

OBJECTIVE

In this study, we aimed to map the real-world studies (RWS) and real-world data (RWD) sources for central nervous system (CNS) diseases in China.

METHODS

We conducted a systematic literature review.

Search strategy: RWS covering the Chinese population published between 1st January 2010 to 31st August 2022 on CNS diseases were searched on 4 bibliographic databases – PubMed and Embase for English articles and China National Knowledge Infrastructure (CNKI) and Wanfang for Chinese articles.

Inclusion criteria

- ✓ RWS in CNS diseases
- ✓ Covered Chinese populations from China
- ✓ Used secondary databases as data sources

Exclusion criteria

- Randomized controlled trials (RCTs)
- Interviews, reviews, case reports/series, commentaries, expert consensus, editorials, education programs, or studies in basic medical science
- Used non-disclosure data sources
- Single center studies without using established databases as data sources

RESULTS 1 – Flow chart

- 1 389 RWS were identified between 2010 and 2022 for CNS diseases in China. Among these, 184 RWD databases were extracted.

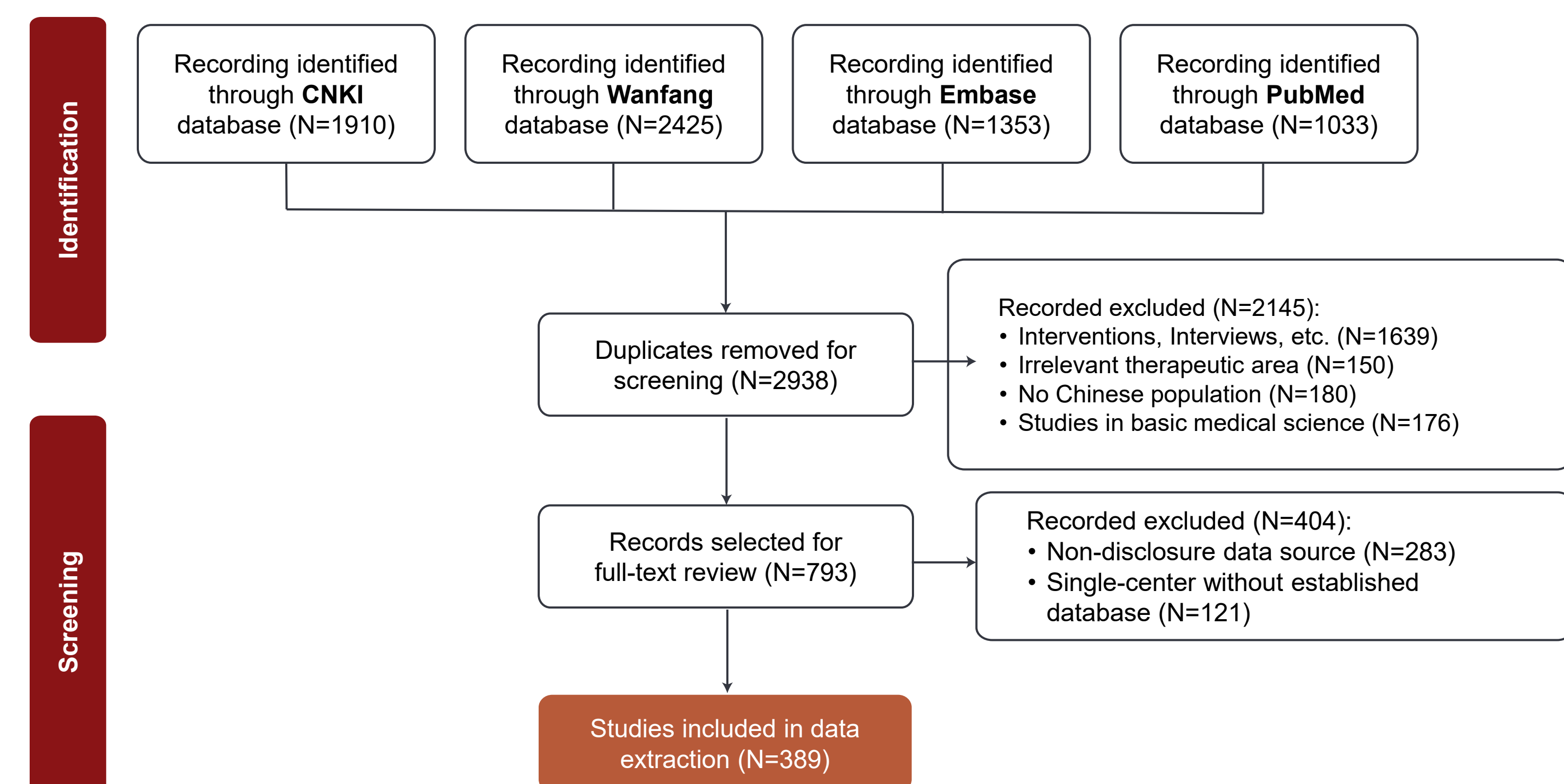


Figure 1. Process flow of identification and screening of RWS articles on CNS diseases

