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**International
Diabetes Federation
Europe**



BEST INFORMATION FOR
PEOPLE WITH DIABETES: TOWARDS
PERSON-CENTRIC DIABETES INDICATORS IN EUROPE

Building a common EU framework using the EUBIROD network

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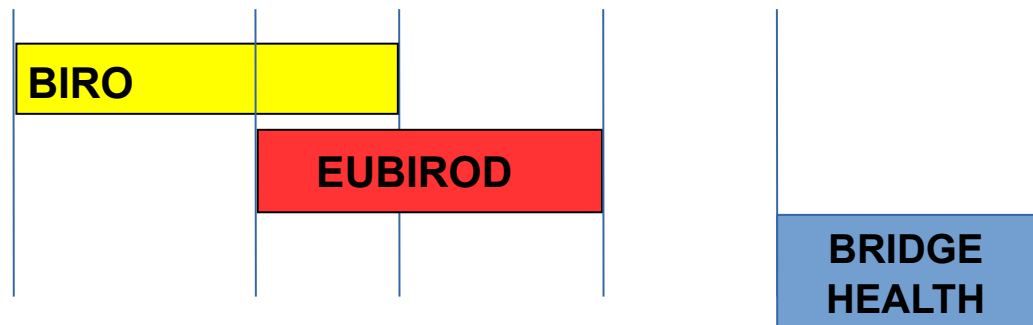
A European Network of Diabetes Data Sources: EUROPEAN BEST INFORMATION THROUGH REGIONAL OUTCOMES IN DIABETES

EU PROJECTS CONSORTIA

1. University of Perugia (I)
 2. Serectrix snc (I)
 3. University of Dundee (GB)
 4. Joanneum Research (A)
 5. NOKLUS (N)
 6. Paulescu Institute (RO)
 7. University of Malta (M)
 8. Republic of Cyprus (CY)
 9. Sahlgrenska Institute (SE)
 10. University of Debrecen (H)
 11. Institute of Public Health (B)
 12. IDF (B)
 13. Adelaide Meath Hospital (IRL)
 14. CBO (NL)
 15. Centre Hospitalier (LUX)
 16. University of Ljubljana (SLO)
 17. IMABIS Foundation (E)
 18. Medical University Silesia (PL)
 19. Havelhoe Hospital (D)
 20. Hillerod University Hospital (DK)
 21. Vuk Vrhovak University (HR)
 22. University of Surrey (UK)
 23. University Tor Vergata (I)
- Collaborating Institutions:*
24. Foundation for Care Information (NL)
 25. Ministry of Health, Latvia
 26. IDIBAPS, Spain
 27. Dasman Diabetes Centre, Kuwait
 28. Ministry of Health of Israel
 29. National Diabetes Register of Sweden (SE)
 30. German Diabetes Surveillance System (D)
 31. National Diabetes Register of Denmark (DK)
 32. THL (FI)

