

A Comparison of Single-Network and Multi-Site Approaches to Real-World Data Collection

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Background + Purpose

Background

- Approaches to real-world data collection which leverage information from only one site can leave out important information from healthcare encounters that occur outside of the study site and can lead to loss to follow-up
- PicnicHealth's patient-centric approach to real-world research retrieves medical records from all sites of care to create a comprehensive, longitudinal health journey.

Purpose

- To assess and compare the duration and completeness of health journeys of multiple sclerosis [MS] patients within a single network of care, which mimics a traditional site-based study, with a curated dataset from all facilities where patients had received care, the PicnicHealth approach.

Methods

Data simulation

- Using PicnicHealth's MS patient cohort (N=4000 patients with an MS diagnosis documented by a neurologist), we simulated a dataset that would be available if patient information was restricted to one of five care networks across the U.S. [the **single-network or "SN" dataset**], and compared with what was observed for the same patients from all facilities where they had received care as captured by PicnicHealth [the **"PH" dataset**].
- Simulated care networks: Dignity Health, HCA Healthcare, Mayo Clinic, Providence Health, Trinity Health

Inclusion Criteria

- 10%+ of in/outpatient visits in one of the target systems
- 1+ visit post-MS diagnosis in one of the target systems

Exclusion Criteria

- No visits in target healthcare system
- Visits in >1 target healthcare systems

Missing clinical information defined as:

- Any clinical visit taking place outside of a care center associated with a target network
- Any clinical event before a patient joined a network
- Any clinical event after a patient had their final in-network visit

Final patient count for analysis: 370

Table 1: Comparison of healthcare resource utilization documented in the PH and SN datasets.

	All PH visits	SN visits only
Years of visits*	9 [6, 14]**	4 [2, 6]
Number of providers	15 [8, 29]	6 [3, 12]
Number of care sites	6 [4, 9]	2 [1, 3]
Number of neurology visits	13 [7, 20]	4 [0, 10]
Number of hospitalizations	2 [0, 7]	1 [0, 3]
Hospital days	4 [0, 14]	1 [0, 7]
Longest obs. period*** [years]	4.80 [2.80, 6.62]	1.61 [0.00, 4.24]

* Calculated as the time between the earliest and latest visit available in the dataset.

** Median [IQR]

*** Observation time captures periods where gaps in record collection are unlikely. Here, it is defined as continuous periods when patients saw a neurologist at least once every 18 months.

Table 2: Statistics on clinical events missing in the SN dataset.

Clinical event (N, %)	Patient N*	Events in PH data	Events missing in SN data	% of events missing, cohort level	% of events missing, patient-level
MS relapses Median [IQR] Mean (s.d.)	262	811	433	53.4%	62.5 [0 - 100] 56.5 (42.1)
New treatments Median [IQR] Mean (s.d.)	339	1028	198	19.3%	0 [0 - 33.3] 15.6 (25.5)
EDSS scores Median [IQR] Mean (s.d.)	86	733	220	30.0%	0.9 [0 - 100] 39.2 (46.1)
Device/disability onset Median [IQR] Mean (s.d.)	267	481	63	13.1%	0 [0 - 0] 13.2 (27.7)
Neurological MRIs Median [IQR] Mean (s.d.)	350	5616	2276	40.5%	321 [0 - 75] 39.9 (38.0)

* Only patients with at least one event in a given clinical event category are included in that row.

