



# ELHS Network Population Health Dashboard



September 19, 2025



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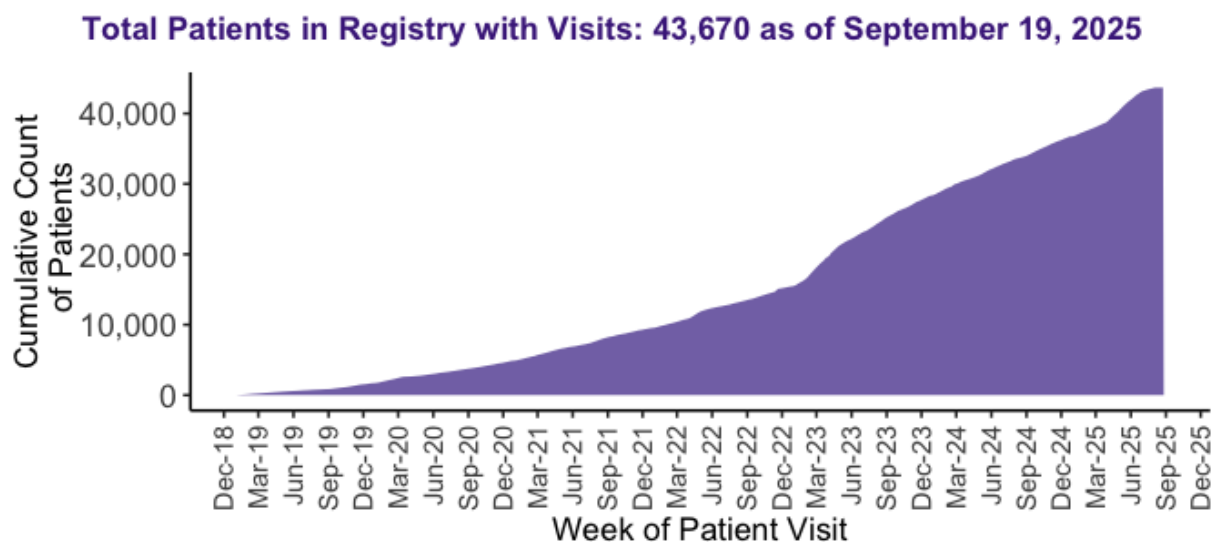
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## 1 Overview

There is a total of 43,670 patients in the registry with visit information (data in the clinic visit form, seizure frequency form, or patient-reported outcomes).



**ELHS Sites  
Contributing Data**



**Sites Contributing  
Provider-Reported Data**

**7**

**Sites Contributing  
Patient-Reported Data**

**8**

**Total Patients in Registry**

**43,670**

**Count of Records by Form**

Provider-Reported Seizure Frequency

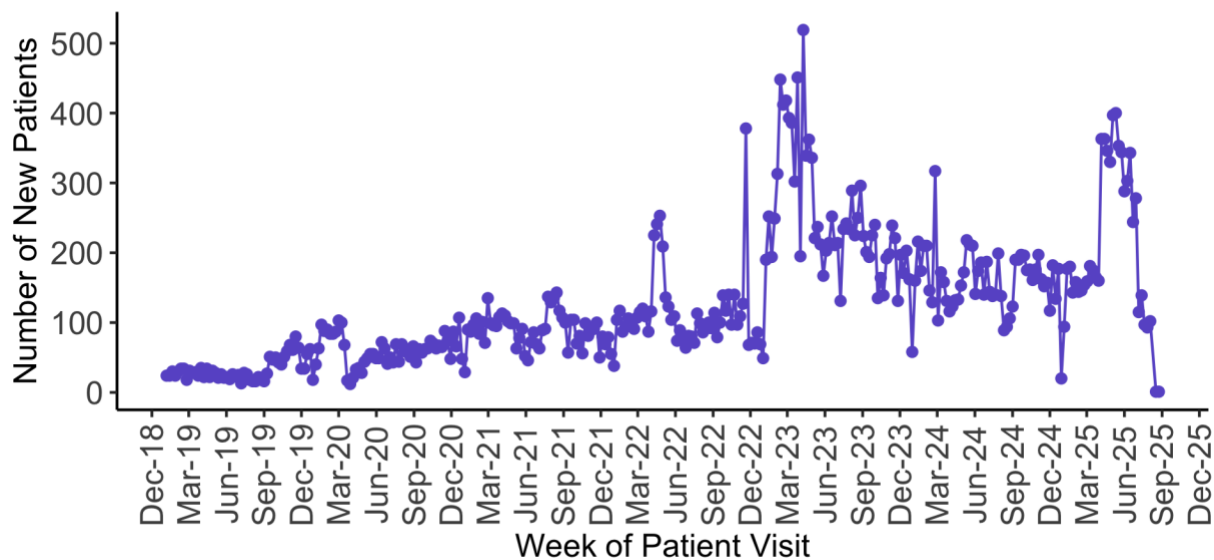
**90,250**

PROs

**66,588**

Legend: Count of Records by Form: Provider-Reported Seizure Frequency Forms (N = 90,250) and PROs (N = 66,588) indicate the form was submitted, this does not mean all fields were completed. An individual patient may have multiple forms submitted, for each seizure type and multiple visits. This metric is meant to indicate the size of the database, and is distinct from the form completion and measures definitions shown below.

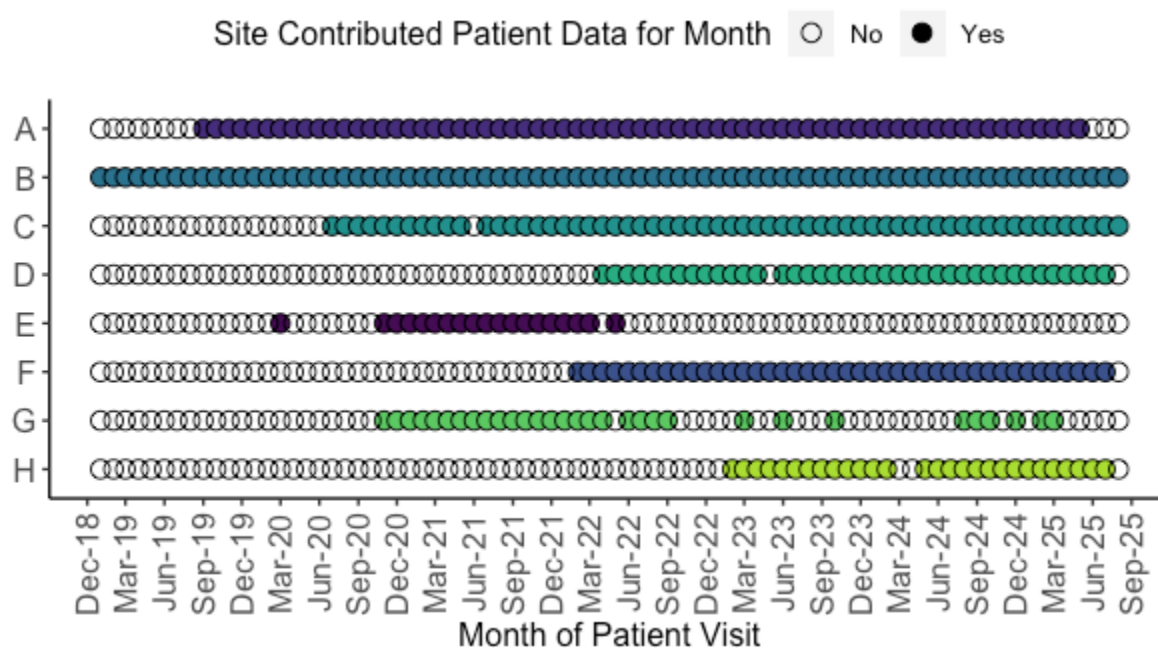
## 1.1 New Patients with Visits Initiated to Registry



Legend: Count of new patients added to the registry by week using the week of the first visit. This captures patients' first visit.



