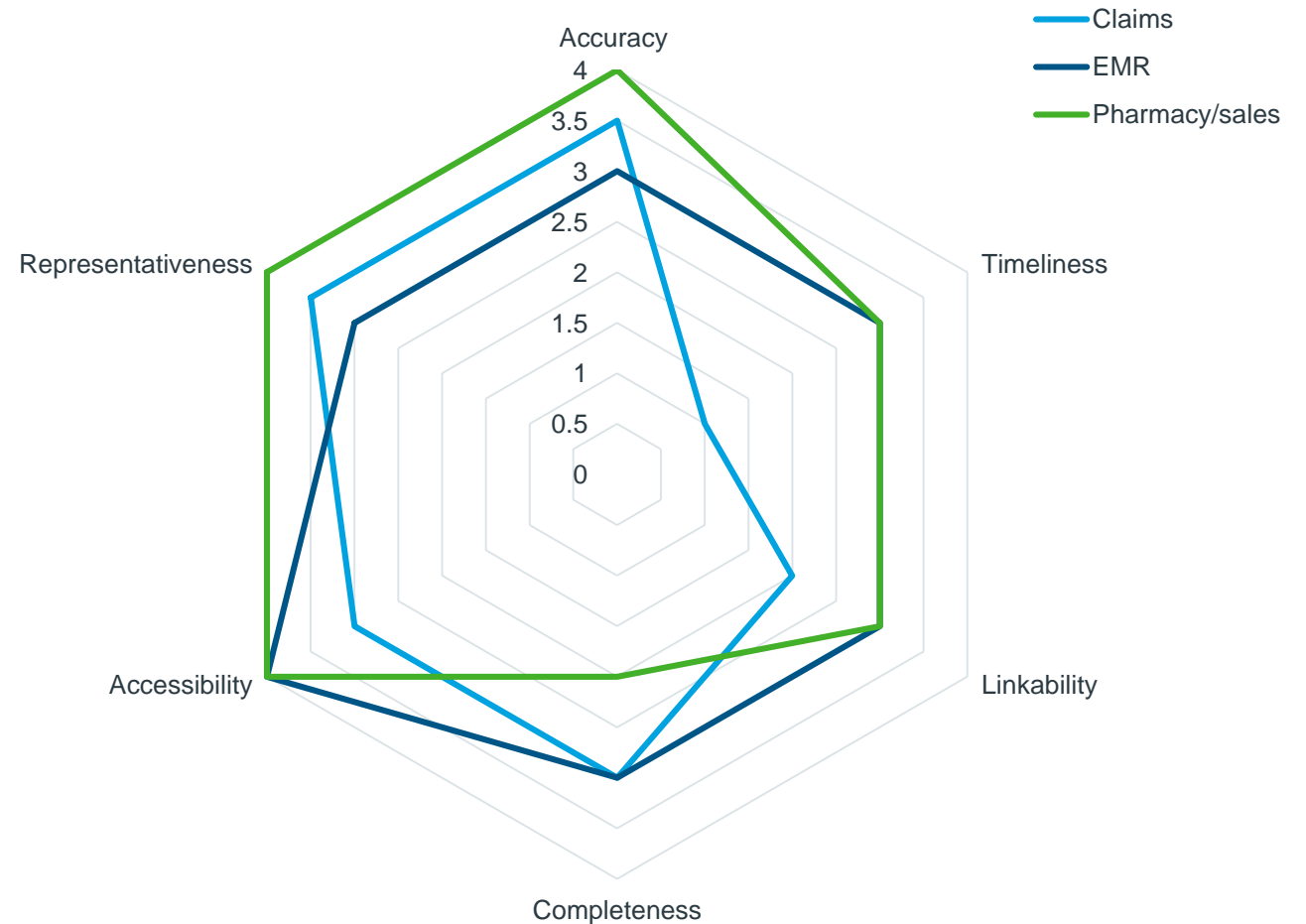
- Demographics
- Drugs (packages sold)

Settings

- Retail pharmacies
- Wholesales
- Company outputs

Good for

- Exposure
- Treatment dynamics (switch, discontinuation...)
- Population movements
- Linkage



Registries

Initial purpose

- Research

Content

- Demographics
- Clinical details
- Procedures
- Drugs
- Lab values
- Relevant markers, genetic data, tests, etc.