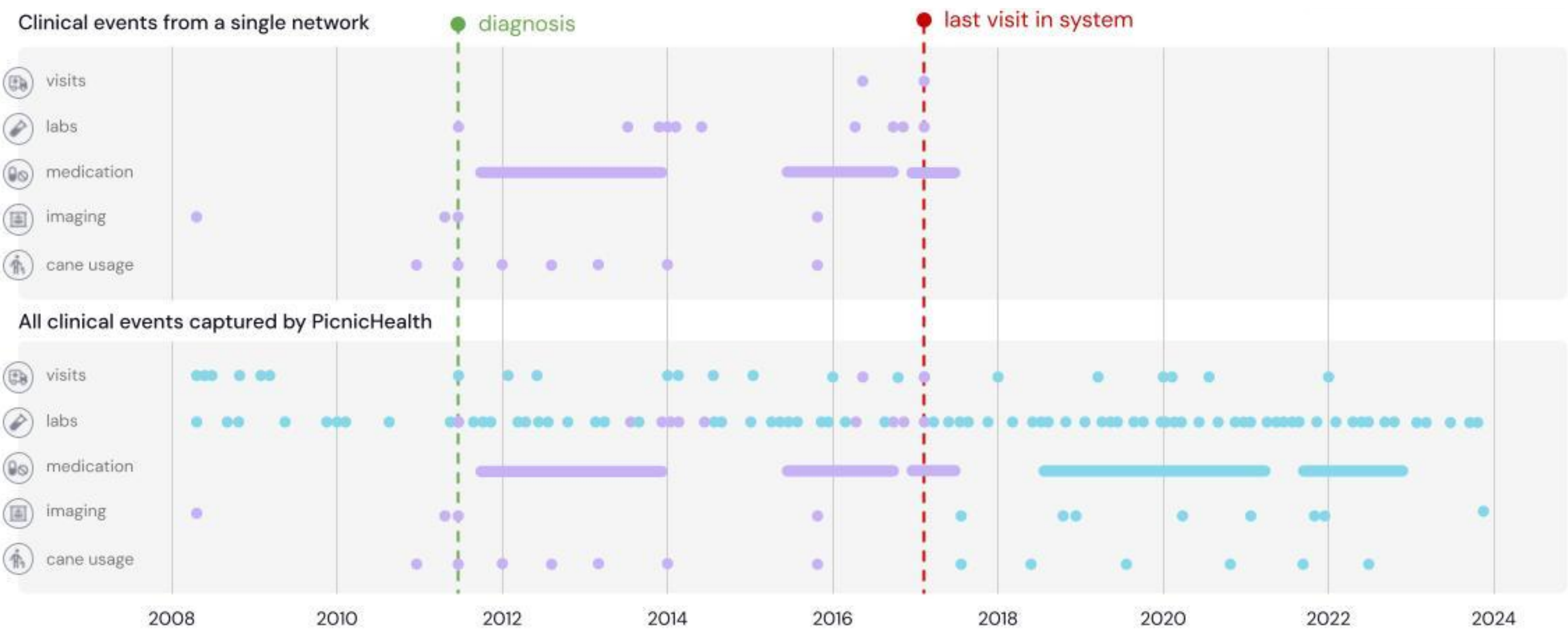


Figure 1: One patient's healthcare journey, showing clinical events known to, and missing from, the single-system dataset.

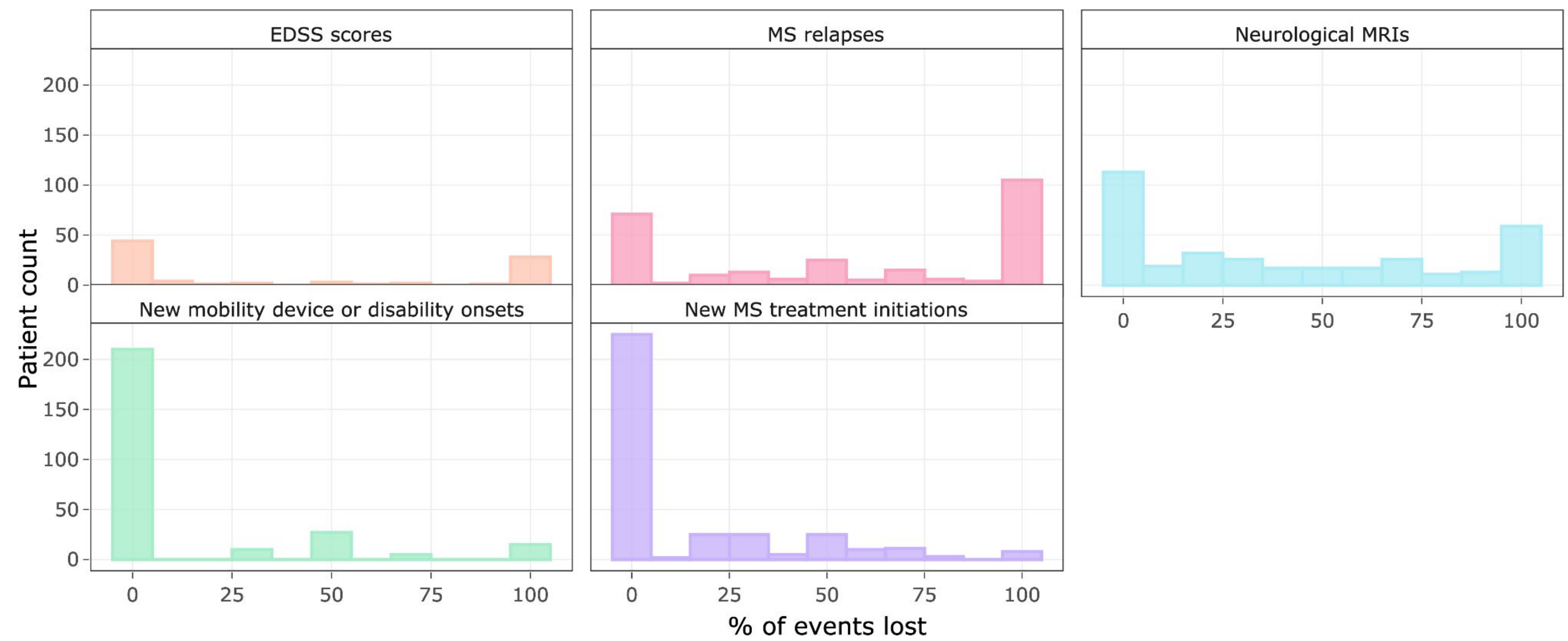


Figure 2: Distribution of the percentage of each patient's clinical events missing in the SN dataset.

Results

- 370 qualifying MS patients were identified. The healthcare journey for a single patient is shown in **Figure 1**.
- Compared with the SN dataset, the median patient in the PH dataset had more:
 - years of visits [SN: 4, PH: 9]
 - neurology encounters [SN: 4, PH: 13]
 - providers [SN: 6, PH: 15]
 - hospitalizations [SN: 1, PH: 2]
 - hospital days [SN: 1, PH: 4] (**Table 1**)
- Using the PH dataset as a "gold standard", the SN dataset would have observed only:
 - 47% of MS relapses
 - 81% of newly-initiated MS treatments
 - 70% of Expanded Disability Status Scale [EDSS] scores
 - 87% of new mobility devices or disability onsets
 - and 60% of neurology magnetic resonance imaging (**Table 2**)
- The proportion of events missing varied greatly across patients (**Figure 2**). For each clinical variable, some patients were not missing any events while others were missing 50% or more.

Conclusion

Our analyses demonstrate that missing information is more likely in traditional site-based methods or analyses limited to single networks than in the PicnicHealth methodology. This may lead to biased insights and erroneous conclusions.

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