## 1.2 Number of Sites Contributing Data per Month



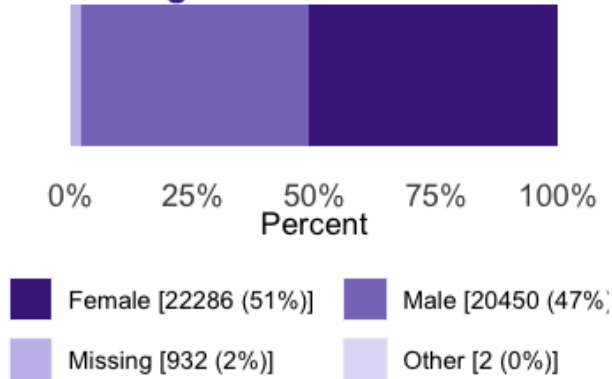
Legend: ELHS sites contributing data by month. A solid filled circle indicates that the site has patient visit data for the given month.



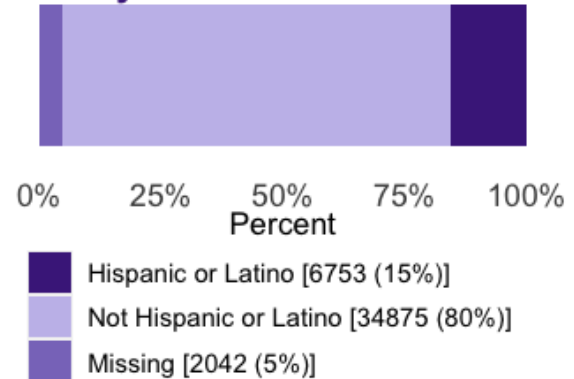
## 2 Demographics

The total number of patients with demographic information is 43,670.

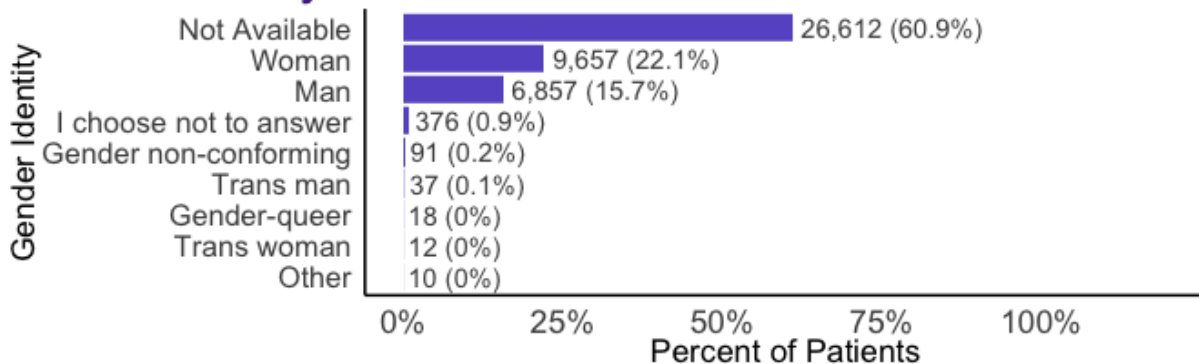
### Sex Assigned at Birth



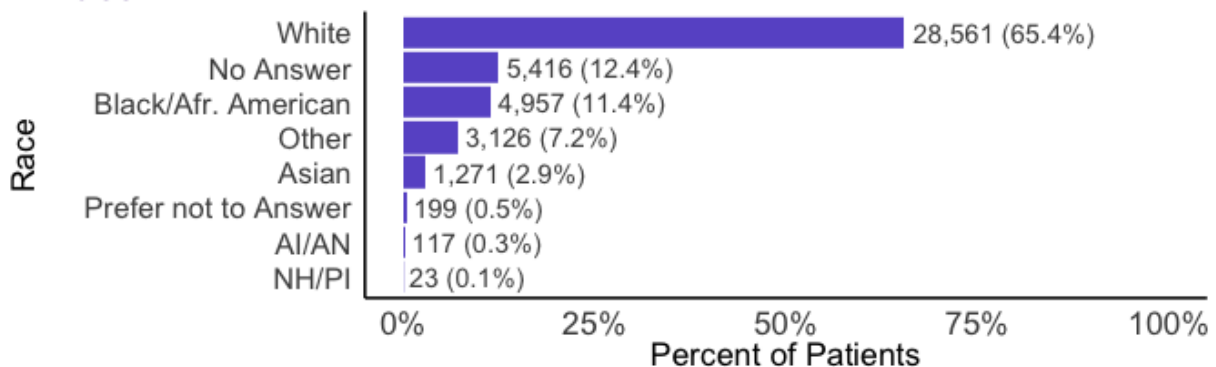
### Ethnicity



### Gender Identity



### Race

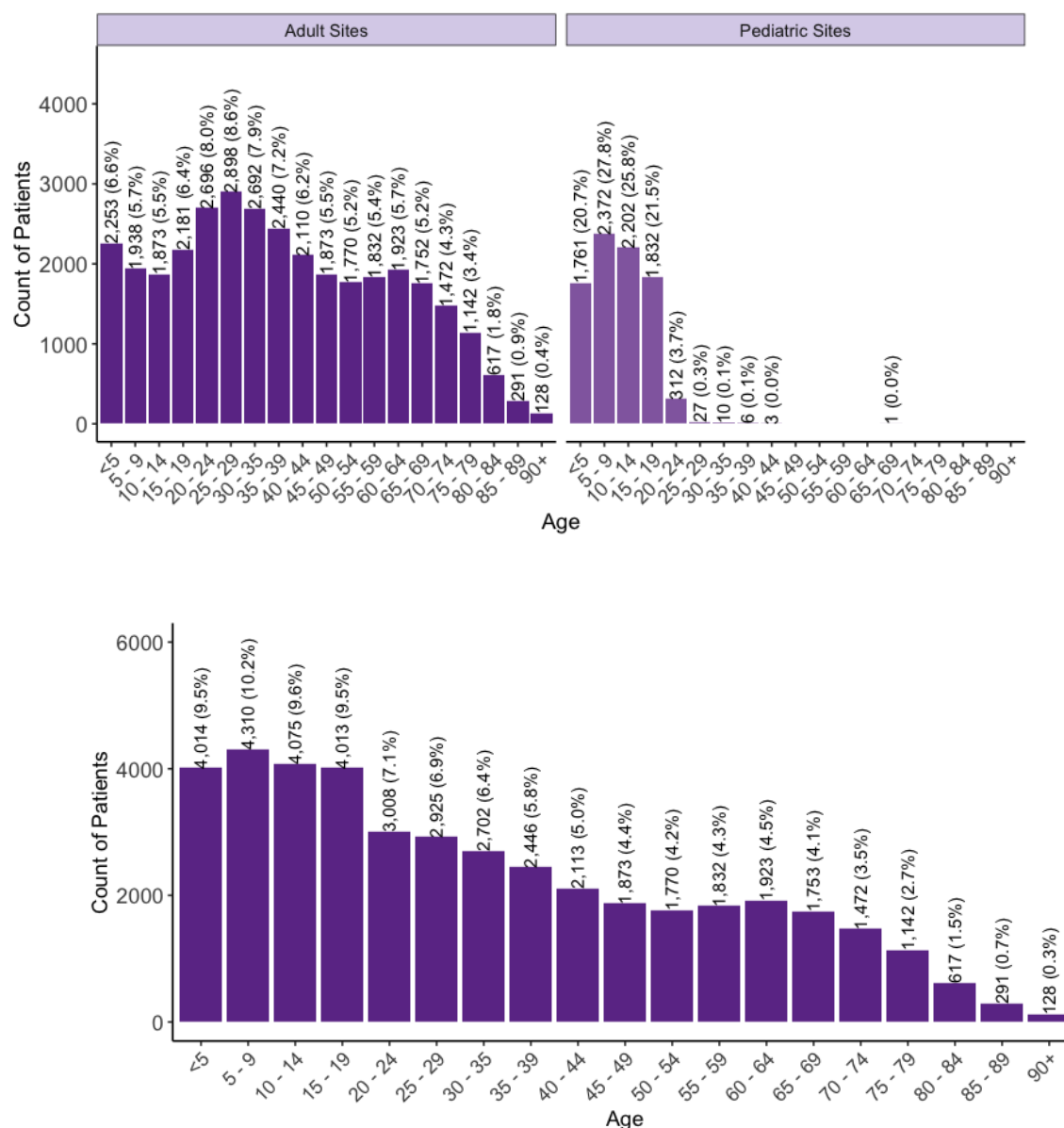


Legend: Percentages are calculated using the demographic information from the patient's most recently completed demographic form. AI/AN, American Indigenous/American Native; NH/PI, Native Hawaiian/Pacific Islander.

