

Role of registries in identifying gaps in Guideline implementation

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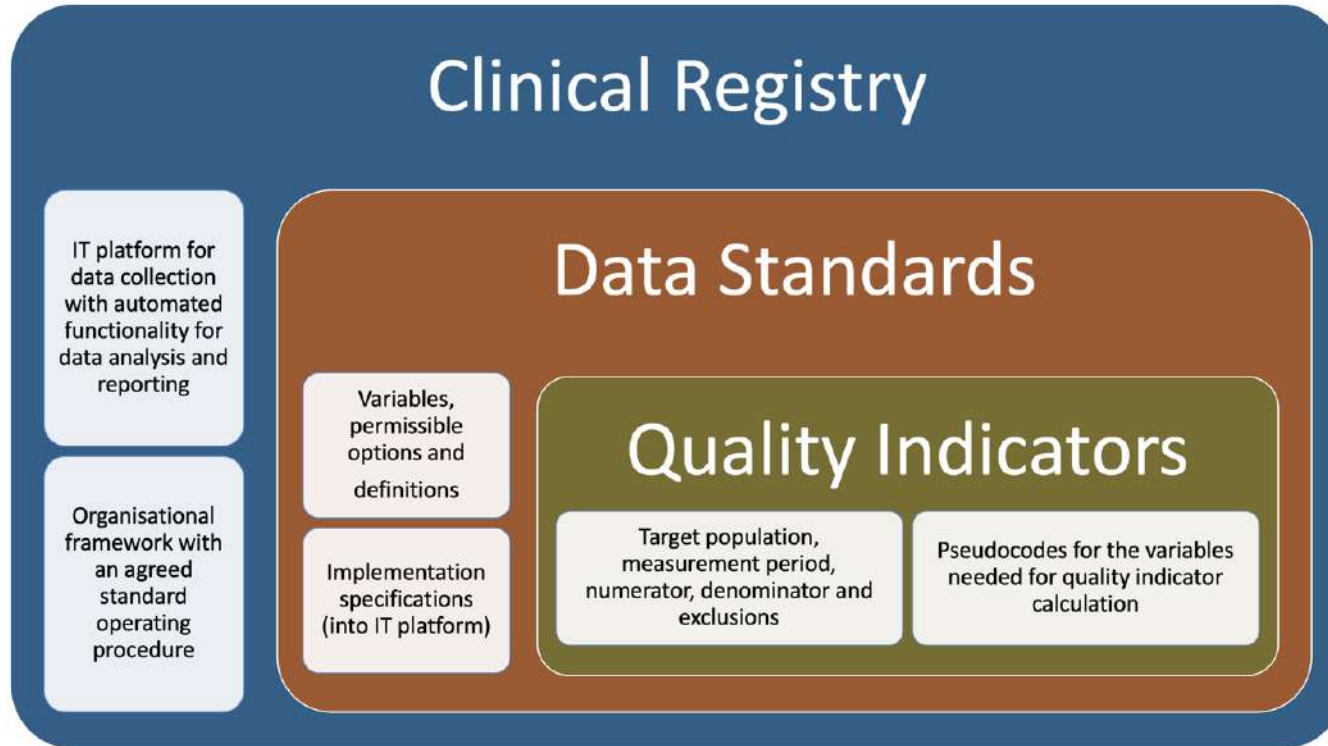
Objectives

- 1. Components of quality registries & ESC initiatives**
- 2. Registries and gaps in guideline implementation**
- 3. The state of contemporary national registries**
- 4. Future directions**

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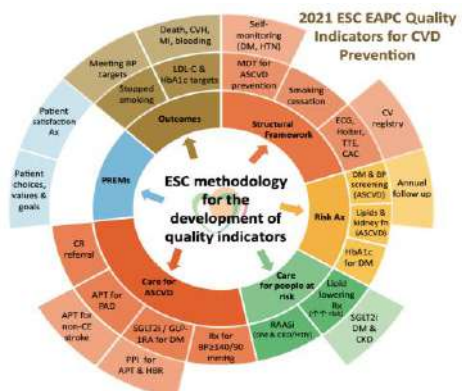
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Quality registry





