

# UNLOCKING THE POTENTIAL OF REAL WORLD DATA THROUGH FEDERATED DATA NETWORKS

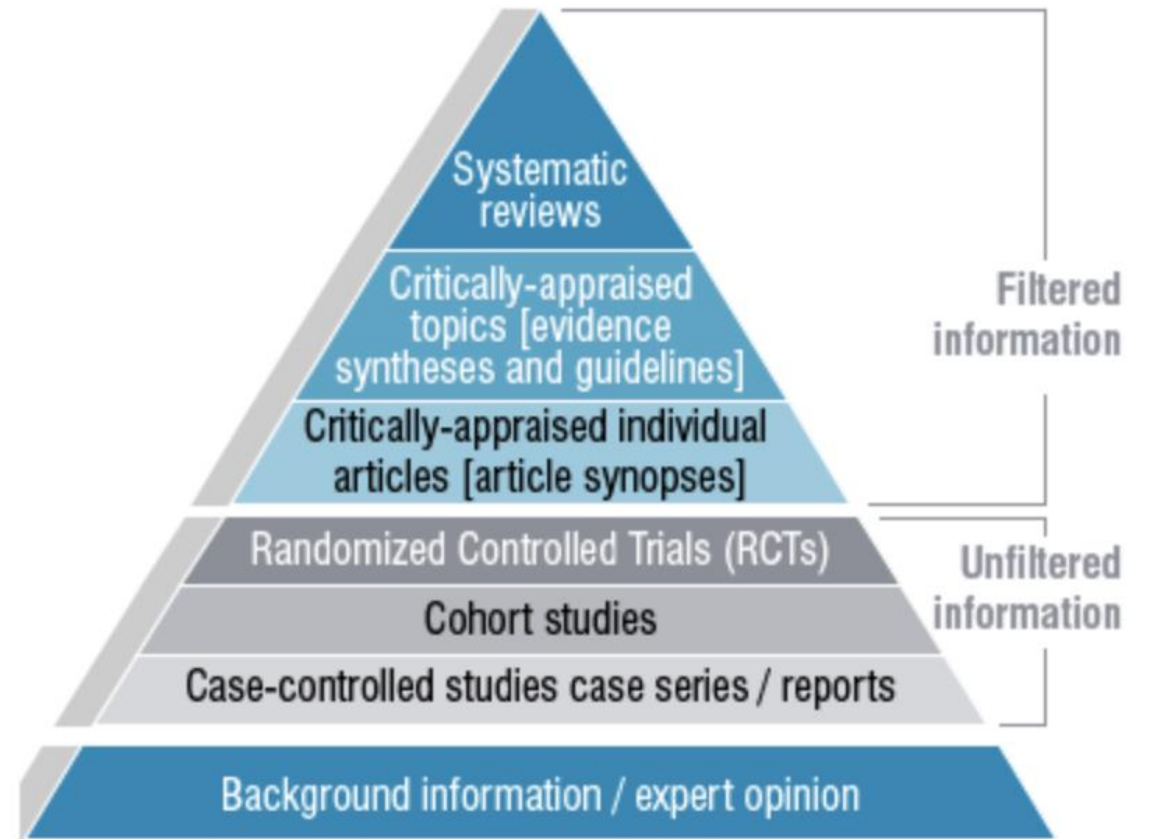