## 2.1 Age

The mean age for adults 18 years old and above is 46 (N = 27415) and the mean age for pediatric patients less than 18 years old is 9 (N = 14992). The total count of patients with complete age information is 42,407 and 1,263 patients are missing age data. There are 33,881 patients at adult ELHS sites and 8,526 patients at pediatric ELHS sites.

## 2.2 Age Distribution at Adult and Pediatric ELHS Sites



Legend: Count of patients in each 5-year age category. Counts are calculated using age at the time of encounter for the patient's last visit.



### 3 ELHS Measures Report

#### ELHS Measures Documented by Site

Years: 2019 to July 2025

Site	Measure	Provider Seizure Freq. Documentati on	Patient Seizure Freq. Documentati on	Patient BMA	Provider BMA	Adherence Barriers Document ation	Adult Anxiety	Adult Depression	QOL Adult	QOL Pediatric	Demograp hics	SDOH
All	N Visits	123233	123233	123233	123233	123233	78259	78259	78259	44974	123233	123233
	N Completed	40786	31190	41596	17803	42092	19687	15953	14316	15071	113832	486
	% Completed	33	25	33	14	34	25	20	18	33	92	0
A	N Visits	633	633	633	633	633	633	633	633	0	633	633
	N Completed	138	288	4	19	23	69	267	182	0	600	0
	% Completed	21	45	0	3	3	10	42	28	0	94	0
B	N Visits	26869	26869	26869	26869	26869	2593	2593	2593	24276	26869	26869
	N Completed	20541	0	5353	0	5353	0	0	0	10927	26421	0
	% Completed	76	0	19	0	19	0	0	0	45	98	0
C	N Visits	5817	5817	5817	5817	5817	5806	5806	5806	11	5817	5817
	N Completed	2940	48	2841	349	2977	0	0	0	0	5706	0
	% Completed	50	0	48	5	51	0	0	0	0	98	0
D	N Visits	48053	48053	48053	48053	48053	47799	47799	47799	254	48053	48053
	N Completed	11985	13911	13390	775	13603	19513	15583	14134	0	45673	486
	% Completed	24	28	27	1	28	40	32	29	0	95	1
E	N Visits	5568	5568	5568	5568	5568	376	376	376	5192	5568	5568
	N Completed	2408	1250	1667	1770	1795	0	0	0	1790	5430	0
	% Completed	43	22	29	31	32	0	0	0	34	97	0
F	N Visits	19841	19841	19841	19841	19841	19841	19841	19841	0	19841	19841
	N Completed	0	15693	14937	14890	14937	0	0	0	0	19728	0
	% Completed	0	79	75	75	75	0	0	0	0	99	0
G	N Visits	16452	16452	16452	16452	16452	1211	1211	1211	15241	16452	16452
	N Completed	2774	0	3404	0	3404	105	103	0	2354	10274	0
	% Completed	16	0	20	0	20	8	8	0	15	62	0

**Legend:** This measures report uses the quality measures definitions established by the ELHS network (shown below). The denominator is visits (N = 123,233; Adult N = 78,259; Pediatric N = 44,974). Site H not shown due to small sample size. Rather than examining individual patient data, the report focuses on the comprehensive data collected across all reported visits. Visits are defined as a unique patient and date submitted on the epilepsy clinic, seizure frequency or patient reported outcomes forms.

**Note:** The definition for a numerator and denominator varies for each of the measures. Please refer to the next page for definitions of ELHS Quality measures.





Measure	Definition/Inclusion	Numerator	Denominator
Provider Seizure Frequency Documentation	Percent of all visits at which the provider documents seizure frequency* AND date range of last seizure for each seizure type. This is a visit-based process measure.	Number of visits that include a seizure frequency documented within 14 days of and including date of visit AND "Seizure Type ILAE Classification, current frequency since last visit" AND "Seizure Type ILAE Classification, date of last seizure" are all non-blank. <b>Patient must have all 3 variables documented for at least 1 seizure type.</b> If patient has zero seizures documented, they are not included. If patient has seizure documented >15 days from visit, they are not included	Number of visits in the reporting month.
Patient Seizure Frequency Documentation	Percent of all visits for patients at which the patient has documented seizure frequency using any method (paper journal, electronic diary, mobile app, or other) within 14 days of the visit. This is a visit-based process measure.	Number of visits with seizure frequency documented equal to "yes". <b>Patient must complete 2 questions: When was your LAST typical seizure (your most common seizure type)? AND How often is your typical seizure during the past four weeks?</b> within 14 days of clinic visit.	Number of visits.
Adherence Barriers Documentation	This process focused measure answers: How often do providers assess for barriers to adherence? Secondary analyses can subdivide by seizure type, epilepsy type, age, and other variables.	Number of visits at which provider documents screening for barriers to adherence. Patient BMA indicates how many visits where the patient completed the PRO checklist. Provider BMA indicates that the provider screened for BMA or medication adherence. BMA includes both Patient and Provider.	Number of visits.
Patient BMA	This process focused measures answers: We realize that taking medicine for your seizures can be hard at times. Some patients have shared that the following things get in the way of taking their anti-seizure medicine. Let us know which of these things, if any, apply to you related to taking your anti-seizure medicine. (Please check all that apply)	Number of patient visits with Patient Reported Outcomes Barriers to medication adherence have any response checked including "None"	Number of Visits
Provider BMA	This process focused measures answers: Did the patient complete an Adherence Barriers Checklist?	Number of visits from the Epilepsy Clinic Form (Completed by Provider) must respond "Yes"	Number of visits
QOL Adult	Percent of all visits at which a QOL assessment* is completed by the patient. This is a visit-based process metric. Includes all patients who are ≥18 years and active patients at the time of the visit.	Number of patient visits with QOL completed by the patient within 14 days of the current visit.	Number of visits for patients who are ≥18 years at time of the visit

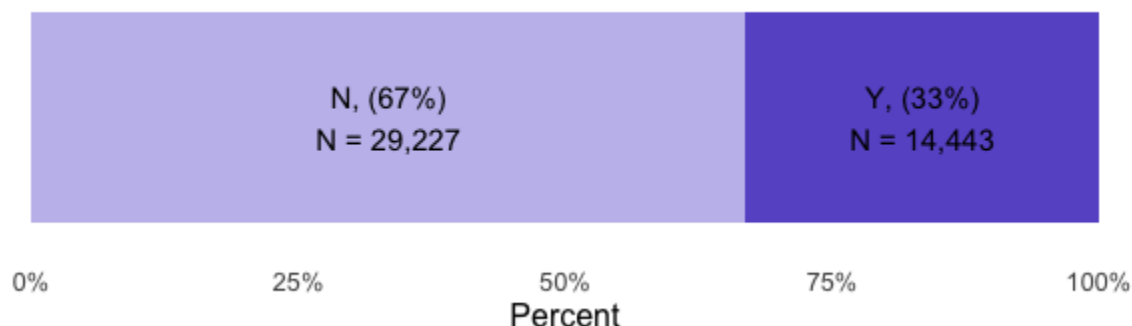


Measure	Definition/Inclusion	Numerator	Denominator
QOL Ped	Percent of all visits at which the provider documents a response to both of the patient/caregiver QOL questions. This is a visit-based process measure.	Number of patient visits with both pediatric QOL questions documented by the provider. Both questions must be answered: <i>Thinking about the child's usual routines, how often in the past 2 weeks have seizures significantly changed those routines?</i> [1 = Everyday, 5= Never] AND <i>Thinking about the child's usual routines, how often in the past 2 weeks have seizure medication side effects significantly changed those routines?</i> [1 = Everyday, 5= Never]. "Uncertain/ Can't remember/ Didn't ask" is not included for response to be part of numerator.	Number of visits for patients who are <18 years at the time of the visit.
Depression Screening	Percent of all visits at which screening for mood disorders (NDDIE and/or PHQ-Q9) is completed. This is a visit-based process metric.	Number of patient visits with mood screening (NDDIE and/or PHQ-9) documented by the patient 450 days (15 months) prior to the current visit for patients ≥18 years at the time of the visit. Any screening tool used needs to be completely answered.	Number of visits for patients ≥18 years at the time of the visit.
Anxiety Screening	Percent of all visits at which screening for anxiety (GAD-7) disorders is completed. This is a visit-based process metric.	Number of patient visits with anxiety screening (GAD-7) documented by the patient 450 days (15 months) prior to current visit for patients ≥18 years at the time of the visit. All questions of the screening tool need to be answered.	Number of visits for patients ≥18 years at the time of the visit.
Demographics	Percent of all visits where "Age, Sex, Race and Ethnicity" are completed.	Number of Visits where Age, Sex, Race and Ethnicity completed.	Number of visits.
SDOH	Percent of visits where "Relationship Status, Education, Occupational Status and Do you live alone?" are completed.	Number of Visits where Relationship Status, Education, Occupational Status and Do you live alone? Are completed.	Number of visits.
Seizure Freedom	Patient Reporting Date of Last Seizure More than 1 Year Ago	Last noted documented visit, where the patient reported date of last seizure more than one year ago on the provider reported outcome response	Number of visits with complete seizure documentation