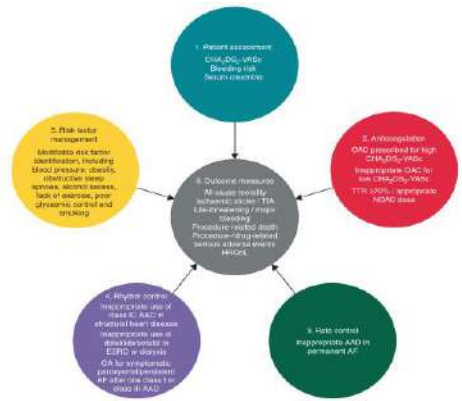
Schiele F, Aktaa S, Rossello X, et al. EHJ-ACVC. 2021



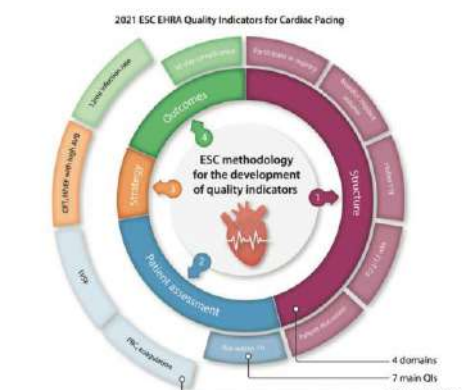
Aktaa S, Gencer B, Arbelo E, et al. Eur J Prev Cardiol. 2021



Aktaa S, Polovina M, Rosano G, et al. EHJ-HF.2022



Arbelo E, Aktaa S, Bollmann A, et al. Europace. 2021

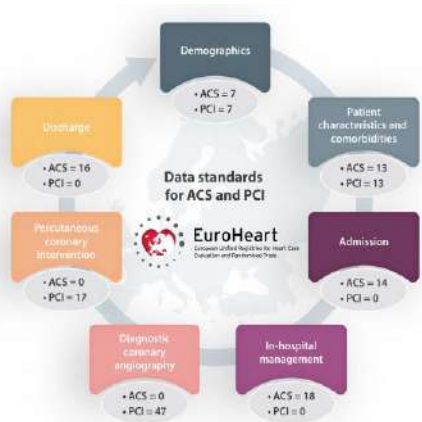


Aktaa S, Abdin A, Arbelo E, et al. Europace. 2021



Aktaa S, Tzeis S, Gale CP, et al. Europace. 2022

Data Standards



Batra G, Aktaa S, Wallentin L, et al. EHJ.2022



Aktaa S, Batra G, Cleland JGF, et al. EHJ.2022



Batra G, Aktaa S, Camm JA, et al. EHJ-QCCO. 2023.



Aktaa S, Batra G, James SK, et al. EHJ-QCCO. 2023

Presentation

Hide 

Presenting symptoms 

Chest pain/discomfort
 Dyspnoea
 Cardiac arrest
 Other
 Unknown

Cardiac arrest prior to hospital arrival 

No
 Yes
 Unknown

Symptom onset date 

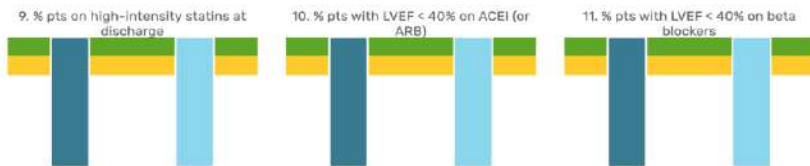

 Unknown

Symptom onset time 

Unknown

Arrival method 

Self-presenter
 Ambulance from home/community
 Transportation from another hospital
 Already in the hospital
 Unknown