Settings

- Disease or drug oriented
- Mostly secondary care
- Mostly research intensive areas (oncology, ...)

Good for

- Disease epidemiology
- Benefit-risk assessment
- Treatment pathways



Social media, wearables, connected devices, etc

Initial purpose

- Networking
- Follow up
- Experimental

Content

- Demographics
- Narrow and specific data

Settings

- Everyday life
- Smoothly entering the healthcare system
- Telemedicine programs

Good for

- Hypothesis generation
- Signal detection / monitoring
- Population behavior
- Public health intervention evaluation

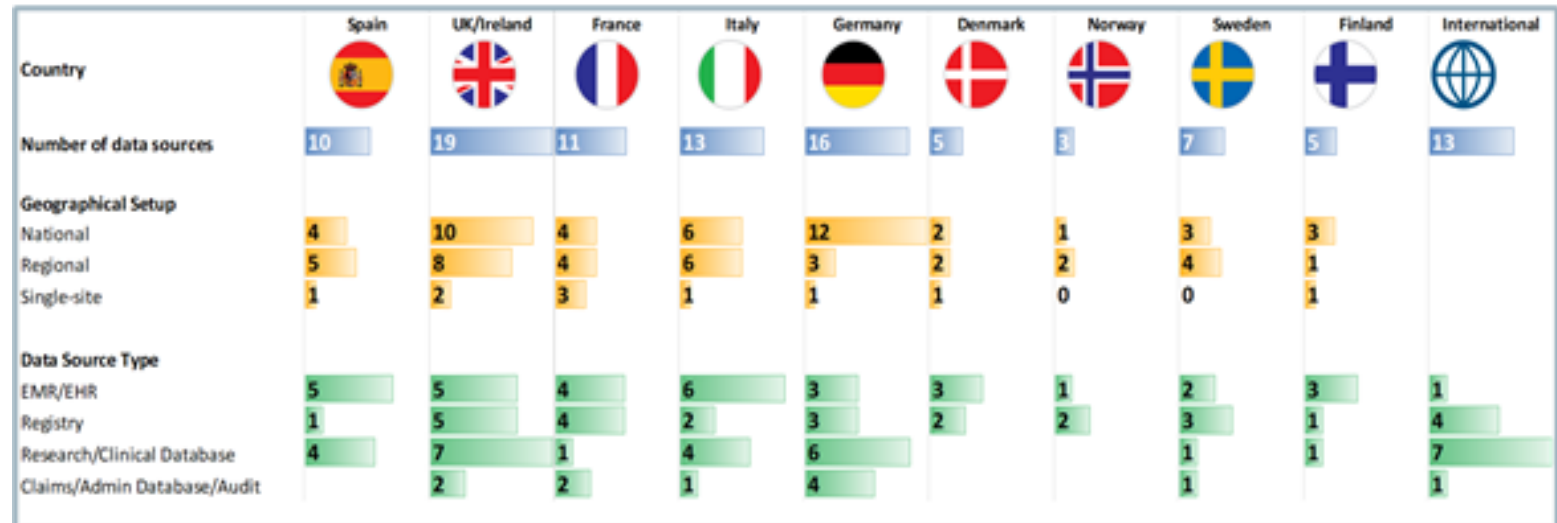


Data source types dictate only a part of the story

A data landscaping or feasibility assessment is necessary to determine the quality of data