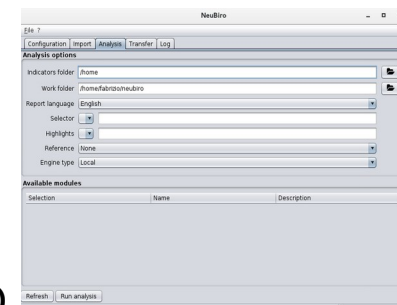
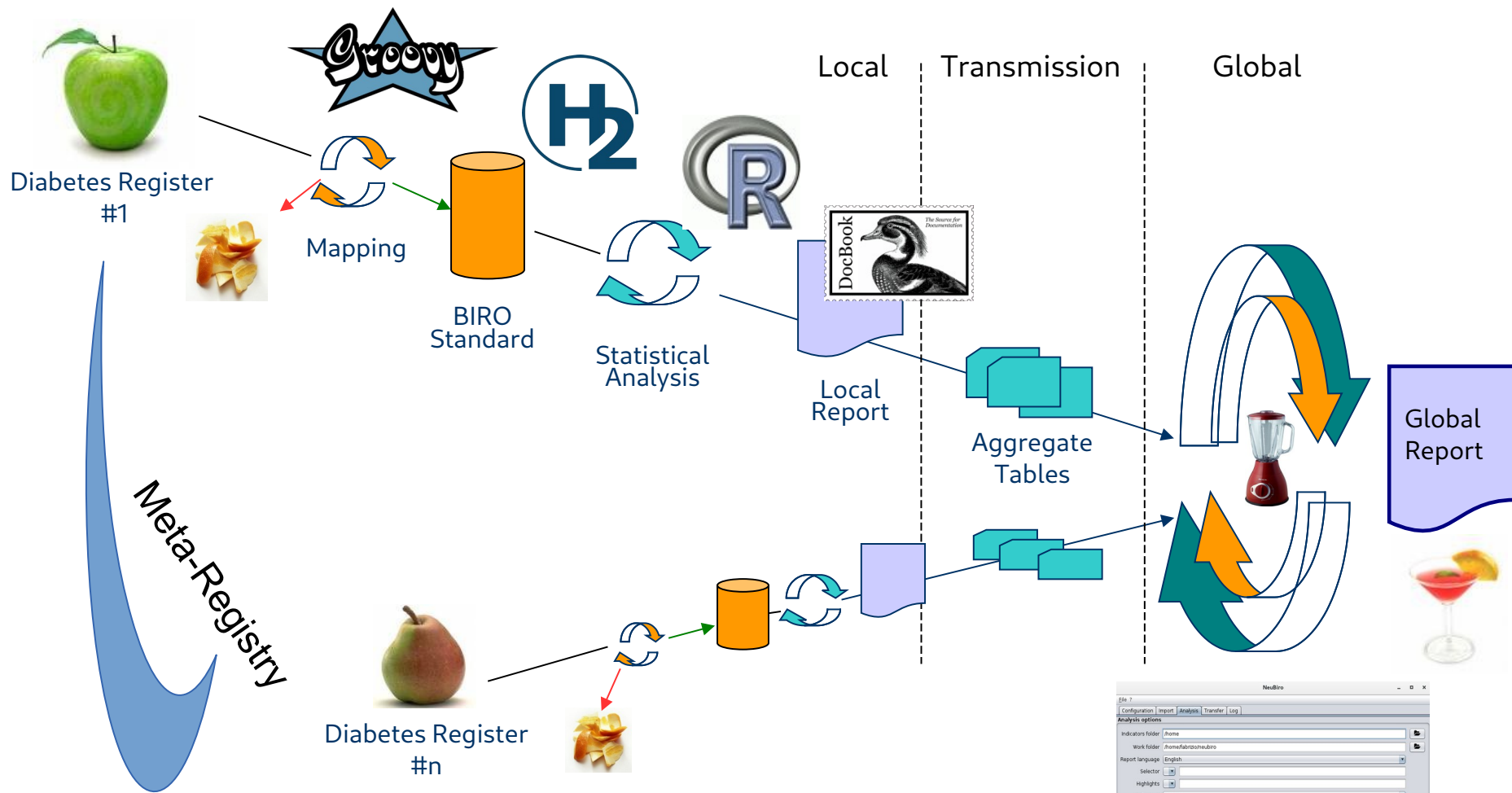


11/2005 9/2008 5/2009 3/2012 5/2015 11/2017



Collaborations through to → 2022

The BIRO system: open source federated analysis since 2004



Diabetes registries include essential clinical information, but they are different



Making Use of Comparable Health Data to Improve Quality of Care and Outcomes in Diabetes: The EUBIROD Review of Diabetes Registries and Data Sources in Europe

OPEN ACCESS

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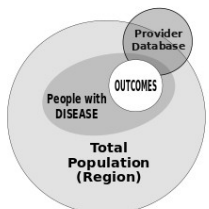
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- A recent review of existing data sources showed different capability in terms of data collection and range of outputs
- Available data should be exploited, but dissemination of best practices is also needed