■ Ward 1
 ■ Completely
 ■ My country
 ■ Partially

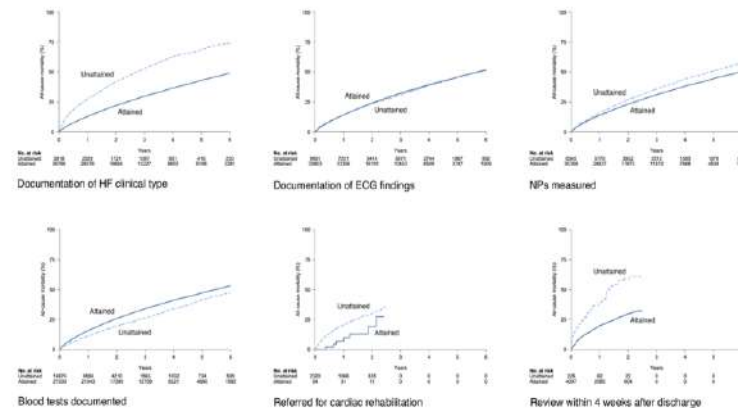
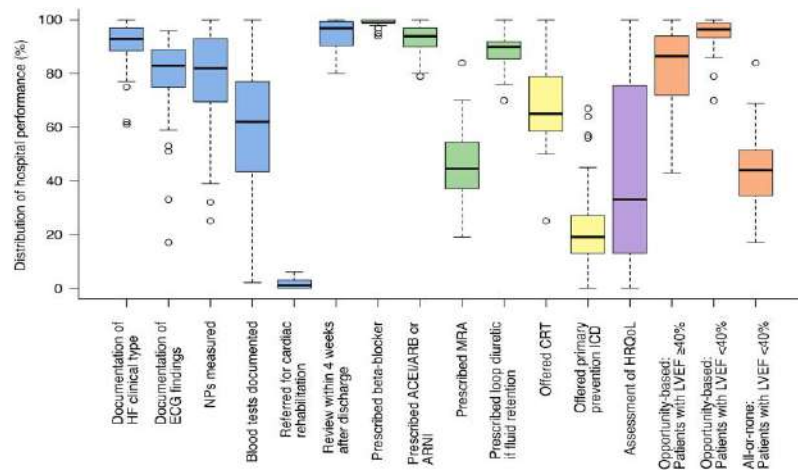
The figures show the degree of goal fulfillment for the unit, the county and the country for the registry's quality index.