## 4 Provider Seizure Documentation Completion

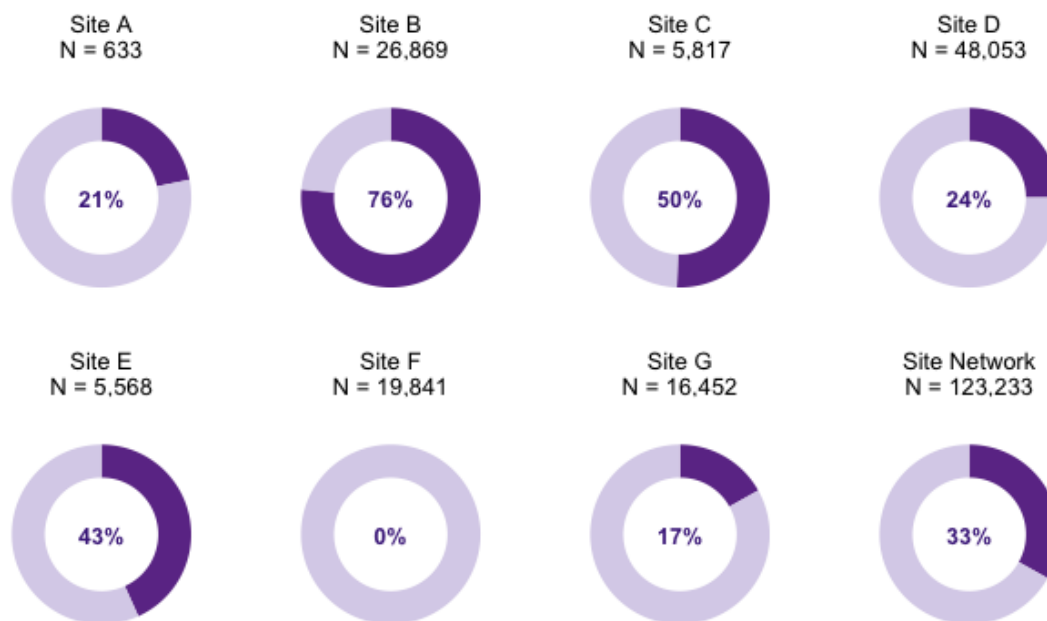
### 4.1 Patients with completed provider seizure documentation



Legend: Number of patients with completed provider seizure documentation for at least 1 visit. Completed seizure documentation is defined as having completed ILAE seizure type, provider-reported seizure frequency and provider-reported date of last typical seizure. Numerator is the count of patients with a complete (all fields completed) provider seizure frequency form on any visit and denominator is the number of unique patients (N = 43,670). This chart indicated the number of patients with at least one complete provider seizure frequency form.



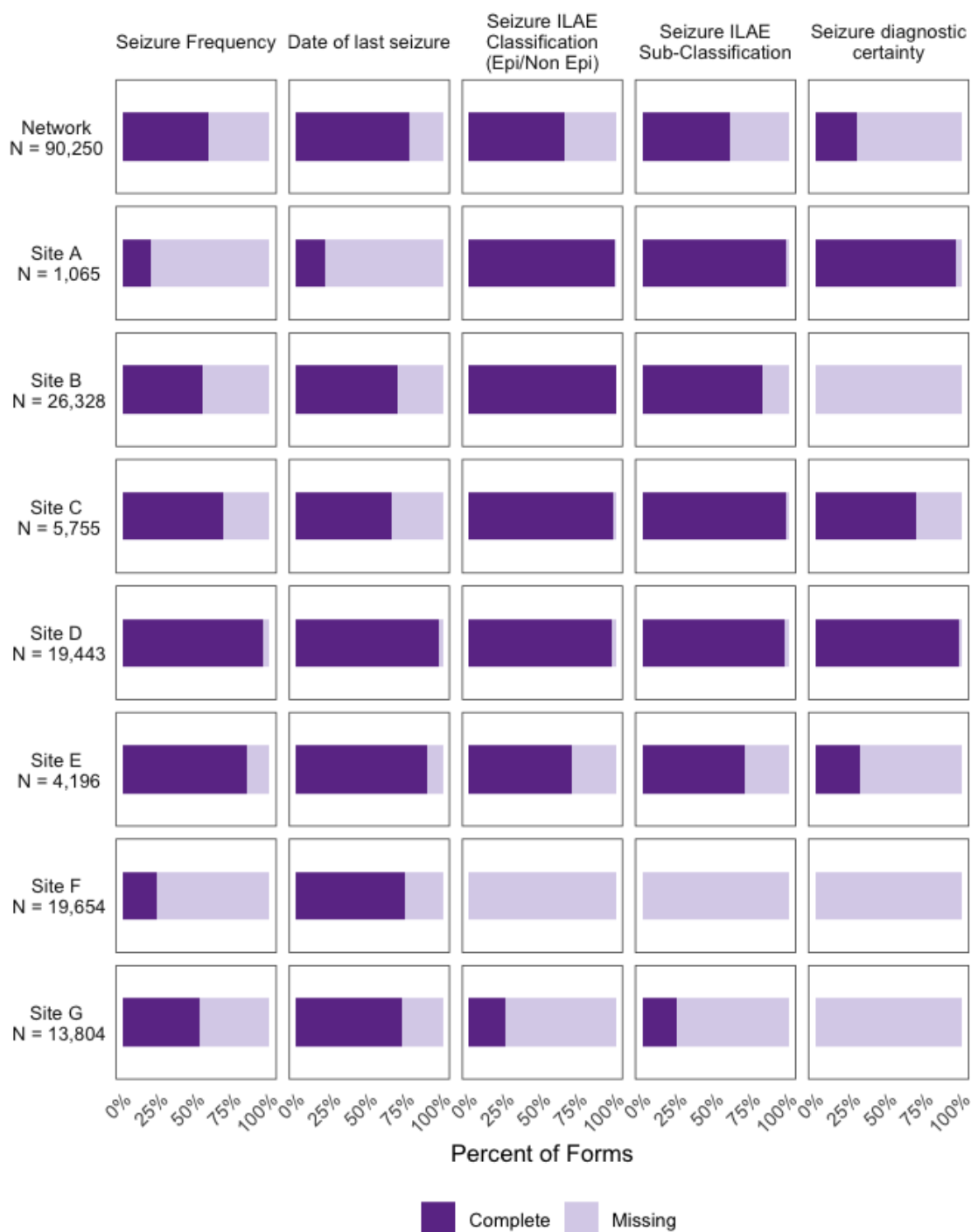
## 4.2 Percent of Visits with Provider Seizure Frequency Form by Site



Legend: We used definitions for Provider Seizure Frequency Documentation in the measures definitions above. Denominator is number of visits (N = 123,233). Site H not shown due to small sample size

