Real World Healthcare Databases- What are the Existing Database Options We Have in the US and EU5?

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EE452
ISPOR EU 2023

INTRODUCTION

- Health Economic and Outcomes Research (HEOR) relies on real-world data (RWD), and utilization of RWD plays a pivotal role in advancing medical knowledge, enhancing patient care, and supporting evidence-based decision-making in various aspects of healthcare research and delivery
- Analysis of various databases as an RWD can inform and elucidate various aspects of care including patient disease burden, unmet needs, patient journey, utilization of pharmacologic/non pharmacologic interventions, and healthcare resource use
- In the US, several data bases are readily available, providing manufacturers with a broad armamentarium of potential data sources to conduct comprehensive analyses to address research goals in various life sciences domains; however, limited database with long-term patient RWD is an ongoing concern
- Notably, in the EU, there is often limited availability of database related RWD. This scarcity of data presents challenges for researchers, making it more difficult to thoroughly understand and analyze real-world patient journey, clinical manifestations, and healthcare resources in the EU

OBJECTIVES

To identify and characterize different real-world databases in the US, UK, Italy, and capture key examples of each database type that are commonly used for evaluating real-world evidence related to healthcare research and delivery

METHODS

- We conducted a targeted and grey literature review while leveraging Global and Regional subject matter experts and resources to collate real-world database sources available in the US, UK, Italy, France, Germany, and Spain
- This search entailed exploring a range of existing real-world databases in the English language, including but not limited to claims databases, Electronic Health Records (EHR), registries, and pricing data in PubMed, Embase, Google Scholar, and CMS

RESULTS

Types of Real-World Evidence Database Available in the US

Data assets	Description	Example
Open Claims	• Medical claims and pharmacy claims sourced from clearing houses, pharmacies and software platforms	DRG, Florian, Healthverity, IQVIA™ LAAD, Komodo Health, MedFuse, Symphony
Closed Claims	• Captures events throughout patient's enrollment period derived from the insurance provider (or payer)	IQVIA™ PharMetrics®, Komodo Health, Merative MarketScan®, Optum®
Electronic Health Record (EHR)	• Provides patient's medical history collected at different facilities of a healthcare delivery network (e.g., hospitals and outpatient clinics)	Cerner®, Flatiron®, Optum®, PicnicHealth
Registries	• Systematically collect patient and physician related information from nationwide medical services and EHR data	AllStripes, Inovalon™
Genomics, Precision Medicine, Lab	• Lab and genomic data provided with an option to integrate with EMR	Labcorp, NEO Genomics™, Prognos health TEMPUS, Quest Diagnostics™
Chargemaster	• Includes procedures and services provided at hospitals along with supplies, devices, products and drugs used during hospital stay	PINC AI™ Healthcare Database (Premier® Chargemaster)

Types of Databases Available in UK, France, Spain, Germany and Italy

Data assets	Description	Example
Claims	• Collects information on doctors' appointments, bills, insurance information, and other patient-provider communications.	CSL UK, Hospital Pharmacy Audit (HPA), IQVIA™ LRx
Audit and survey data	• Data from hospital-based survey focusing on patient safety issues, medical error, and event reporting in the hospital	ADELPHI, Oncology Dynamics
Sales, Script & Pricing Data	• Data on sale, number of prescriptions and pricing of drugs	IQVIA™, MI Portal, VEEVA CRM
Registries	• Systematically collect health-related information within an overall governance and management structure	European Network of Cancer Registries (ENCR), European Cancer Information System (ECIS)
Linked Claims and EMR Data	• Linked or matched EHR data with health insurance claims	CPRD™ (UK), IQVIA™ Germany
Profile and Affiliation Data	• Information about HCPs, such as their name, specialty, title, education, training, experience, and practice affiliations. This data can be used to identify and locate healthcare providers	Insight Health™

Types of Public Real-World Evidence Databases Available in the US

Database	Description
CDC Centers for Disease Control and Prevention	• Health and vital statistics, surveillance and HCRU data from sources such as state and local health departments, HCPs, Laboratories, etc.
CMS Centers for Medicare & Medicaid Services	• HCRU data, enrollment and utilization of healthcare program and provider data, used to access quality, efficiency, and affordability
H·CUP Healthcare Cost and Utilization Project	• Gathers data on hospital costs and utilization from a variety of sources, including state and local data partners.
SEER / USRDS United States Renal Data System	• They can be used to track diseases, and to evaluate the effectiveness of treatments and interventions.