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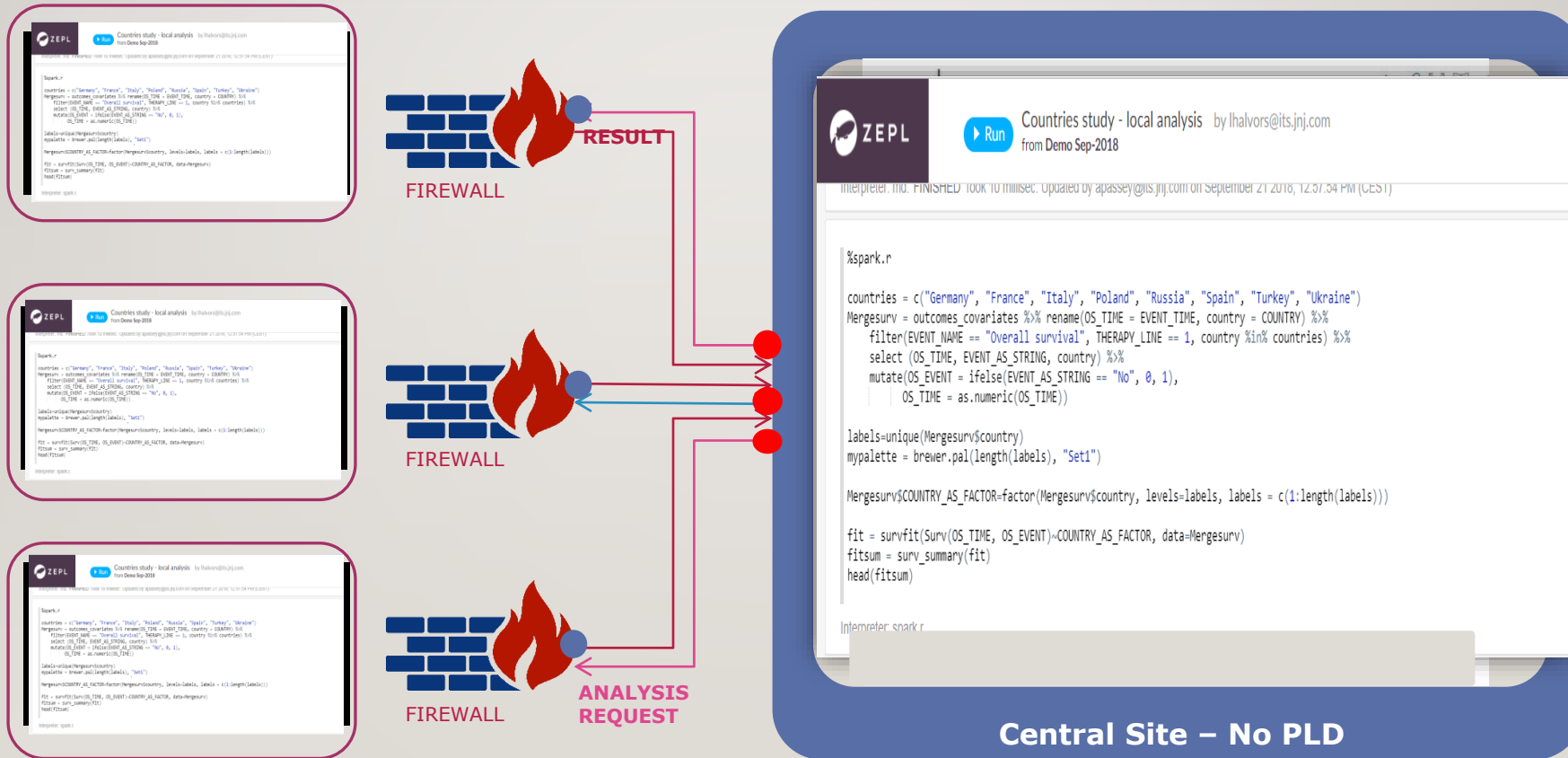
# REAL WORLD DATA IN THE EVIDENCE HIERARCHY