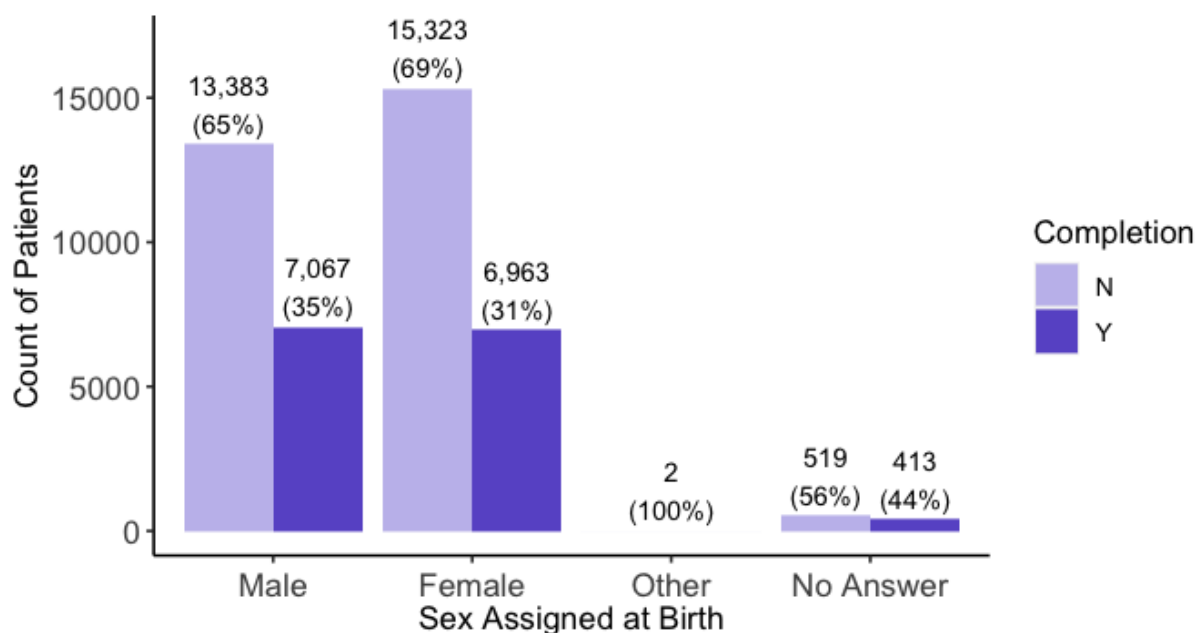


### 4.3 Percent Provider Seizure Frequency Form Completion by Question



Legend: Percent completeness of provider seizure frequency forms by question.  
Denominator is count of seizure frequency forms where at least 1 field was submitted.  
Site H not shown due to small sample size.

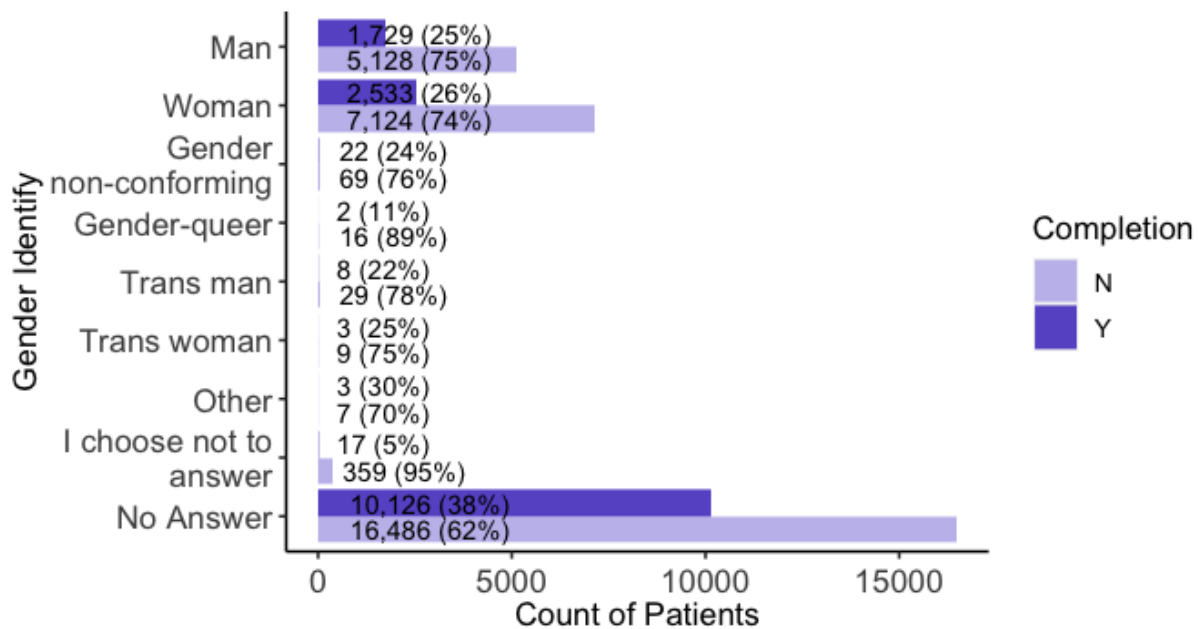
#### 4.4 Provider Seizure Frequency Form Completion: Stratified by Sex



Legend: Number of patients with completed provider seizure documentation for at least 1 visit. Completed seizure documentation is defined as having completed ILAE seizure type, provider-reported seizure frequency and provider-reported date of last typical seizure. Numerator is the count of patients with a complete (all fields completed) provider seizure frequency form on any visit and denominator is the number of unique patients in the given category of sex assigned at birth; Overall N = 43,670; Female N = 22,286, Male N = 20,450, Other N = 2, and Missing N = 932. This chart indicates the number of patients with at least one complete provider seizure frequency form.



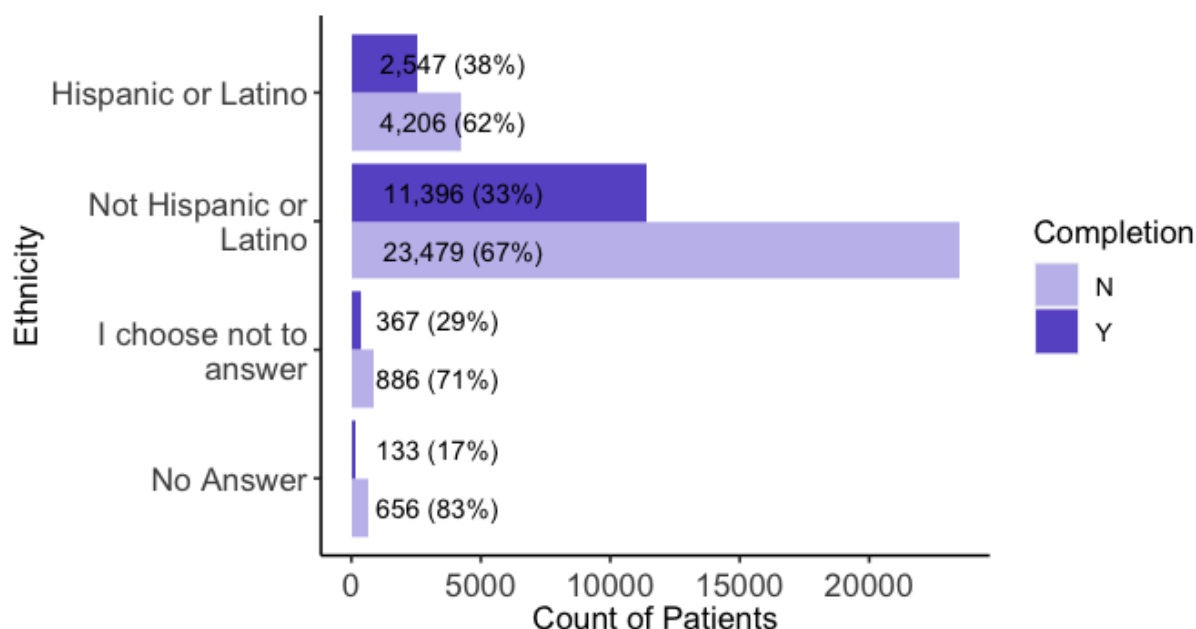
#### 4.5 Provider Seizure Frequency Form Completion: Stratified by Gender Identity



Legend: Number of patients with completed provider seizure documentation for at least 1 visit. Completed seizure documentation is defined as having completed ILAE seizure type, provider-reported seizure frequency and provider-reported date of last typical seizure. Numerator is the count of patients with a complete (all fields completed) provider seizure frequency form on any visit and denominator is the number of unique patients in the given category of sex assigned at birth; Overall N = 43,670; Woman N = 9,657, Man N = 6,857, Gender non-conforming N = 91, Gender queer N = 18, Transgender man N = 37, Transgender female N = 12, Other N = 10, I choose not to answer N = 376 and Missing N = 26,612. This chart indicates the number of patients with at least one complete provider seizure frequency form.



