

Alignment of Prophylactic Medication Data in Medical Records and Patient-Reported Surveys Among Patients with Hemophilia A

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Objective

- Background**
- Accurately capturing medication use is critical for researchers to reduce misclassification bias in observational studies
 - Medical records (MRs) may not accurately reflect current medication use due to intermittent visits, lack of visibility across different care providers, and inconsistent medication reconciliation practices, while patient-reported medication use may be subject to recall bias
 - Two types of alignment are assessed in this study:
 - Status** – both data sources (MRs and surveys) contain the same information regarding whether a patient was taking any prophylactic hemophilia medication
 - Name** – among patients with prophylactic medication in both MRs and surveys, both sources contain the same specific prophylactic hemophilia medication name

- Purpose**
- To assess prophylactic hemophilia medication use alignment between medications abstracted from MRs reported in patient surveys among patients with hemophilia A (HA)

Methods

- Data Source**
- PicnicHealth engages with patients who consent to participate in research, collects MRs on their behalf, provides records for patients, and abstracts data from MRs for research purposes
 - Hemophilia medication treatment era information is abstracted from physician notes and medication lists in MRs
 - Patients are invited to answer surveys, one of which is administered every 2 weeks and includes questions about which medications patients are currently taking for prophylaxis

- Inclusion Criteria**
- Hemophilia A diagnosis by a hematologist in medical records
 - At least 1 survey taken between 3/30/2022 and 9/30/2022
 - Surveys were included if they occurred during periods for which patients had ≥1 visit with a hematologist at least once a year to ensure MR availability for the study period

- Analysis**
- Medication status and name for prophylactic hemophilia medications in surveys and abstracted MRs were compared for each date the survey was completed. Percent of surveys for each patient for which data aligned was calculated [Figure 1]
 - Mean and standard deviation (SD) percent alignment were calculated
 - Hemophilia severity was defined as baseline factor labs <1% mild, 1-5% moderate, and 5-50% severe from MR data
 - Physician chart review determined possible reasons for misalignment

Table 1: Patient characteristics

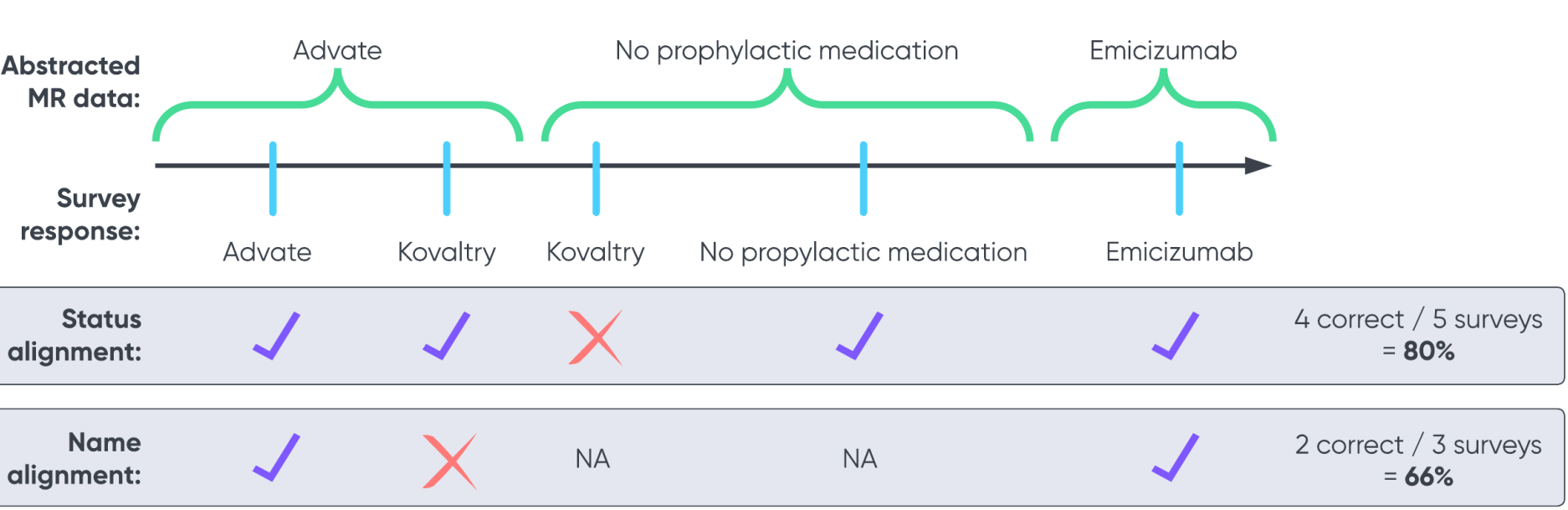
Characteristic	N = 76 N (%)
Age in years, median (Q1-Q3), mean (SD)	32.0 (17.0-42.2); 30.8 (16.8)
Sex	
Female	3 (3.9)
Male	73 (96.1)
Race	
Asian	2 (3.0)
Black or African American	9 (13.6)
White	51 (77.3)
Other / more than one	4 (6.1)
Ethnicity	
Hispanic or Latino	18 (25.4)
Not Hispanic or Latino	53 (74.6)
Hemophilia severity	
Mild	9 (11.8)
Moderate	13 (17.1)
Severe	54 (71.1)
Surveys completed, median (Q1-Q3), mean (SD)	8.0 (4.0-12.0); 7.9 (4.5)
Patient-reported prophylactic medication during study period	
Any	65 (85.5)
FVIII (all)	37 (48.7)
SHL FVIII	21 (27.6)
EHL FVIII	16 (21.1)
Emicizumab	34 (44.7)
Abstracted MR prophylactic medication during study period	
Any	59 (77.6)
FVIII (all)	31 (40.8)
SHL FVIII	17 (22.4)
EHL FVIII	15 (19.7)
Emicizumab	33 (43.4)