POPULATION-BASED
DISEASE REGISTER



POPULATION-BASED
DISEASE REGISTER
LINKED TO A
PROVIDER SOURCE



PROVIDER-BASED
SOURCE

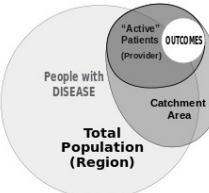
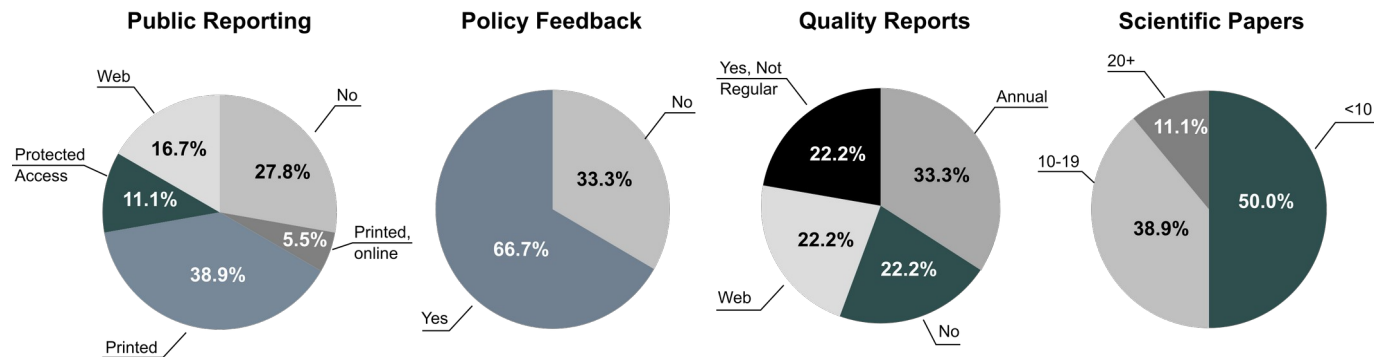


Figure 3. Outputs










Statistical models are needed to make diabetes indicators more “actionable”

- **Amputations after foot ulcer is a case in point**

Research Article

Adherence to General Diabetes and Foot Care Processes, with Prompt Referral, Are Associated with Amputation-Free Survival in People with Type 2 Diabetes and Foot Ulcers: A Scottish National Registry Analysis

Bernardo Meza-Torres ^{1,2} Scott G. Cunningham ³ Christian Heiss ^{1,4} Mark Joy ²
Michael Feher ² Graham P. Leese,³ Simon de Lusignan ² and Fabrizio Carinci ⁵

- Shifting focus on amputation-free survival as a key outcome indicator
- Using clinical and quality of care predictors at individual level in a single large-scale diabetes register in Scotland **identified care-related risk patterns**
- The model is transferable to other registries and can be adopted for data pooling across Europe

Diabetes indicators that are fit for purpose can help countries to “learn from events”