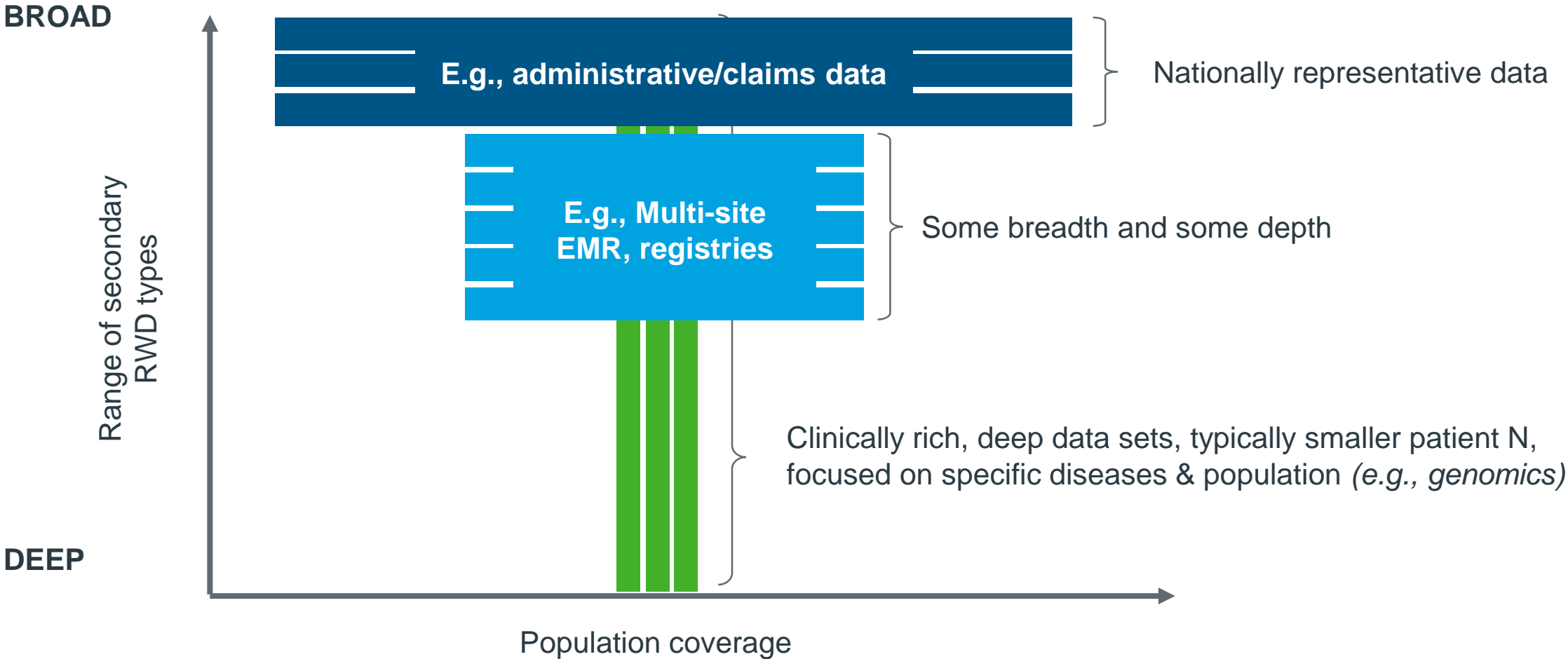
- Databases must be **fit-for-purpose**, i.e. to be able to provide answers to our research questions based on our expectations of access, coverage, validity, likability, timelines, budget, etc.
- A **feasibility study** is often necessary to inform the most fit-for-purpose data sources for any given set of research questions.

Criteria	Data Source 1	Data Source 2	Data Source 3	Data Source 4	Data Source 5	Data Source 6	Data Source 7	Data Source 8
	EMR	Database	EMR	Audit	Registry	Biobank	Registry	Registry
Demographics	Green	Green	Green	Green	Green	Green	Green	Green
Methods of diagnosis	Green	Green	Yellow	Green	Red	Red	Yellow	Yellow
Treatments	Green	Green	Green	Not reported	Red	Red	Yellow	Yellow
Outcomes	Yellow	Green	Green	Not reported	Red	Red	Red	Red
Safety and AEs	Green	Green	Grey	Not reported	Red	Red	Grey	Grey
PROs	Red	Red	Red	Yellow	Yellow	Red	Red	Red
HCRU	Red	Red	Red	Green	Red	Red	Green	Green



The fit-for-purpose data may need combining and linkage

T-shaped data linkage allows the extrapolation of high-depth data to larger populations.





Thank You!

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