Abbreviations: Q: Quantile; SD: Standard Deviation; FVIII: Factor 8; SHL: Standard Half-Life; EHL: Extended Half-Life; MR: Medical Record

88% average medication **status** alignment

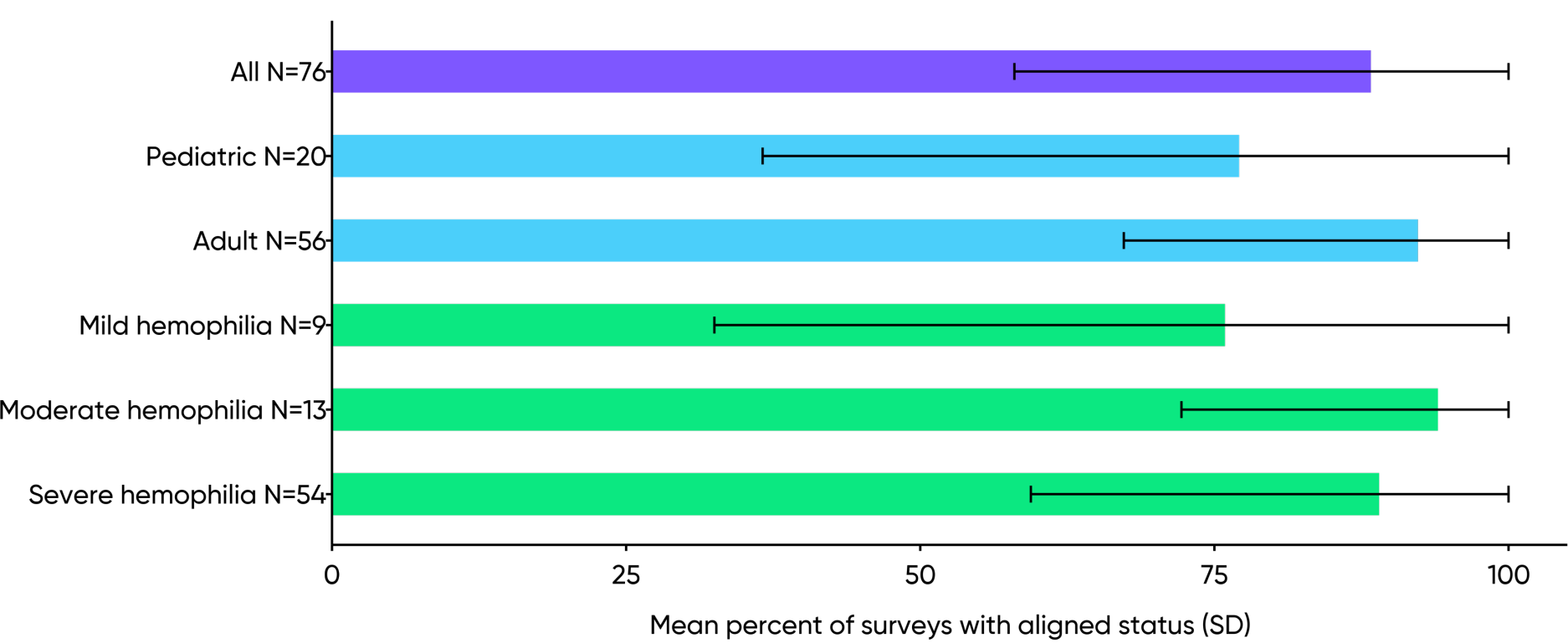
79% average medication **name** alignment