#### 4.6 Provider Seizure Frequency Form Completion: Stratified by Ethnicity

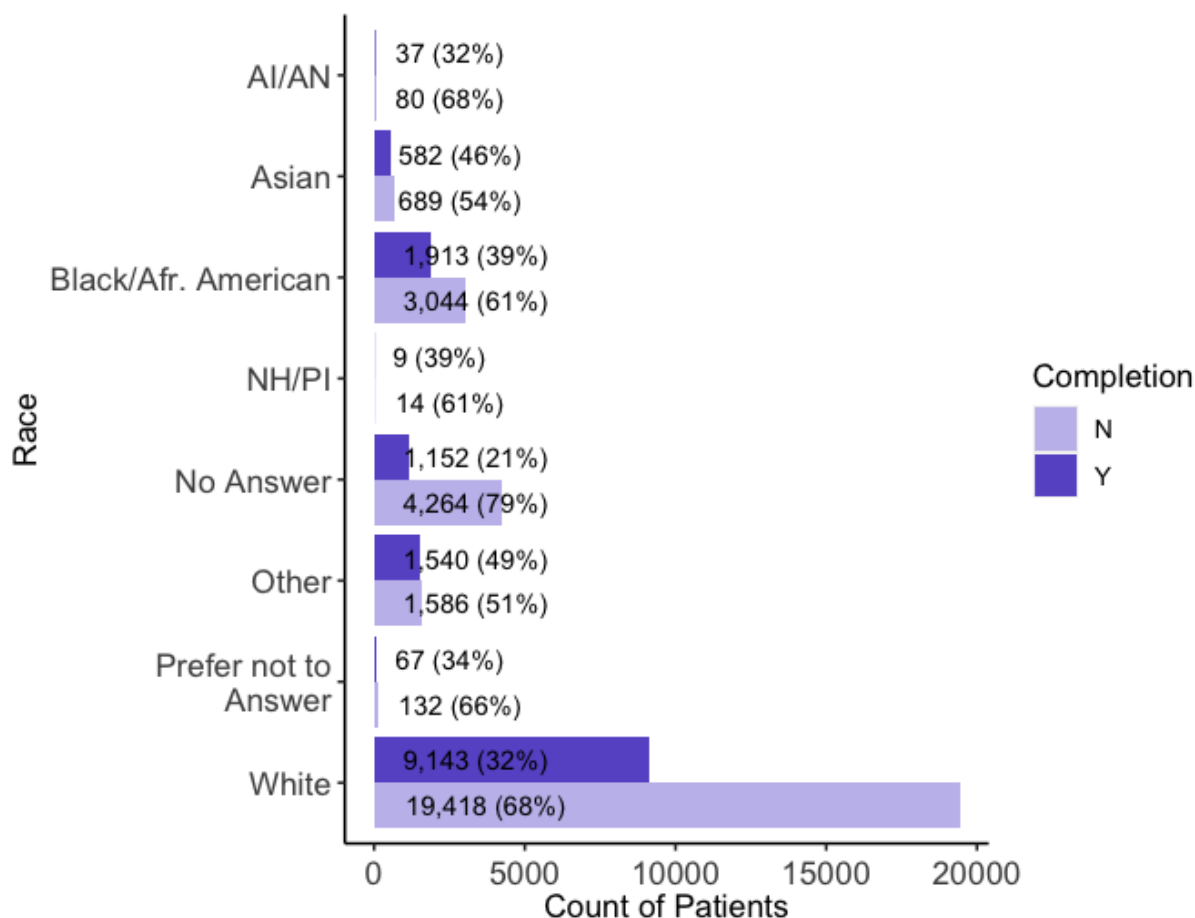


Legend: Number of patients with completed provider seizure documentation for at least 1 visit. Completed seizure documentation is defined as having completed ILAE seizure type, provider-reported seizure frequency and provider-reported date of last typical seizure. Numerator is the count of patients with a complete (all fields completed) provider seizure frequency form on any visit and denominator is the number of unique patients in the given category of ethnicity; Overall N = 43,670; Not Hispanic or Latino N = 34,875; Hispanic or Latino N = 6,753; I choose not to answer N = 1,253; Missing N = 789.





#### 4.7 Provider Seizure Frequency Form Completion: Stratified by Race



Legend: Number of patients with completed provider seizure documentation for at least 1 visit. Completed seizure documentation is defined as having completed ILAE seizure type, provider-reported seizure frequency and provider-reported date of last typical seizure. Numerator is the count of patients with a complete (all fields completed) provider seizure frequency form on any visit and denominator is the number of unique patients in the given category of ethnicity; Overall N = 43,670; American Indian or Alaskan Native N = 117; Asian N = 1,271; Black N = 4,957; Native Hawaiian or other Pacific Islander N = 23; Other N = 3,126; Prefer not to answer N = 199; White N = 28,561.

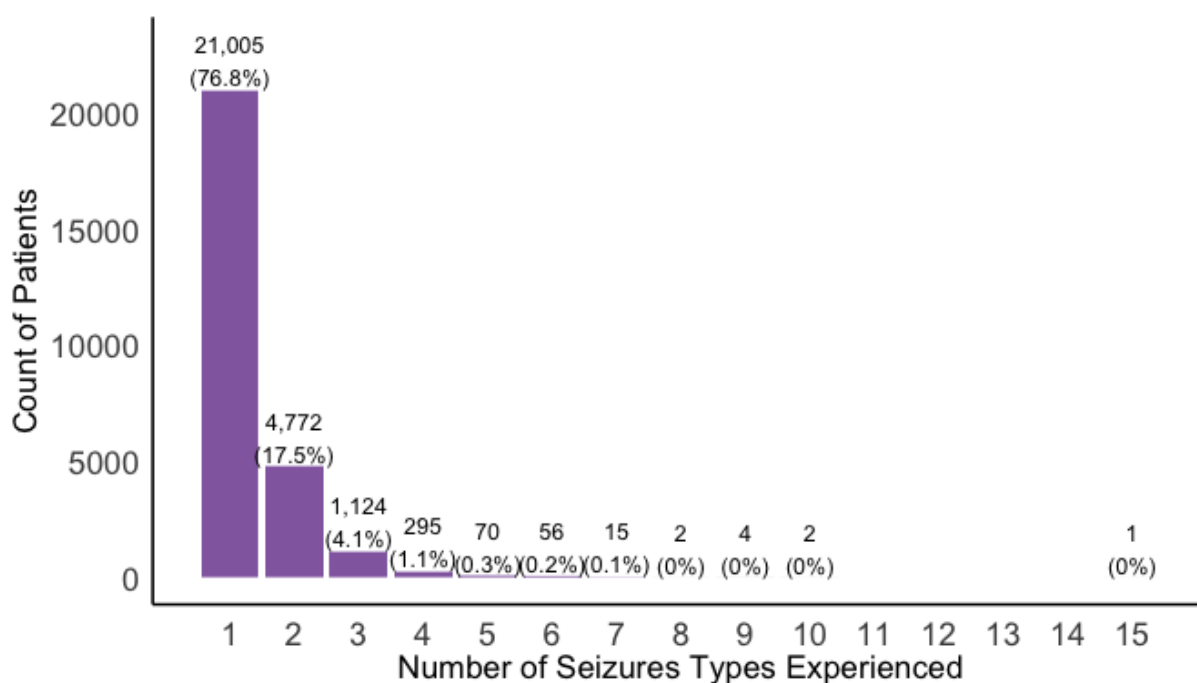
## 5 Seizure Type

A total of 90,250 seizure frequency forms were submitted, representing 27,346 unique patients. A total of 16,324 patients missing all seizure documentation.

Of the 90,250 seizure forms, 52,274 had responses for seizure frequency, 69,538 had responses for date of last seizure. For ILAE Classification, 58,430 had the field for Epileptic/Non-Epileptic completed and 46,801 had the full seizure ILAE classification completed.