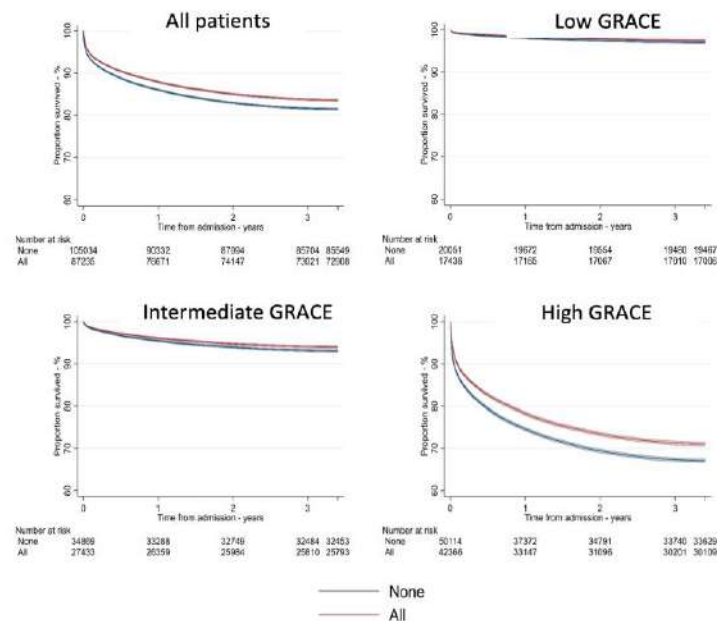
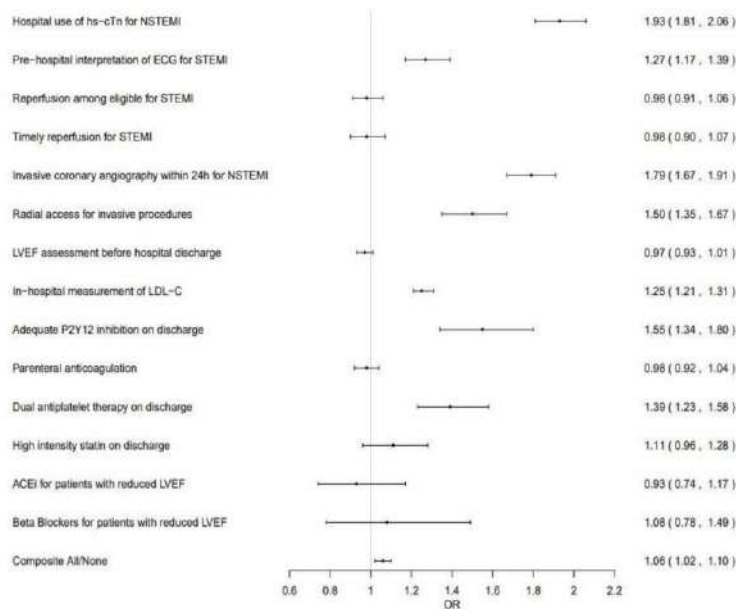
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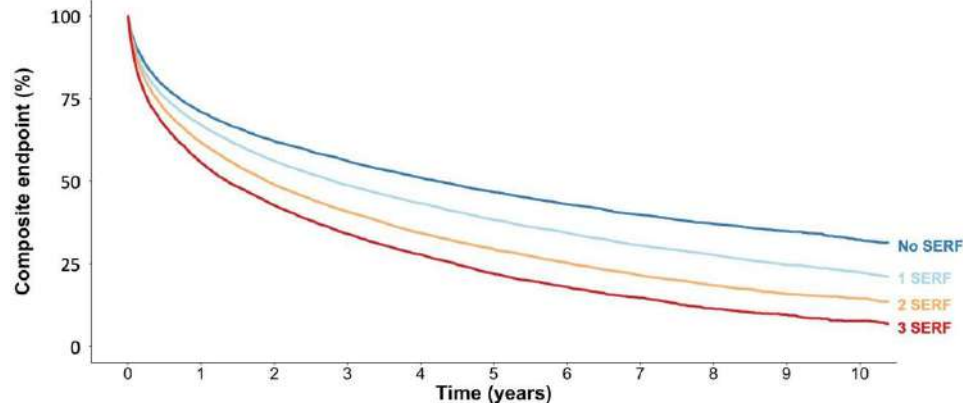
ESC QIs for HF – SWEDEHEART



ESC QIs for AMI – UK

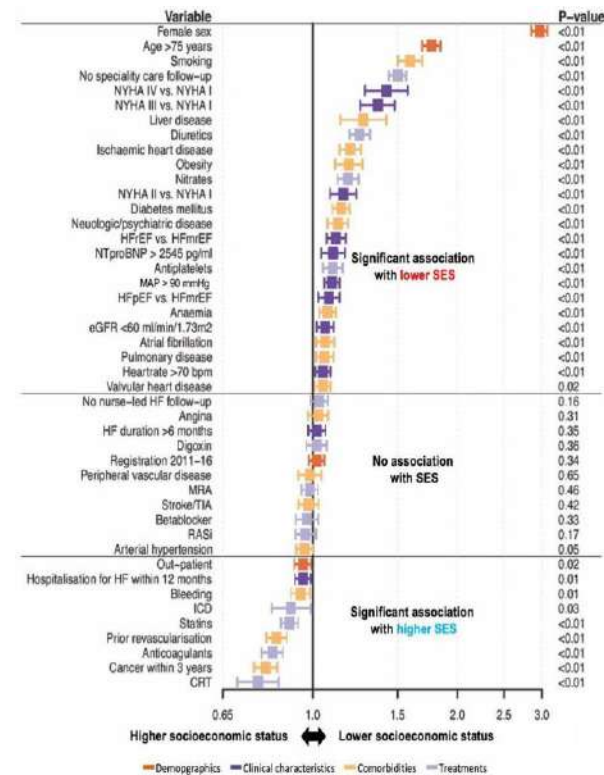
QI attainment during lockdown
OR (95% CI)