Figure 1: Visualization of alignment determination for an example patient



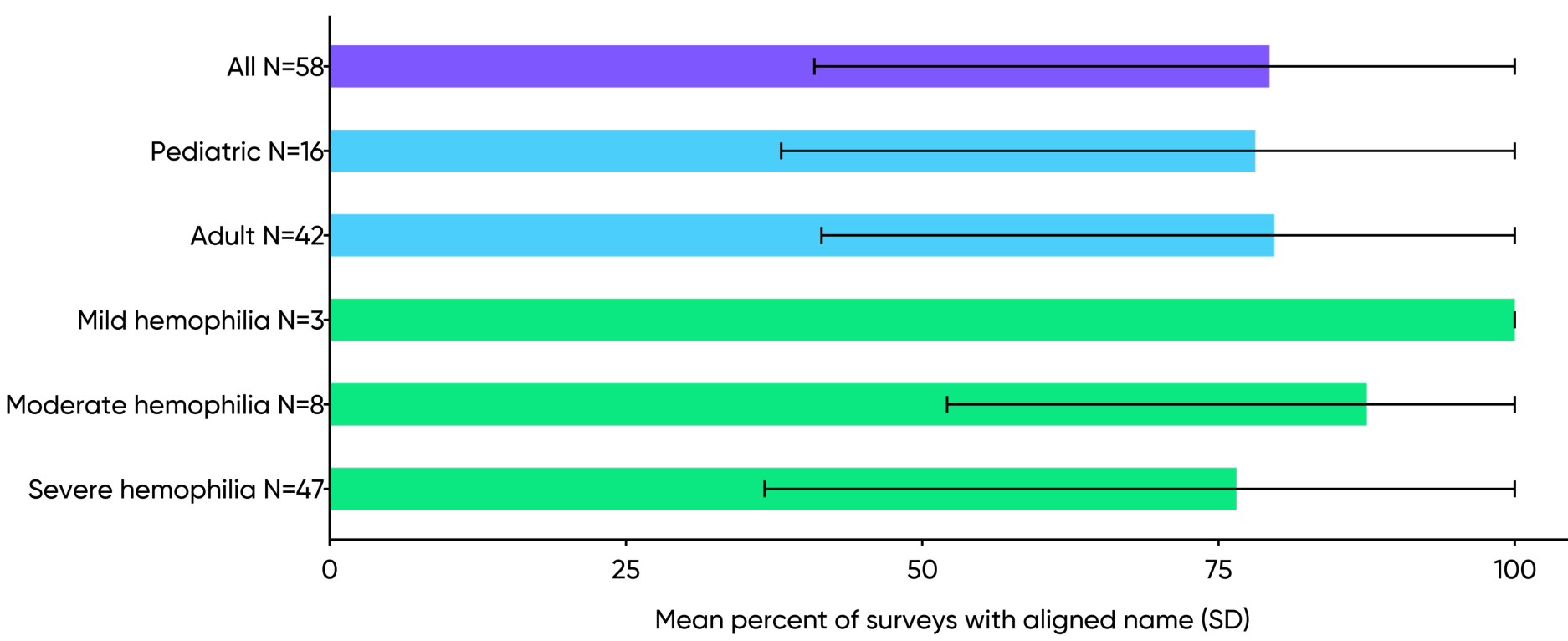
Abbreviations: MR: Medical Record

Figure 2: Prophylactic medication status alignment, overall and by subgroup



Abbreviations: SD: Standard Deviation

Figure 3: Prophylactic medication name alignment*, overall and by subgroup



*calculated only among patients with prophylactic medication in both survey and abstracted MR data
Abbreviations: SD: Standard Deviation

Results

- Patient Characteristics**
- 76 patients with HA and ≥1 survey [Table 1]
 - Mean age 31 years; 74% adults; 96% male
 - 71% severe hemophilia; 17% moderate; 12% mild
 - Average of 8 surveys completed
 - 86% reported prophylactic medication use on surveys
 - 78% had prophylaxis use during the study period in abstracted MRs

- Medication Status Alignment**
- On average, 88% (SD 30%) of surveys for each patient had the same medication status as abstracted MRs [Figure 2]

- Medication Name Alignment**
- On average 79% (SD 38%) of surveys for each patient had the same medication name in abstracted MRs (among those with prophylactic medication use on surveys and abstracted MRs) [Figure 3]

- Common Reasons for Misalignment**
- Not reporting emicizumab as a prophylactic medication on surveys. Patients may not consider emicizumab as a prophylactic therapy
 - Reporting two prophylactic medications on surveys with one medication identified as prophylactic in abstracted MRs and one medication identified as being used on-demand

Conclusion

Medical records are an important resource for identifying medication use for real-world evidence generation in hemophilia, and the ability to supplement this data with patient-reported information may be important for identifying and reducing misclassification