RESULTS 2 – Findings from 389 RWS

- 2 Most CNS RWS were single-purpose (78.7%), primarily focusing on disease epidemiology (59.1%) and treatment effectiveness (10.5%).

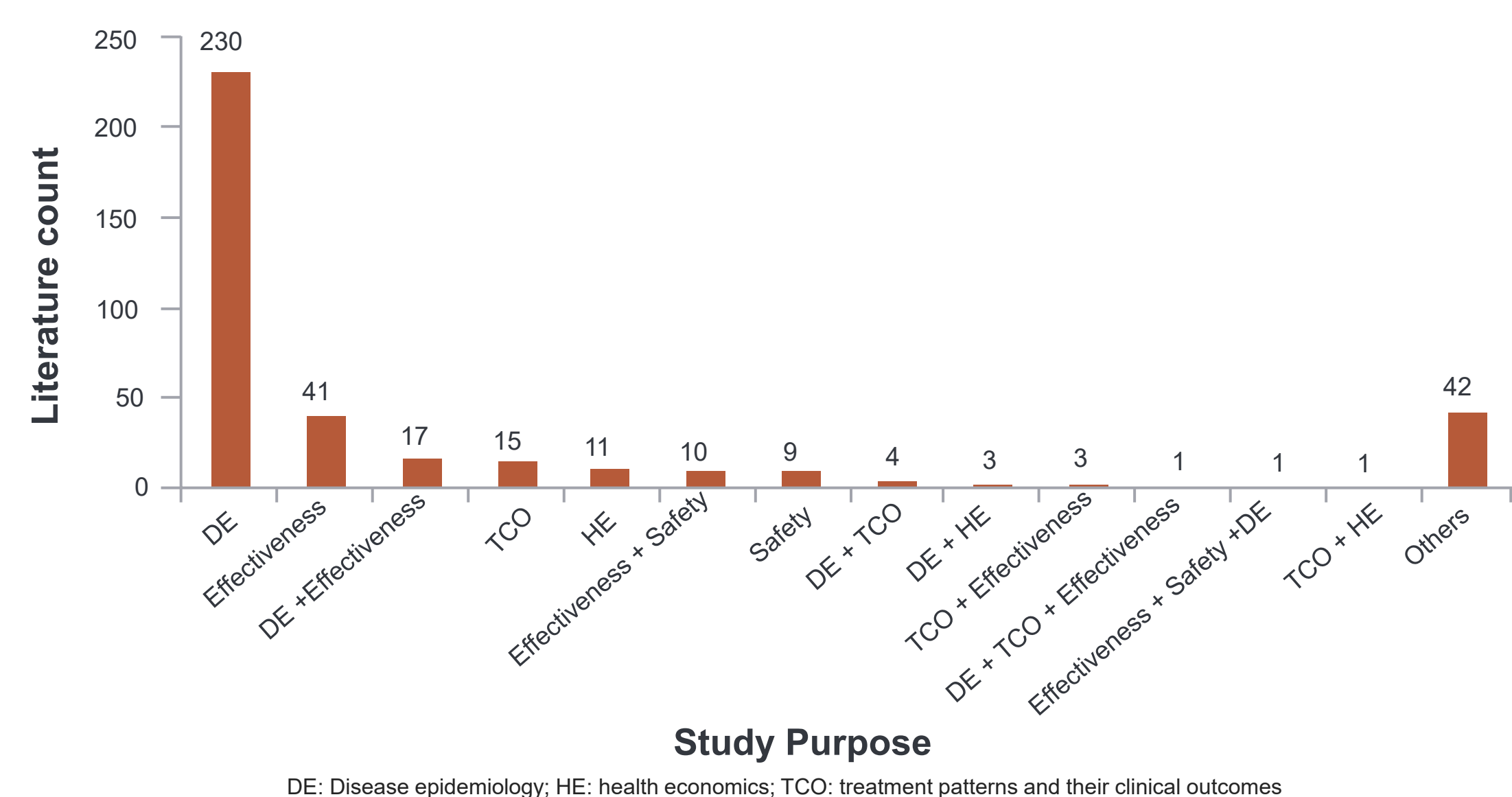


Figure 2. Number of RWS by study purpose

- 3 Provinces from coastal regions (Jiangsu, Zhejiang, Taiwan), Sichuan, and Beijing published more RWS than others.