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Source: Hoffman, T., Bennett, S., & Del Mar, C. (2013). *Evidence-Based Practice: Across the Health Professions* (2nd ed.). Chatswood, NSW: Elsevier.

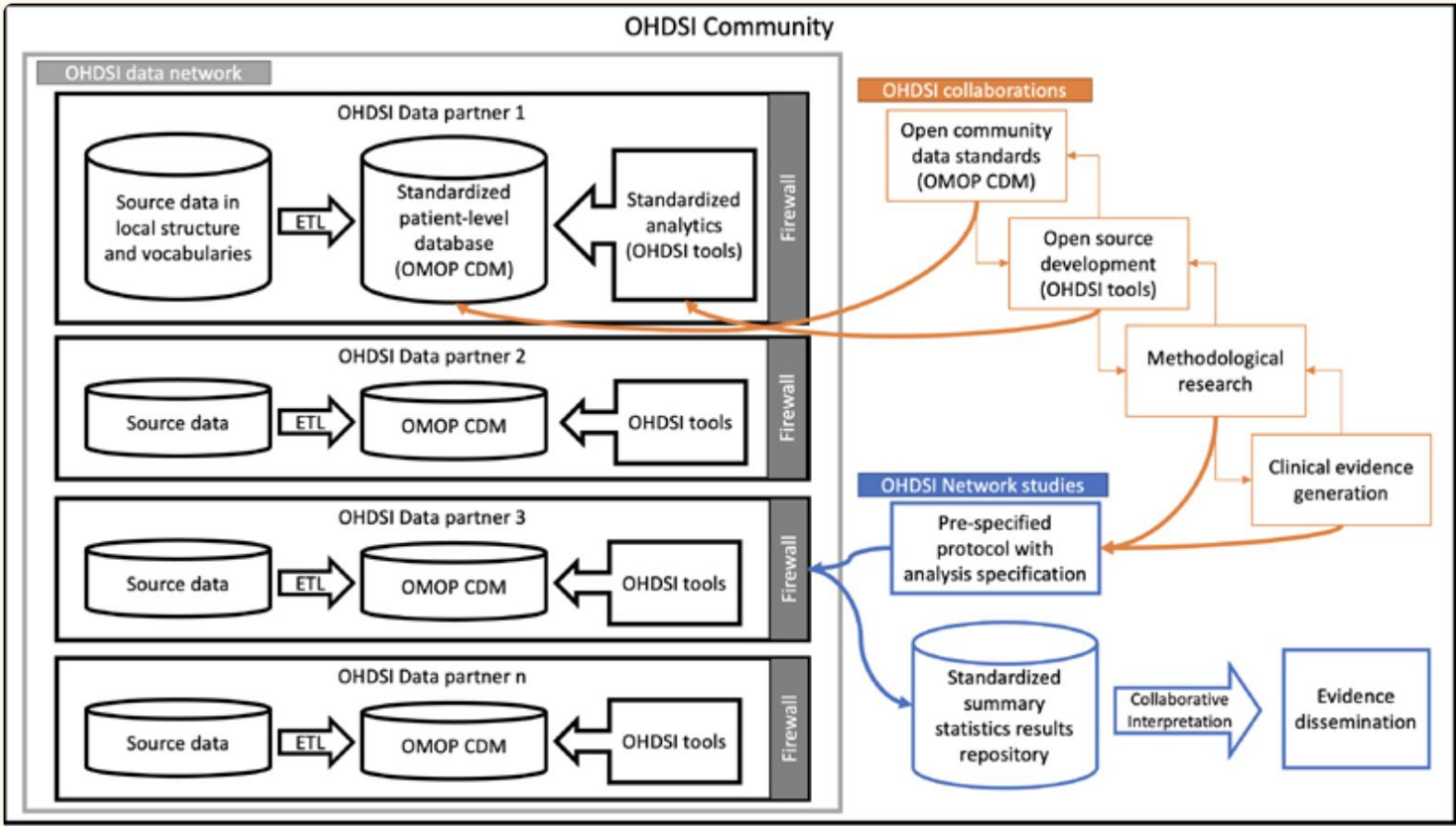
# PRINCIPLE OF A FEDERATED DATA NETWORK



# WHICH QUESTIONS CAN BE ANSWERED THROUGH FEDERATED DATA NETWORKS

Type of Questions	Example
Disease Natural History	What is the overall survival for patients with colorectal cancer
Safety Surveillance	What is the risk of dyspnea after radiotherapy of lung cancer?
Treatment Pathways	What are the real-world treatment patterns for the chronic, comorbid conditions of depression, hypertension, and type 2 diabetes mellitus in patients with cancer?
Comparitive Effectiveness	What are the survival and oncological outcomes between patients undergoing laparoscopic versus open colectomy in colon cancer?
Cost / Resource use	What is the prescriber compliance with liver monitoring guidelines?






# SOLID EVIDENCE GENERATION THROUGH OHDSI



Source: Hripcsak G, Schuemie MJ, Madigan D, Ryan PB, Suchard MA. Drawing Reproducible Conclusions from Observational Clinical Data with OHDSI. Yearb Med Inform. 2021

# CHALLENGES AND OPPORTUNITIES

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- Structural harmonization 
- Semantic harmonization 
- Metadata 
- Methodological consistency 
- Large scale validation 

# ADDRESSING THE CHALLENGES

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- SEMANTIC HARMONIZATION:
  - IMPLY CONVENTIONS AND RULES ON TOP OF STANDARDS
  - PHENOTYPE DEFINITIONS AND EVALUATIONS OF PHENOTYPES
- METADATA:
  - APPLY ADDITIONAL TOOLS SUCH AS FAIR DATA CATALOGUES TO CAPTURE ADDITIONAL ELEMENTS
  - DEVELOP ANALYTICAL TOOLS AND METHODS TO ASSESS / INSPECT THE CONTEXTUAL DATA FOR A DATASET.

# KEY MESSAGES

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- FDN'S HAVE COME TO MATURITY AND ARE IN ACTIVE USE FOR EVIDENCE GENERATION
- THE FULL POTENTIAL HOWEVER IS SIGNIFICANTLY BIGGER THAN THE CURRENT BEST PRACTICES ALLOW TO DO. IMPROVEMENTS IN DATA COLLECTION, STRUCTURING AND ADOPTION OF STANDARDS WILL INCREASE THE VALUE FURTHER