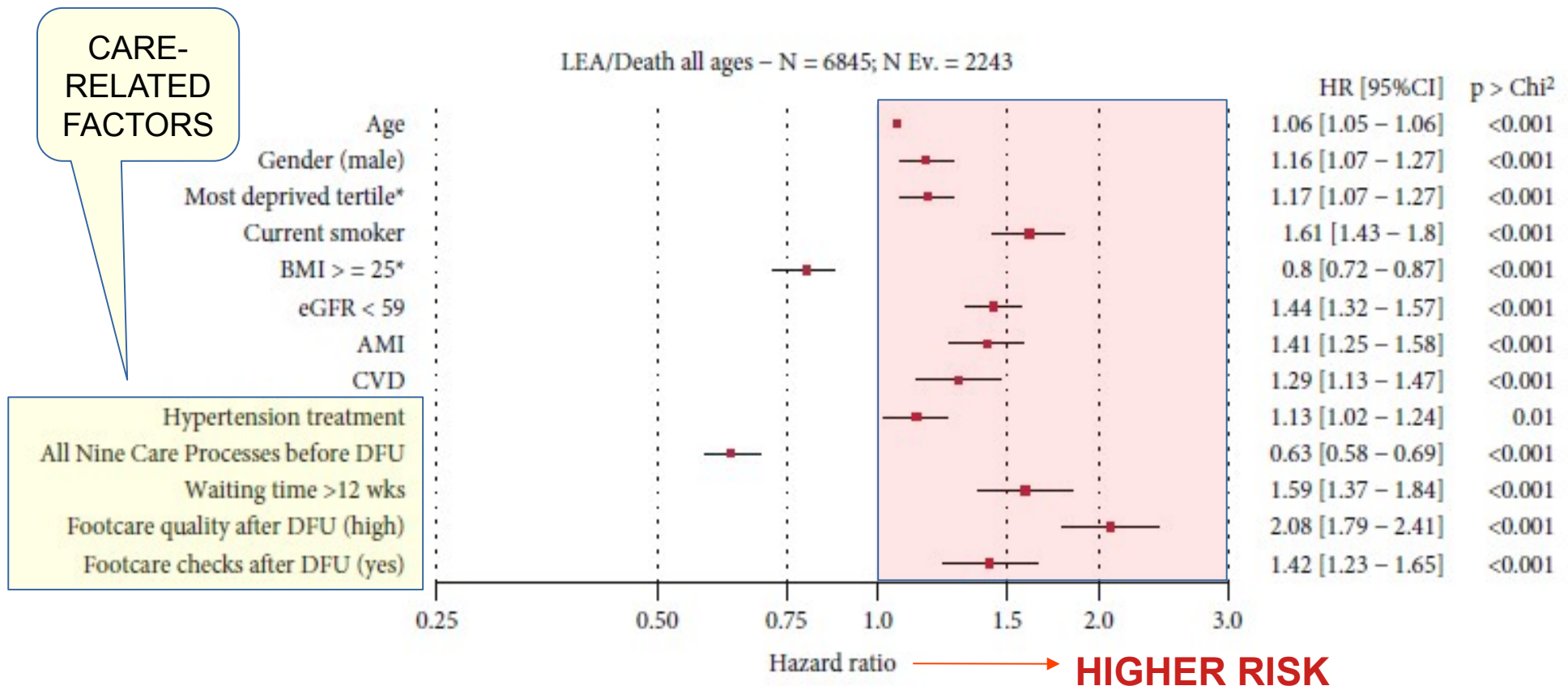
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RELEVANT QUESTIONS FOR HEALTH INDICATORS:

- Is it true everywhere?
- How many are at risk in Country A vs Country B?
- How to treat the next person based on his/her risk profile?