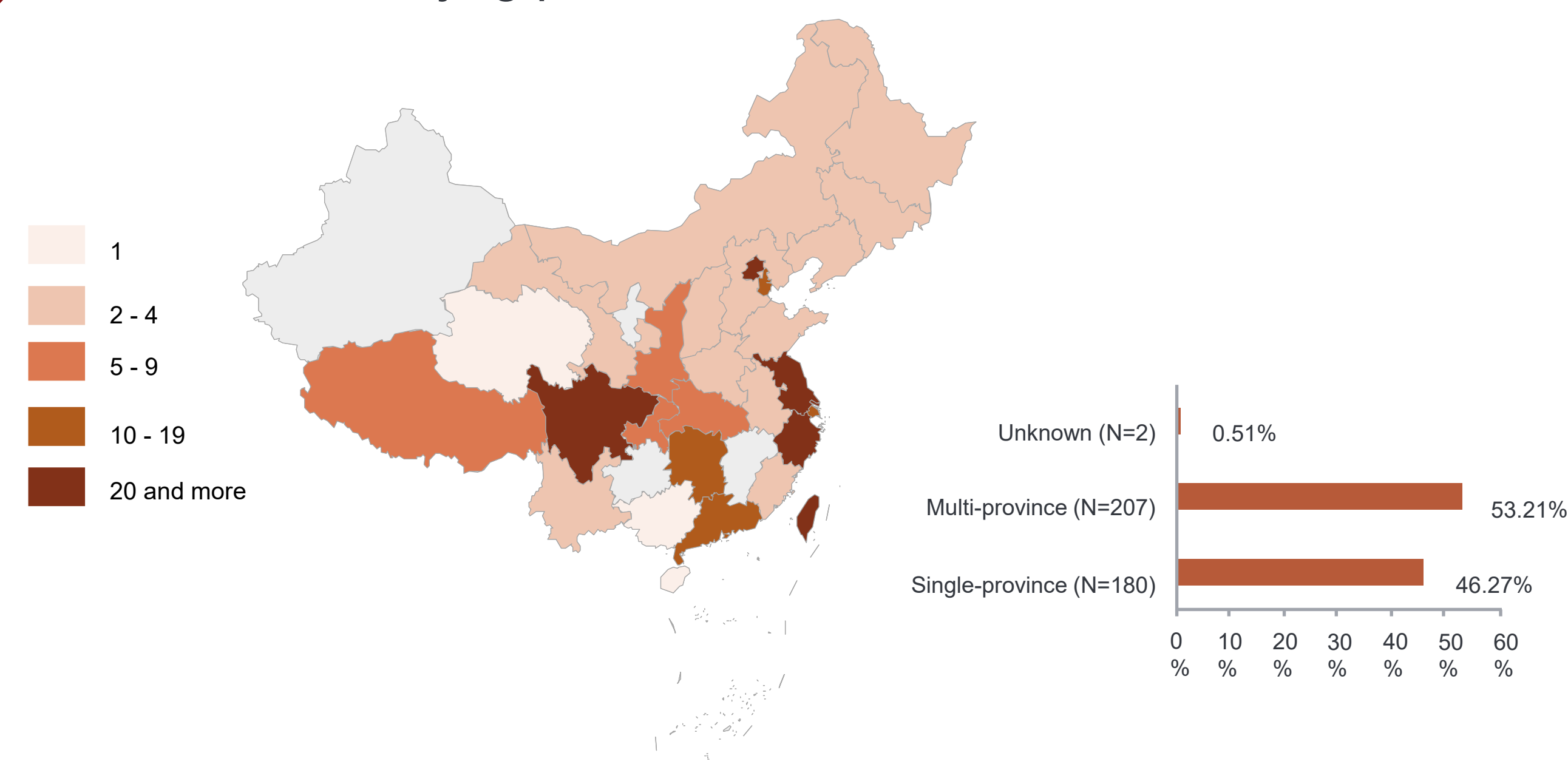


Figure 3. Geographical distribution of published RWS on CNS diseases

RESULTS 3 – Findings from 184 RWD databases

- 4 Categorized by disease types, stroke had most RWD databases (n=82, 44%), followed by epilepsy, Parkinson's disease, multiple sclerosis and Alzheimer's disease.

