

Background

Real-world data (RWD) can be used to address a variety of questions in Multiple Sclerosis (MS) research. While there are a many RWD sources for MS including disease registries, electronic medical records (EMRs), and administrative claims data, the availability of data parameters among individual RWD sources varies, limiting their overall potential¹. As such, the linkage of multiple databases offers a unique opportunity, expanding real-world evidence capabilities in MS.

Objectives

The German AOK PLUS sickness fund and the Multiple Sclerosis Management System 3D (MSDS^{3D})²⁻⁴ at the Center for Neuroscience (Zentrum für Klinische Neurowissenschaften, ZKN) in Dresden were used to generate a linked database (MSDS-AOK PLUS). The objective of this study is to introduce the novel linked database via a use case example which combines the strengths of administrative claims databases and MS patient registries.

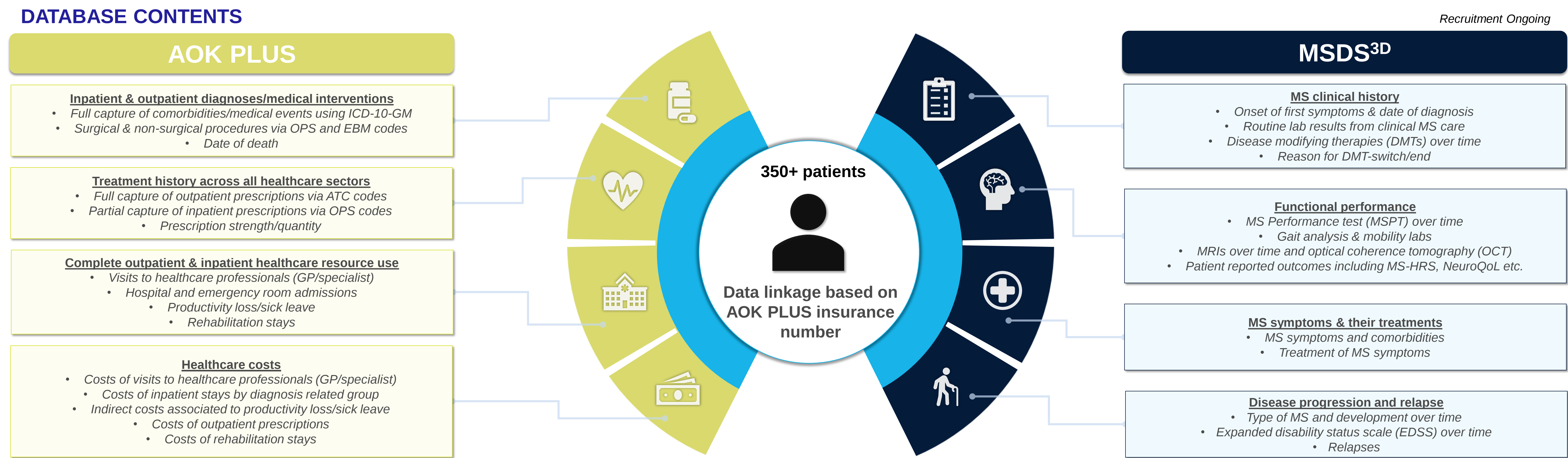
Methods

DATABASE GENERATION & LINKING

- To generate the linked database, patients within the MSDS^{3D} system insured by AOK PLUS were recruited during visits to ZKN and asked for informed consent.
- ZKN transferred a list of pseudonymized registry IDs and AOK PLUS insurance numbers pertaining to the patient to AOK PLUS for linkage. Using the insurance number, the registry ID was mapped to a pseudonymized claims data ID.
- After subsequent deletion of patient insurance numbers, a linked complementary dataset was generated and is currently accessible for subsequent analysis through IPAM, a university affiliated research institute.

USE CASE

- We selected patients with MS in MSDS-AOK PLUS who had at least one documented EDSS score between 01/10/2015 and 30/06/2019.
- Patients who were not continuously insured in the one year after the first documented EDSS (index date) were excluded.
- The number of and respective costs of all-cause and MS-specific hospitalizations, defined by a main or primary diagnosis ICD-10-GM: G35.-, were assessed stratified by EDSS score in the year after the index date.



Results: Use Case

PATIENT CHARACTERISTICS

- Overall, 158 continuously insured patients with at least 1 EDSS score in the inclusion period were included for analysis (mean age 47.5 years, 76.6% female; **Table 1**).
- At index, 77.2%, 10.8%, and 5.7% of patients had RRMS, SPMS, and PPMS, respectively. Across all patients, the EDSS ranged from 1.0 to 8.0 (mean 3.2).

HEALTHCARE RESOURCE USE & COSTS

- The highest mean number of all-cause and MS-specific hospitalizations in the year after index were incurred among patients with EDSS 6-6.5 (0.85 all-cause; 0.77 MS-specific admissions) and by EDSS 4-4.5 (0.79 all-cause; 0.58 MS-specific admissions; **Figure 1**).
- Accordingly, the highest mean costs observed were €3,522.24 (SD 4,458.21) and €3,167.52 (SD 4,947.64) for all-cause hospitalizations, and €3,236.24 (SD 4,562.64) and €2,998.08 (SD 4,961.75) for MS-specific admissions among patients with EDSS 6-6.5 and EDSS 4-4.5, respectively (**Figure 2**).

Table 1: Patient characteristics at index

	N = 158
Female, n (%)	121 (76.6)
Age, mean years (SD)	47.5 (13.0)
Time since diagnosis*, mean years (SD)	9.9 (8.5)
MS Subtype, n (%)	
Relapse remitting MS (RRMS)	122 (77.2)
Primary progressive MS (PPMS)	9 (5.7)
Secondary progressive MS (SPMS)	17 (10.8)
Newly diagnosed/Clinically Isolated Syndrome (CIS)	8 (5.7)
Unknown	1 (0.6)
EDSS at index, mean (SD)	3.2 (1.7)

*Missing for 7 patients

Figure 1: Number of hospitalizations by EDSS

Figure 2: Costs of hospitalizations by EDSS

Limitations

- Patient selection is based on the health insurance provider (AOK PLUS) in Saxony/Thuringia, potentially presenting some selection/regional bias. Furthermore, patients were treated at ZKN, a specialized center of excellence, questioning representativity compared to the wider German MS population. Despite this, uniform healthcare regulations exist across Germany, minimizing bias.
- Data is derived from routine medical practice and may exhibit a degree of missing/unstructured data and/or coding error. However, claims data is considered to be valid and various systems for MSDS^{3D} are in place to ensure data quality.

Conclusions

The combination of clinical factors and resource use across different settings in the MSDS-AOK PLUS database presents a novel opportunity in MS research. The linked database can be used for a variety of RWD studies, including:

- Comparative or cost effectiveness,
- Outcome measure validation,
- Understanding disease behavior and prognosis,
- Analysis of treatment patterns,
- Post-authorization safety studies.

References

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Disclosures

M.G. and T.W. are employees of IPAM and E.Z. is an employee of Cytel. A.D. has received personal compensation and travel grants from Biogen, Celgene, Janssen, Roche and Sanofi for speaker activity. T.Z. has received consulting fees, grants, and research support from various pharmaceutical companies e.g. Almirall, Bayer, Biogen, Genzyme, Merck, Novartis, Roche, Sanofi. T.W. has received honoraria from several pharmaceutical/ consultancy firms e.g. Roche, Abbvie, Merck, GSK, BMS, Bayer.

Contact information

evi.zhuleku@cytel.com

www.cytel.com