Socioeconomic disparities

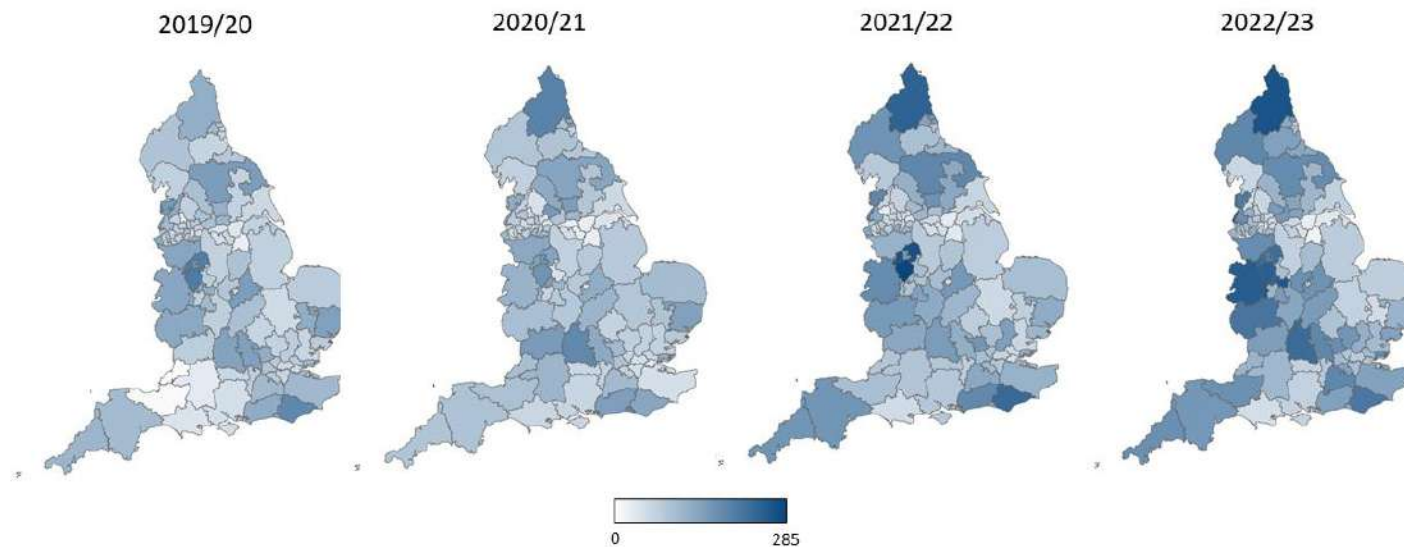


	Number at risk										
	0	1	2	3	4	5	6	7	8	9	10
No SERF	9362	6409	5470	4774	3797	2945	2162	1619	1103	667	352
1 SERF	14600	9390	7619	6380	4949	3662	2706	1895	1229	690	366
2 SERF	13594	8095	6260	5034	3730	2719	1903	1284	813	459	246
3 SERF	7085	3819	2866	2223	1584	1059	689	429	229	117	54