Types of Public Real-World Evidence Databases Available in the EU5 region

Database	Description
NHS Digital Hospital Episode Statistics (HES)	• Data on all hospital admissions and discharges in England. It includes information on demographics, diagnoses, procedures, and length of stay.
NHS	• Performance data such as waiting time, patient demographics, health expenditures such as staff, drugs, and equipment
eurostat	• Data on HCRU, structure, financing, and performance of healthcare systems, and epidemiology
Red Española de Registros de Cáncer (REDECAN) / nda National Diabetes Audit	• They can be used to track diseases, and to evaluate the effectiveness of treatments and interventions.

Note: The data sources listed above are only the ones most frequently utilized and do not represent an exhaustive compilation

DISCUSSION, LIMITATIONS AND CONCLUSION

Discussion

- Analyses conducted using these data assets can help answer a variety of commercial and HEOR / medical research questions, depending on the nature of the data fields captured, including:
  - Patient Journey: Capturing patient comorbidities, treatment rates, HCP interactions, ER visits, ICU admissions, time to diagnosis, etc.,
  - Epidemiology & Patient identification: Using AI algorithms to identify patients with rare diseases that do not have existing ICD-10 codes, diagnosing guidelines
  - KOL Identification & Influence Mapping: Identifying top prescribers in the therapeutic area of interest to develop database of go-to KOLs for supporting product uptake
  - Cost of Care: Capture the healthcare resource utilization and associated costs for the disease of interest from the database using specific business rules to identify target population of interest
- Our research indicates the availability of broadly applicable, commercially available databases is lower in the EU compared to the US. This is particularly true of data resources that are validated and not just applicable to patient- or physician-reported sources, perhaps due to higher bars for privacy and GDPR
- This limits manufacturers' ability to conduct real-world data analyses in EU5 and subsequently limits understanding of the burden of the disease, unmet needs, and economic burden/HCRU
- In an absence of a broadly applicable, singular, country-level data source(s) in the EU, manufacturers may need to rely on US databases to conduct such analyses, and carry forward learning to the EU5, as and when appropriate and applicable, given the differences in the two geographies, healthcare systems and populations
- ***Given these complex considerations, our research team proposes that to effectively enable similar analyses, custom solutions are likely needed to improve visibility in EU countries e.g., custom-build medical chart audit and burden of illness studies with patients and HCPs, in adherence with GDPR***

Conclusion

- **Data assets available across the US and EU5:** Numerous organizations are making efforts to capture patient-level data and link that data from various sources to allow longitudinal mapping of patient journeys using a single data asset. Currently there are more options available in the US than in the EU
- **Need for development of standardized datasets:** The paucity of RWD in the EU has the potential to inhibit the utilization of this important tool for HEOR researchers. Given the lack of options in the EU, researchers will need to continue to rely on custom approaches such as methodologically rigorous surveys and medical chart audit studies, in adherence with GDPR. New approaches may be needed to evaluate the feasibility of selectively using US based claims databases to provide preliminary estimates for EU markets while mindfully accounting for differences between the two geographies, as well as differences within EU markets

Limitations

- **Narrow scope of comparison:** A more comprehensive review including a broader range of regions like APAC, LATAM could provide a more holistic identification of available data assets
- **Lack of quantitative data**: This literature review did not quantify the use of real-world data (US vs. Ex-US) by data type / vendor / use case in publications

Acknowledgments: Poster content was developed in coordination with Ahan Ali from Trinity's Real-World Evidence (RWE) team and the Quality & Delivery team (Q&D) provided poster formatting support

ACRONYMS

CDC: Centers for Disease Control and Prevention; CMS: Centers for Medicare & Medicaid Services; EHR: Electronic Health Record; HEOR: Health economic and outcomes research; HCRU: Healthcare Cost and Resource Utilization; HCP: Healthcare Practitioner; HCUP: Healthcare Cost and Utilization Project; HES: Hospital Episode Statistics; NHS: National Health Service; NDR: National Diabetes Audit; National Rare Disease Registry; OUS: Outside US; REDECAN: Spanish Network of Cancer Registries; SME: Subject Matter Expert; SEER: Surveillance, Epidemiology, and End Results; USRDS: United States Renal Data System

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