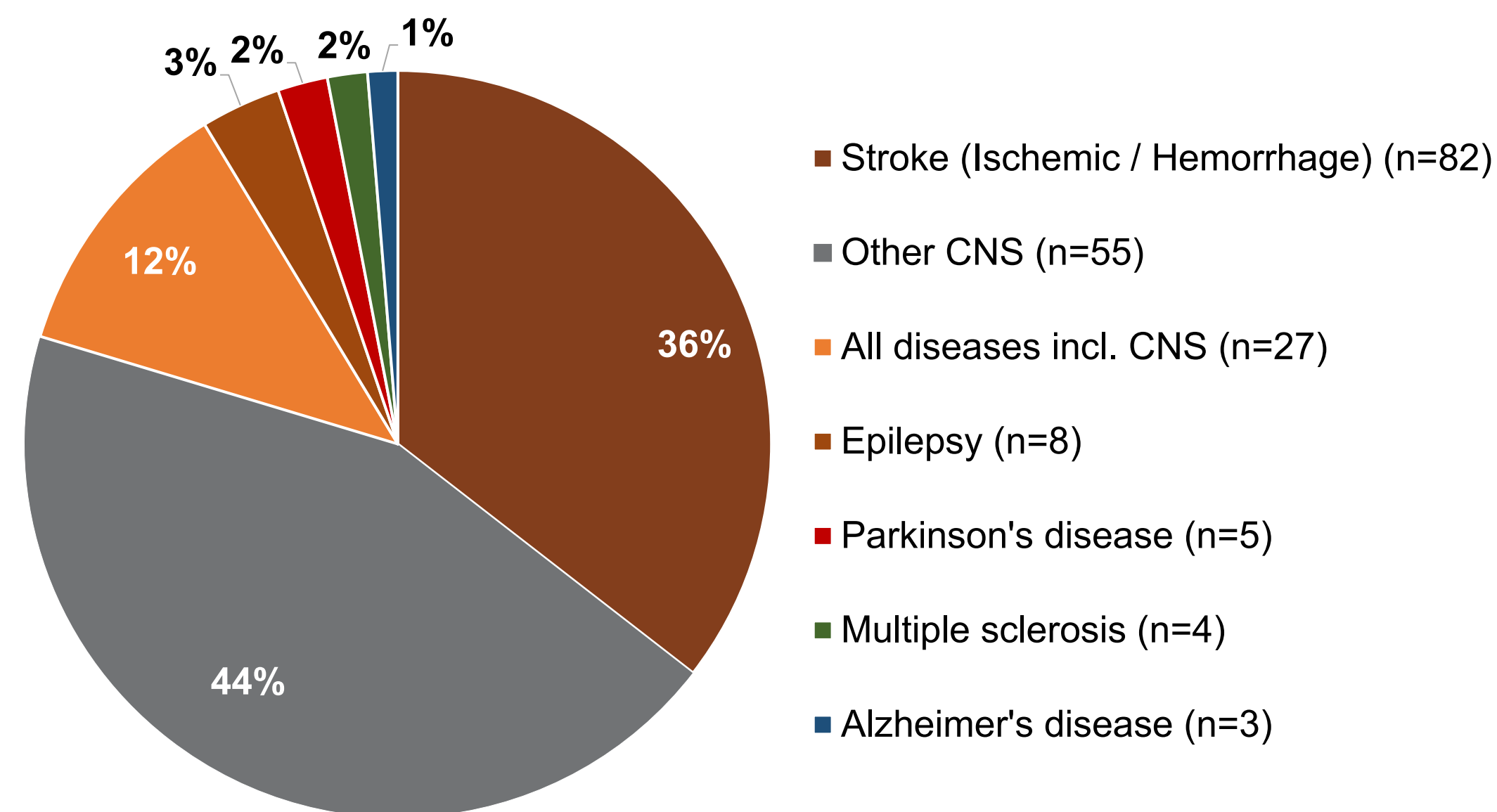


Figure 4. Number of databases by disease type

RESULTS 3 – Findings from 184 RWD databases

- 5 Regarding database types, most were registry (n=119, 64.7%), followed by EMR (n=41, 22.8%), claims (n=10, 5.4%), Regional EHR (n=7, 3.8%), and surveillance (n=7, 3.8%).