CEP: heart failure hospitalisation or all-cause death



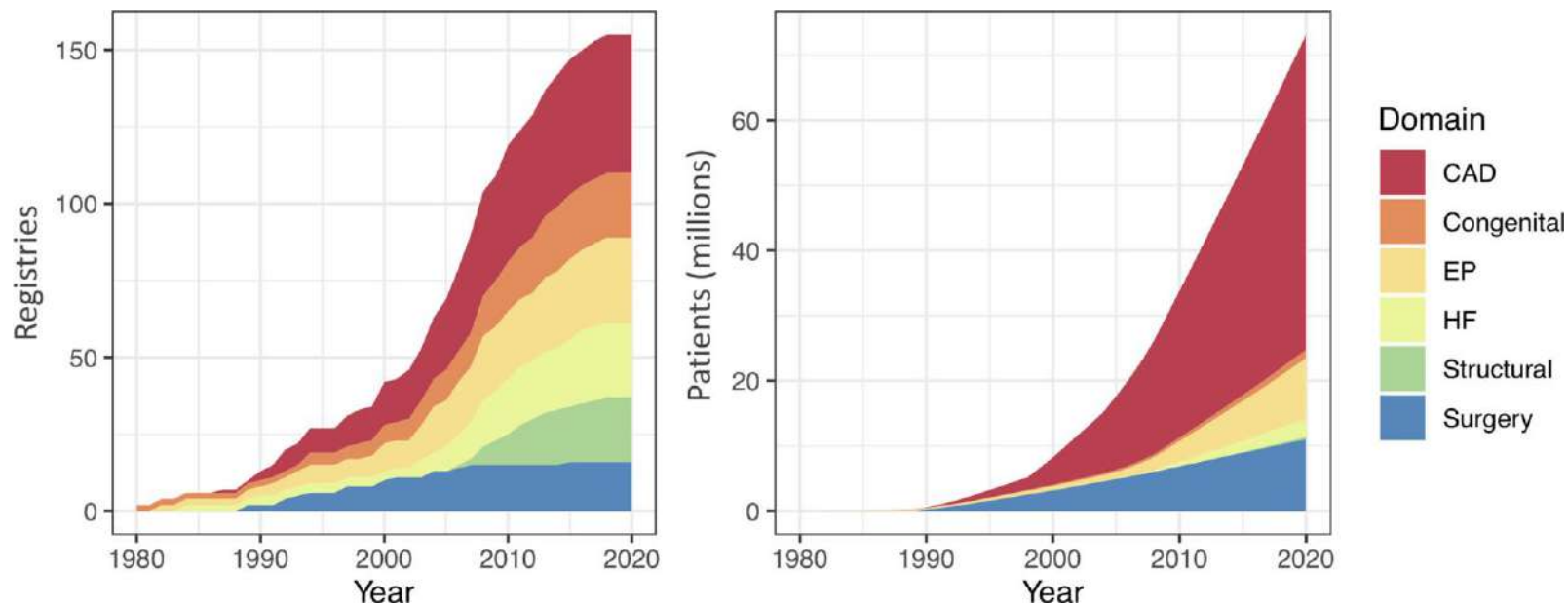
Geographic variation



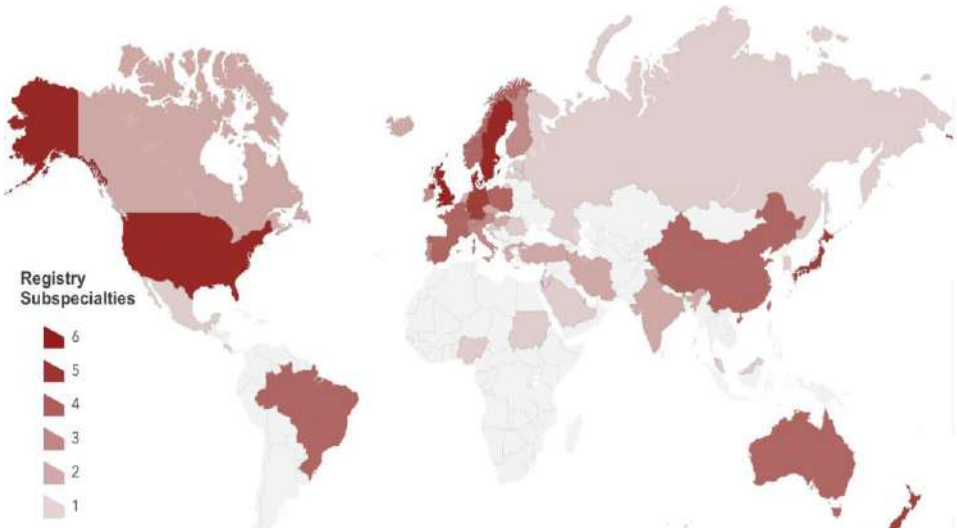
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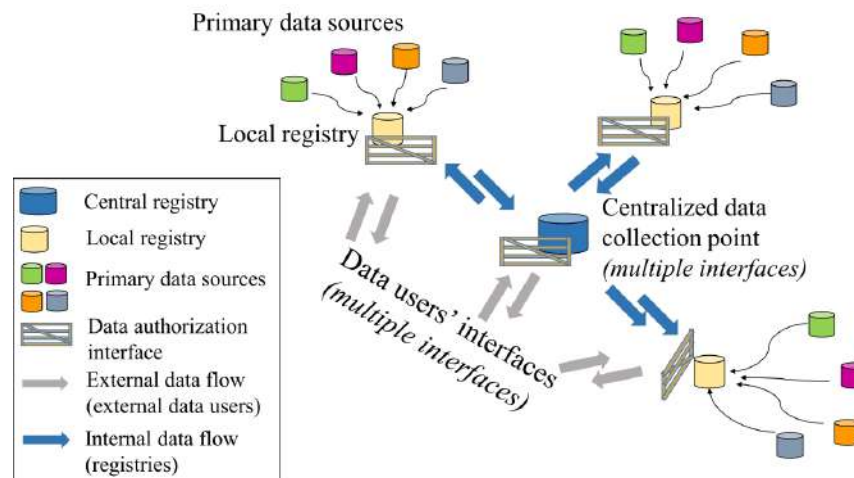
National registries