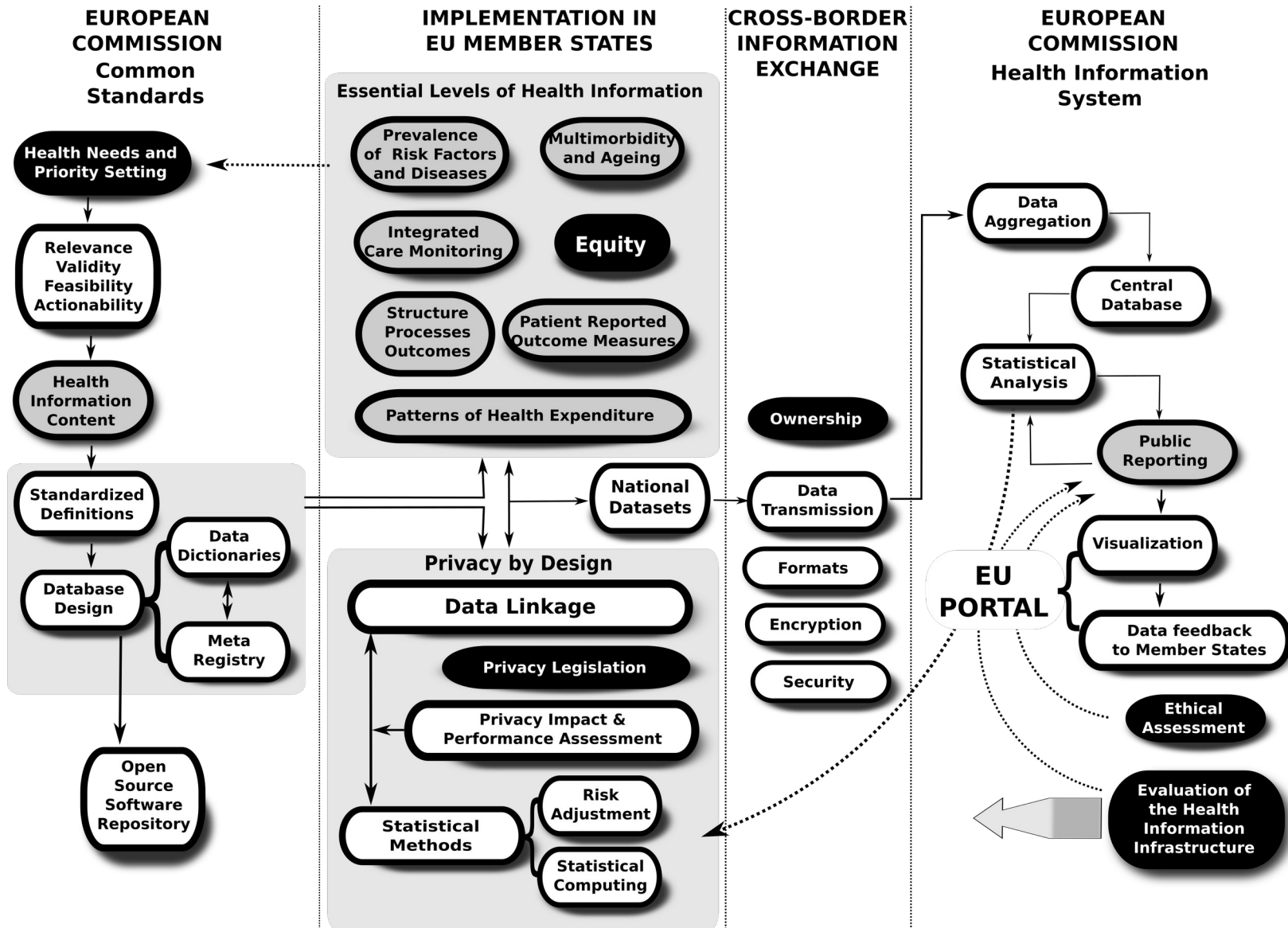


Using EUBIROD to build a EU Framework

Essential levels of health information in Europe: An action plan for a coherent and sustainable infrastructure

Fabrizio Carinci^{a,b,*}

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^b Consorzio per Bioinformatica, Italy



Preliminary activity of the "Diabetes Design Working Group" [CHIEF-diabetes.dwg]



Scoping Document



PILOT STUDY- three areas of activity (2023):

- 1. Meta-data**
- 2. Federated data analysis**
- 3. Barriers and enablers towards implementation**

Meta-data

- **The work will help the European Commission understand the type and contents of the documentation required to integrate the different data sources available, for the continuous production of NCD indicators across disease domains.**
- This area of work will define the **data infrastructure** in terms of **data elements** (with a specific attention on risk factors common to other NCDs), **evaluation methods** (reliability of data sources for the calculation of indicators, data quality score and capture-recapture methods) and **target indicators** (epidemiology, prevention, diagnosis, treatment and outcomes).

Federated data analysis

- The work will showcase a set of relevant analytical solutions that will be needed by the European Commission to report on NCDs effectively, while overcoming some of the major methodological challenges
- The activity will allow evaluating the validity of **time to diagnosis**, by calculating the percentage of patients who enter the registry and experience any of the main complications identified, as a proxy of accuracy of the recordings. The results will be stratified by type of registry.