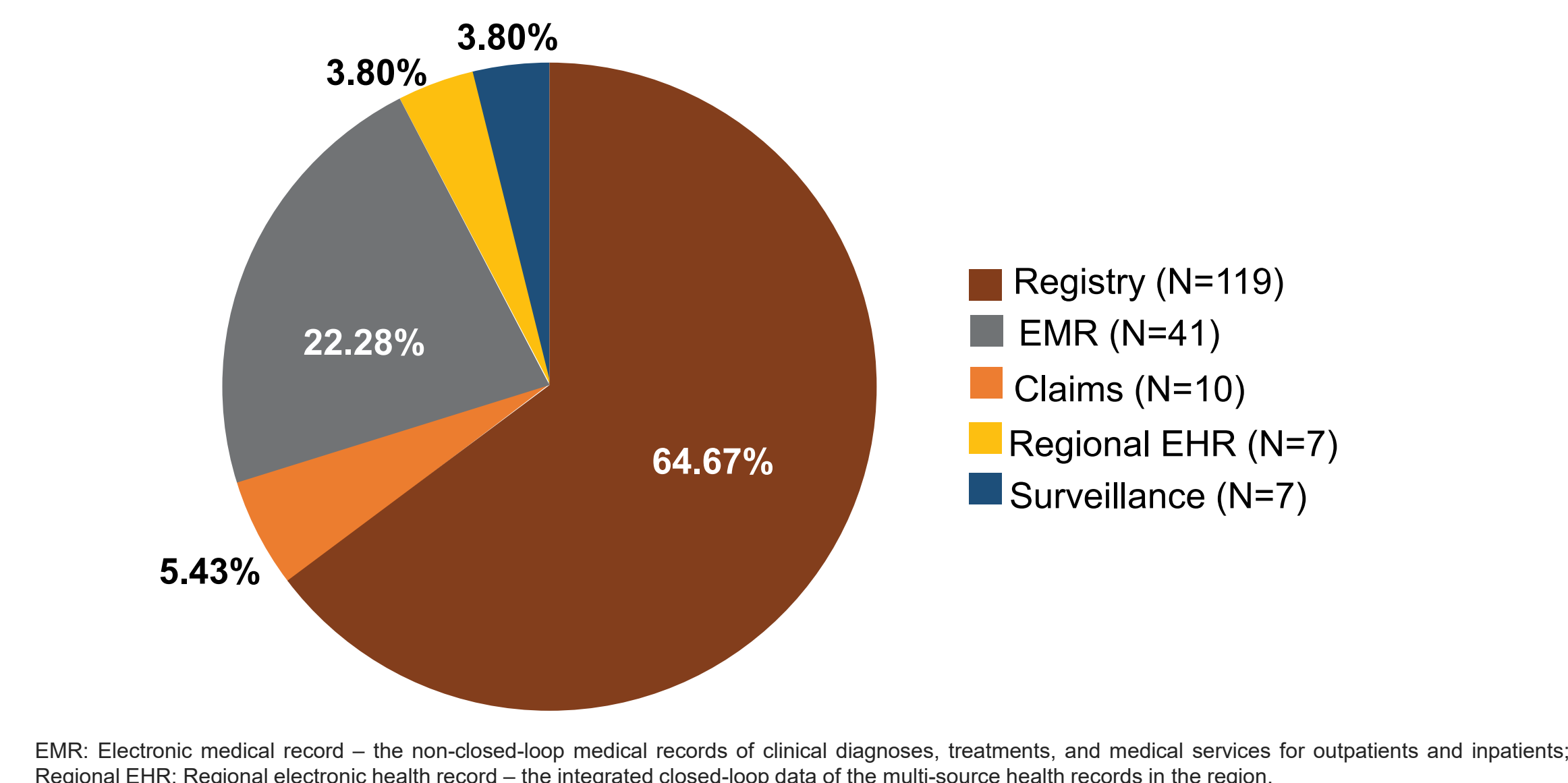


Figure 5. Distribution of RWD database types

- 6 Beijing had most databases (n=23), followed by Sichuan and some coastal provinces (Guangdong, Zhejiang, Hong Kong (not shown)).