National registries

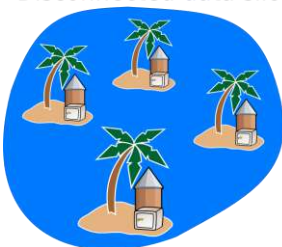


Integration within & between data collection sources



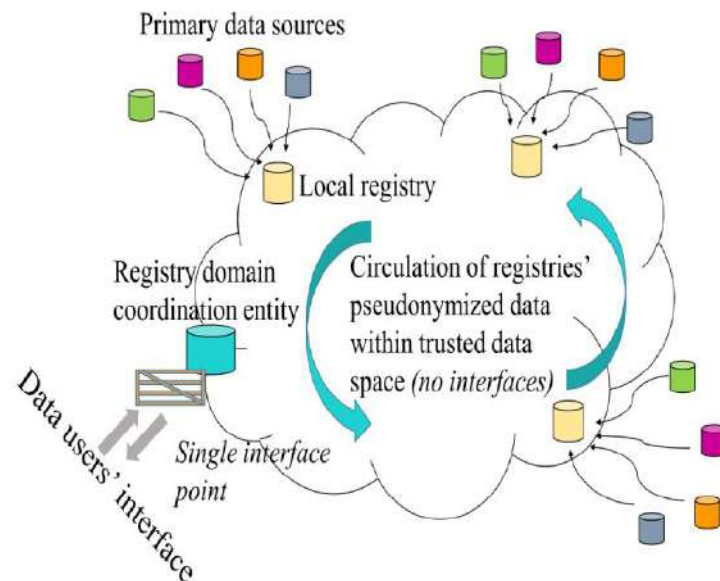
Islands of data

Disconnected data silos

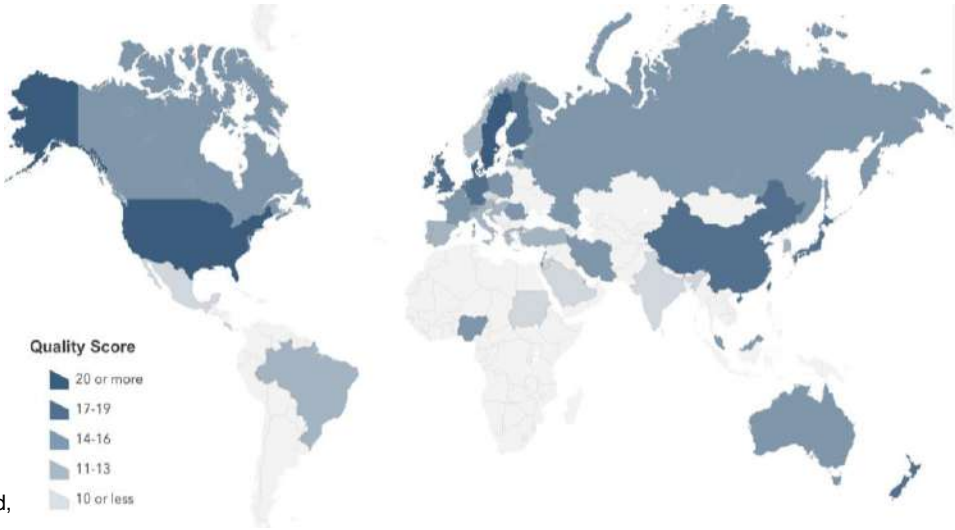


Different:
Standards
Quality
Databases
Semantics

Integration within & between data collection sources



National registries



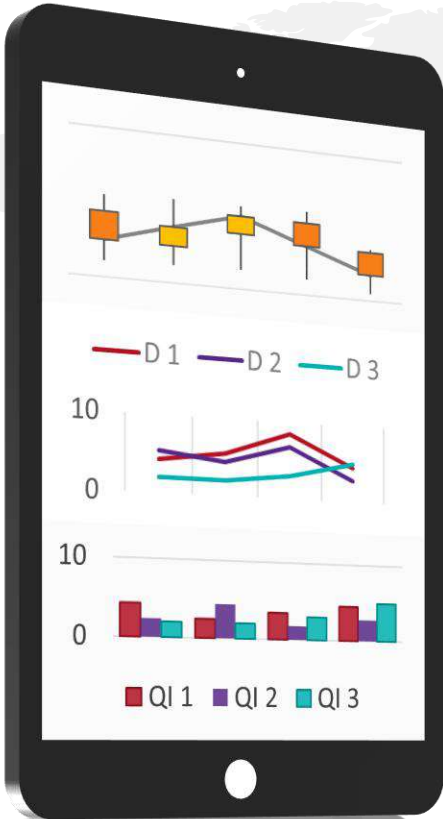
Median score 15
(IQR 12–19)
24 is a perfect score)

- (1) Proportion of the target population enrolled,
- (2) Degree of inter- & intra-rater reliability,
- (3) Audits for range & consistency,
- (4) Independent observations of outcomes,
- (5) Data missingness, and
- (6) Explicit documentation of standardized variable definitions

- Outcomes**