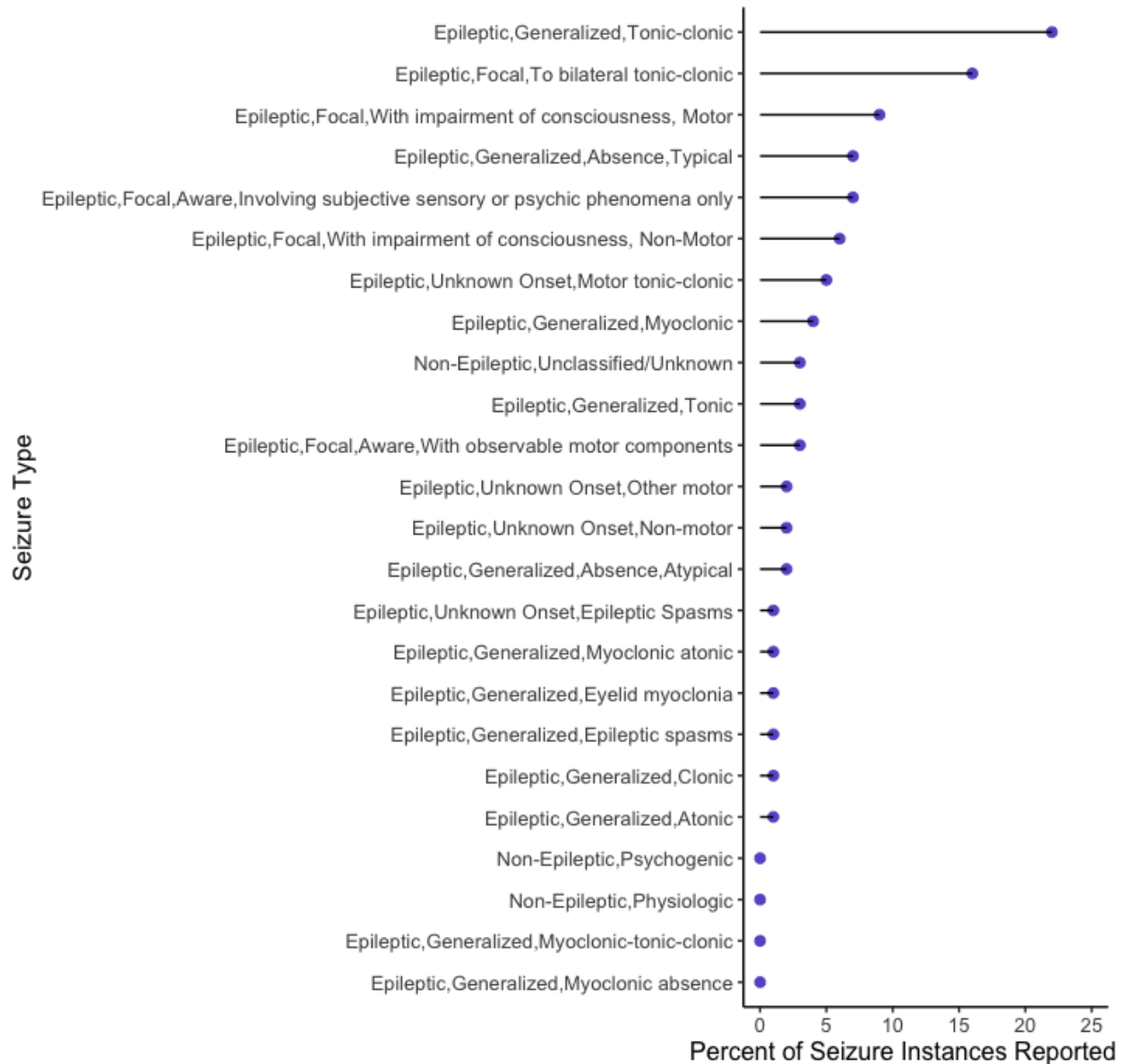
### 5.1 Number of Distinct Seizure Types for each Patient

We calculated the number of seizure types documented at a single visit for patients using the number of seizure frequency forms submitted per visit. To summarize by unique patients, we used the maximum of seizure frequency forms per visit.



Legend: N = 27,346, A total of 16,324 patients missing all seizure documentation

## 5.2 Frequency of Seizure Type out of All Documented Instances



Legend: Numerator is the count of seizure frequency forms with each Seizure ILAE Classification. Denominator is the count of all seizure frequency forms with complete (all sub-fields completed) documented ILAE classification (N = 46,801). Removed 43,449 of 90,250 rows missing complete ILAE classification.



## 5.3 Seizure ILAE Classification by Demographics

### 5.3.1 Adults >= 18 years old

	Focal Onset (N=3519)	Generalized Onset (N=1941)	Generalized & Focal Onset (N=284)	Unknown Onset (N=427)	Epileptic - No Sub Classification (N=63)	Overall (N=6234)
<b>Age (y)</b>						
Mean (SD)	43.6 (18.0)	33.2 (15.5)	38.6 (15.6)	33.0 (16.2)	26.0 (12.1)	39.3 (17.7)
Median [Min, Max]	40.0 [18.0, 96.6]	28.4 [18.0, 88.7]	34.5 [18.0, 92.1]	25.8 [18.0, 82.0]	20.5 [18.1, 66.1]	35.0 [18.0, 96.6]
<b>Sex Assigned at Birth</b>						
Male	1586 (45.1%)	833 (42.9%)	112 (39.4%)	230 (53.9%)	29 (46.0%)	2790 (44.8%)
Female	1933 (54.9%)	1108 (57.1%)	172 (60.6%)	197 (46.1%)	34 (54.0%)	3444 (55.2%)
<b>Ethnicity</b>						
Hispanic or Latino	428 (12.2%)	277 (14.3%)	33 (11.6%)	56 (13.1%)	8 (12.7%)	802 (12.9%)
Not Hispanic or Latino	2940 (83.5%)	1542 (79.4%)	232 (81.7%)	362 (84.8%)	51 (81.0%)	5127 (82.2%)
I choose not to answer	138 (3.9%)	84 (4.3%)	11 (3.9%)	7 (1.6%)	0 (0%)	240 (3.8%)
Missing	13 (0.4%)	38 (2.0%)	8 (2.8%)	2 (0.5%)	4 (6.3%)	65 (1.0%)
<b>Race</b>						
White	2779 (79.0%)	1421 (73.2%)	200 (70.4%)	303 (71.0%)	36 (57.1%)	4739 (76.0%)
Black or Afr. American	263 (7.5%)	145 (7.5%)	28 (9.9%)	60 (14.1%)	15 (23.8%)	511 (8.2%)
Asian	114 (3.2%)	72 (3.7%)	10 (3.5%)	22 (5.2%)	5 (7.9%)	223 (3.6%)
American Indian or Alaskan Native	18 (0.5%)	4 (0.2%)	2 (0.7%)	2 (0.5%)	0 (0%)	26 (0.4%)
Other	258 (7.3%)	160 (8.2%)	27 (9.5%)	32 (7.5%)	6 (9.5%)	483 (7.7%)
I choose not to answer	6 (0.2%)	5 (0.3%)	0 (0%)	0 (0%)	0 (0%)	11 (0.2%)
Missing	81 (2.3%)	134 (6.9%)	17 (6.0%)	8 (1.9%)	1 (1.6%)	241 (3.9%)

Legend: Count of adult patients >= 18 years old by seizure type and demographic variables. Percentage out of column total shown in parenthesis. Only Epileptic Seizure Types shown. Total adult population in the registry is 27,415. This report this includes 2790 male and 3444 females. The count of missing records is 21,181.