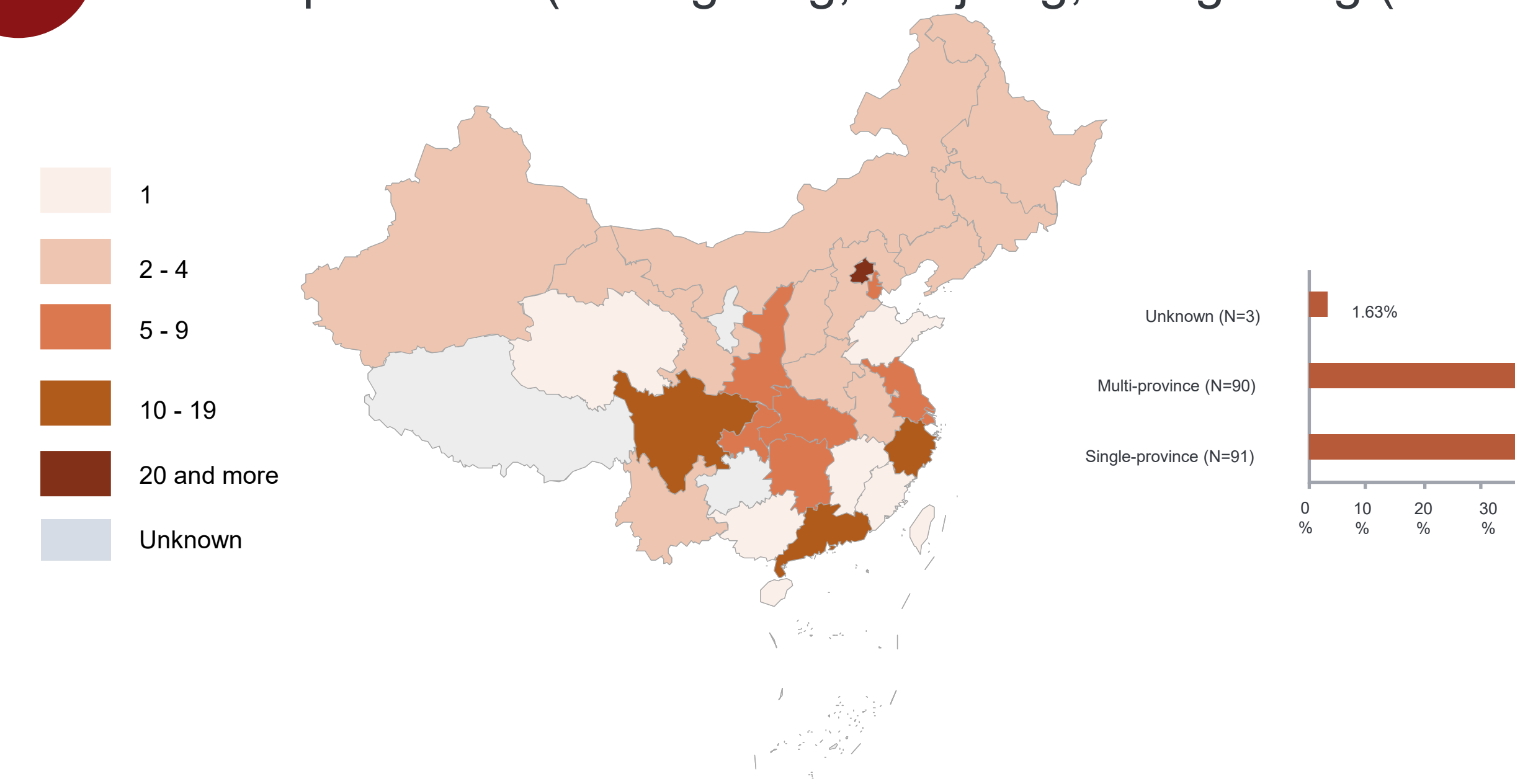


Figure 6. Geographical distribution of RWD databases

- 7 Despite extensive hospital networks and participant cohorts, there were significant data gaps in the RWS, including missing information on hospital numbers (29.3%), enrollees (20.1%) and observation periods (28.8%), as these details were unreported.

CONCLUSIONS

- The landscape of RWS and RWD databases on CNS is broad and includes diversified data types in China.
- However, the full potential of RWD is hindered by data deficiencies in completeness, quality, and accessibility.
- This review's limitations, such as potential publication bias and the exclusion of non-indexed sources, may limit the findings' applicability.
- To enhance the impact of real-world evidence on the understanding and management of CNS diseases, it is critical to improve data integrity and reporting standards.