- 43 (28%) = in-hospital
 - 100 (65%) = beyond in-hospital period
 - 12 (8%) = no outcomes

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Primary care data
Including community follow up (e.g. CR)



Electronic health records
Including hospital events & procedures



Clinical registries
From all CV domains

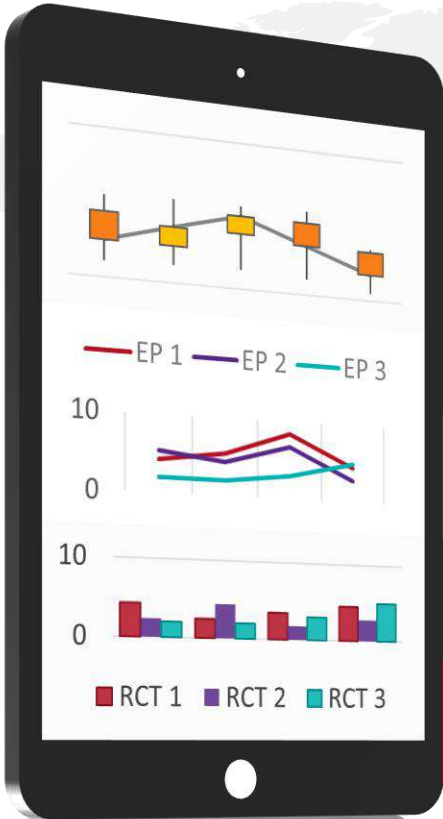


Longitudinal outcomes
Including PROMs



Data standards & governance

AI-based data abstraction



Real-world data

Patterns, disparities, observational research

Surveillance of products

New drugs & devices, health economics

Quality improvement

Gaps in care delivery, impact of QIP & initiatives

Public reporting

Report cards, resource allocation

R-RCT

Evidence development, generalizable evidence