Barriers and enablers towards implementation

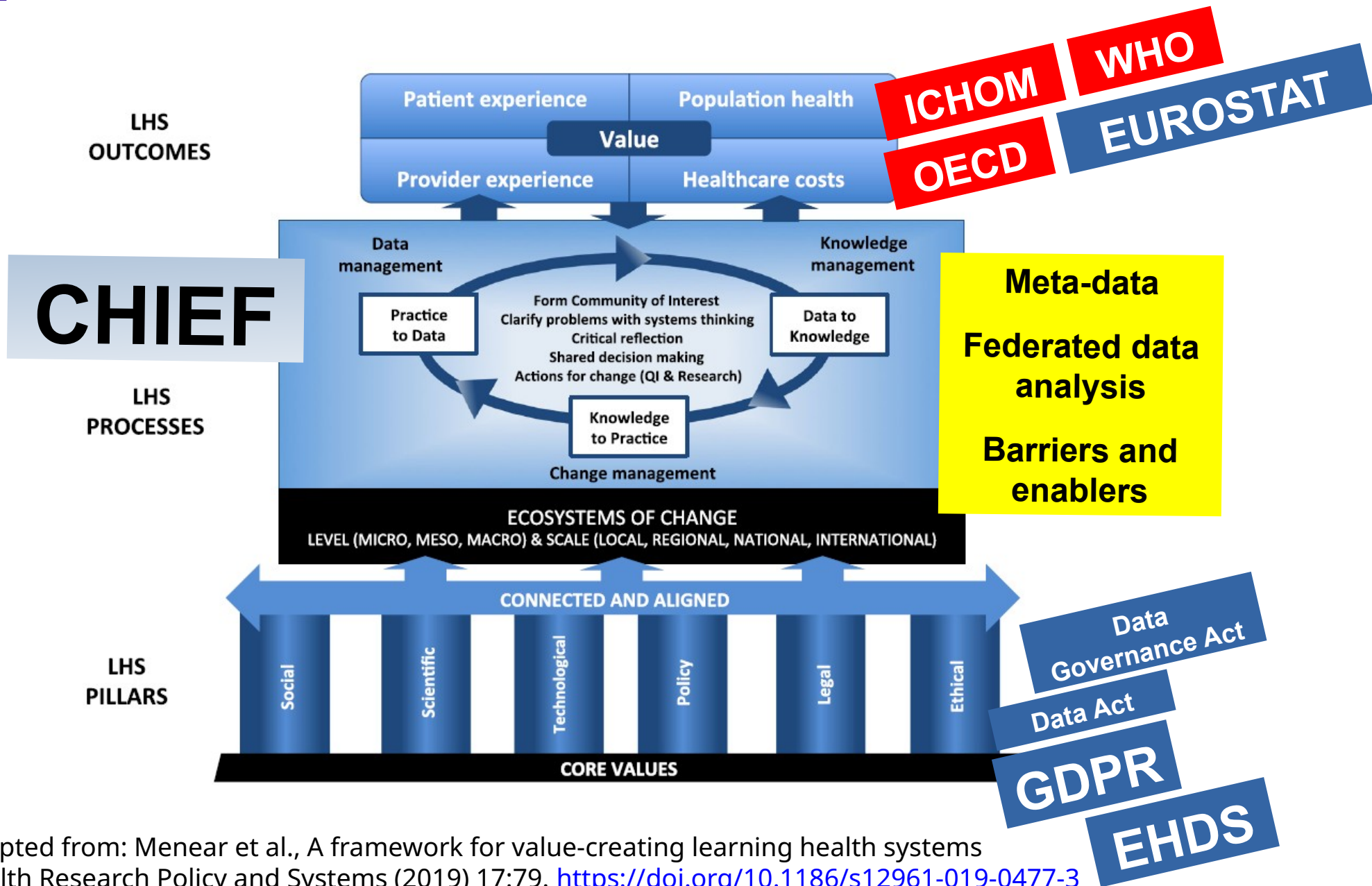
- **The work will help the European Commission understand the barriers hampering the implementation of regulations with the direct participation of relevant stakeholders**
- The activity will carry out a review of social **barriers** to the implementation of information systems for chronic diseases, including the effects of current EU regulations
- The work will explore **the state of implementation of data linkage** across NCDs, taking into account the evolution of EU regulations, through case studies of best practices in EU Member States



Case studies

- **The pilot will be conducted through case studies that will help exploring each of the three work areas, including:**
 - Application to a pool of regions/countries with different capabilities
 - Ability to report on a small pool of “mission critical” indicators
 - Showing potential to scale up at EU level
 - Capacity to involve national and sub-national registries
 - Applying FAIR principles and “Privacy by design”
 - Enabling the practical use of indicators by different stakeholders
 - Sustainability and transferability across NCDs
 - Sound methodology and timely delivery
 - Ability to respond to the information needs of the EU

A framework for Learning Health Systems: CHIEF as a tool to implement processes



Adapted from: Menear et al., A framework for value-creating learning health systems
 Health Research Policy and Systems (2019) 17:79. <https://doi.org/10.1186/s12961-019-0477-3>



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Thanks for your attention