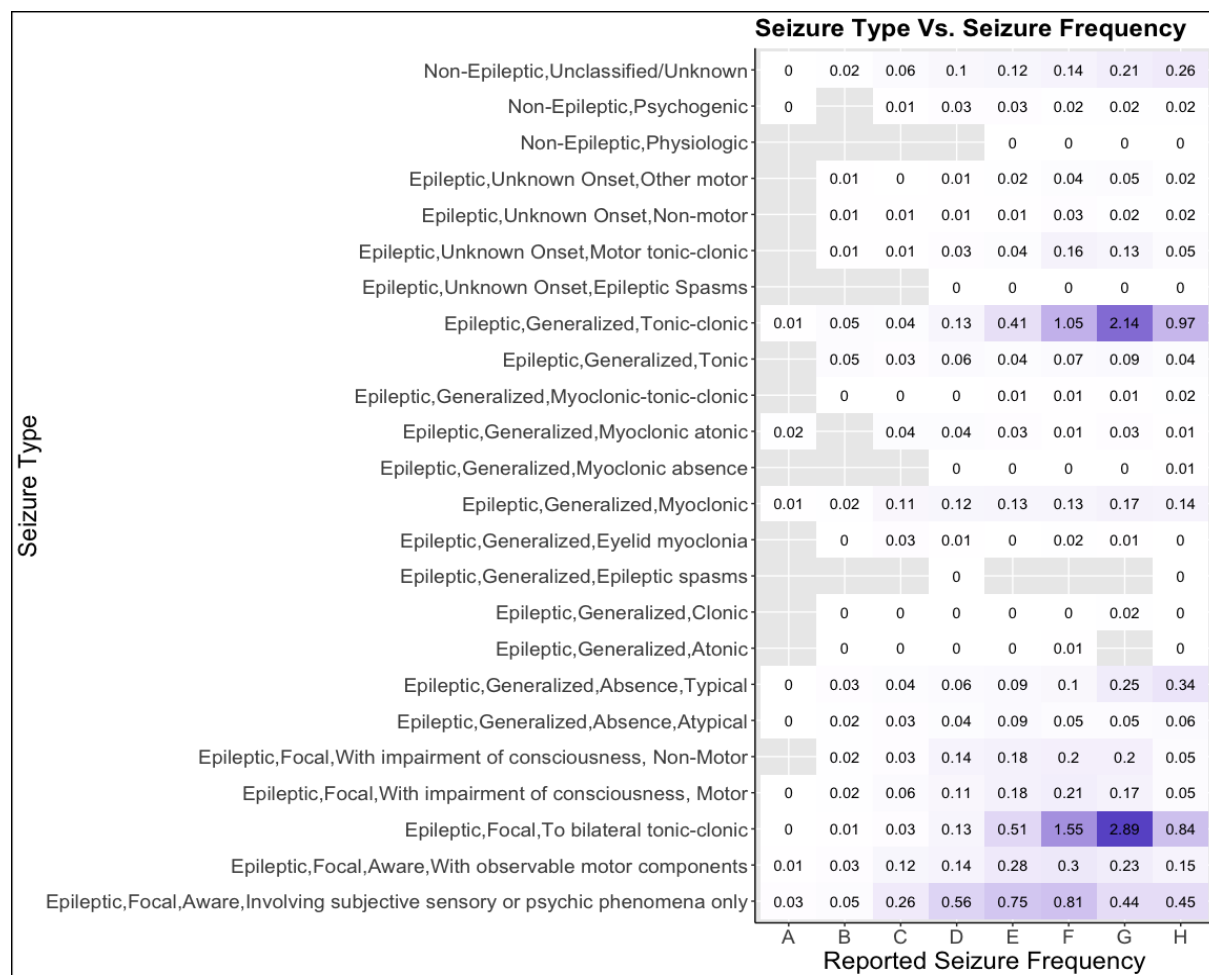
### 5.3.2 Pediatric < 18 years old

	Focal Onset (N=2240)	Generalized Onset (N=3245)	Generalized & Focal Onset (N=150)	Unknown Onset (N=1209)	Epileptic - No Sub Classification (N=376)	Overall (N=7220)
<b>Age (y)</b>						
Mean (SD)	9.46 (4.65)	10.0 (4.80)	9.13 (4.48)	9.00 (4.76)	7.99 (4.33)	9.55 (4.75)
Median [Min, Max]	9.60 [0, 17.9]	10.0 [0, 17.9]	8.05 [1.00, 17.7]	8.50 [0, 17.9]	7.35 [0.600, 17.9]	9.60 [0, 17.9]
<b>Sex Assigned at Birth</b>						
Male	1231 (55.0%)	1758 (54.2%)	89 (59.3%)	699 (57.8%)	204 (54.3%)	3981 (55.1%)
Female	1009 (45.0%)	1487 (45.8%)	61 (40.7%)	510 (42.2%)	172 (45.7%)	3239 (44.9%)
<b>Ethnicity</b>						
Hispanic or Latino	367 (16.4%)	809 (24.9%)	36 (24.0%)	200 (16.5%)	64 (17.0%)	1476 (20.4%)
Not Hispanic or Latino	1817 (81.1%)	2352 (72.5%)	107 (71.3%)	975 (80.6%)	307 (81.6%)	5558 (77.0%)
I choose not to answer	26 (1.2%)	29 (0.9%)	4 (2.7%)	12 (1.0%)	0 (0%)	71 (1.0%)
Missing	30 (1.3%)	55 (1.7%)	3 (2.0%)	22 (1.8%)	5 (1.3%)	115 (1.6%)
<b>Race</b>						
White	1260 (56.3%)	1710 (52.7%)	85 (56.7%)	646 (53.4%)	192 (51.1%)	3893 (53.9%)
Black or Afr. American	423 (18.9%)	539 (16.6%)	20 (13.3%)	255 (21.1%)	89 (23.7%)	1326 (18.4%)
Asian	106 (4.7%)	146 (4.5%)	7 (4.7%)	70 (5.8%)	16 (4.3%)	345 (4.8%)
American Indian or Alaskan Native	2 (0.1%)	8 (0.2%)	0 (0%)	4 (0.3%)	1 (0.3%)	15 (0.2%)
Other	331 (14.8%)	370 (11.4%)	20 (13.3%)	205 (17.0%)	76 (20.2%)	1002 (13.9%)
I choose not to answer	22 (1.0%)	21 (0.6%)	1 (0.7%)	17 (1.4%)	1 (0.3%)	62 (0.9%)
Missing	96 (4.3%)	451 (13.9%)	17 (11.3%)	12 (1.0%)	1 (0.3%)	577 (8.0%)

Legend: Count of pediatric patients by seizure type and demographic variables. Percentage out of column total shown in parenthesis. Only Epileptic Seizure Types shown. Total pediatric population in the registry is 14,992. This report this includes 3981 male and 3239 females. The count of missing records is 7772.

## 5.4 Seizure Frequency by Seizure ILAE Classification

### 5.4.1 Adults >= 18 years old



Legend: Seizure frequency across seizure ILAE Classification. The number in the matrix is the percent of provider-documented seizures, i.e. the number of provider-documented seizures with the corresponding seizure type and frequency out of all provider-documented seizures. Light purple indicates a lower percentage and dark purple indicates a higher percentage. N = 19,459. We removed 30,193 patients missing seizure type and seizure frequency.

Reported Seizure Frequency Group Legend	Description
A	Innumerable (≥10 per day on most days)
B	Multiple per day (4 days per week with ≥2 seizures)
C	Daily (4 or more days in the past week)
D	Weekly but not daily (1 - 3 in the past week)
E	Monthly but not weekly (1 - 3 in the past month)
F	At least once per year, but not every month (≤10 in past 12 months)
G	Less than once per year
H	Frequency not well defined

## 5.4.2 Pediatric < 18 years old

Seizure Type	Reported Seizure Frequency							
	A	B	C	D	E	F	G	H
Non-Epileptic,Unclassified/Unknown	0	0.01	0.02	0.03	0.01	0.04	0.01	0.02
Non-Epileptic,Psychogenic			0	0	0			
Non-Epileptic,Physiologic		0						0
Epileptic,Unknown Onset,Other motor		0.05	0.04	0.09	0.08	0.25	0.05	0.05
Epileptic,Unknown Onset,Non-motor		0.12	0.07	0.08	0.06	0.19	0.02	0.1
Epileptic,Unknown Onset,Motor tonic-clonic		0.04	0.03	0.07	0.16	0.71	0.09	0.13
Epileptic,Unknown Onset,Epileptic Spasms	0	0.07	0.02	0.02	0.01	0.07	0.02	0.05
Epileptic,Generalized,Tonic-clonic	0	0.22	0.11	0.25	0.3	1.01	0.86	1
Epileptic,Generalized,Tonic	0.01	0.14	0.08	0.08	0.05	0.13	0.02	0.05
Epileptic,Generalized,Myoclonic-tonic-clonic		0.01	0.01	0.01		0.01	0	0.01
Epileptic,Generalized,Myoclonic atonic	0	0.04	0.01	0.01	0.01	0.02	0.01	0.02
Epileptic,Generalized,Myoclonic absence	0	0.02	0	0.01	0.01	0.01	0.01	0.01
Epileptic,Generalized,Myoclonic	0.01	0.23	0.11	0.09	0.05	0.11	0.04	0.11
Epileptic,Generalized,Eyelid myoclonia	0.01	0.08	0.03	0.03	0.02	0.01	0	0
Epileptic,Generalized,Epileptic spasms		0.11	0.03	0.02	0.02	0.04	0.01	0.05
Epileptic,Generalized,Clonic	0	0.01	0	0.01	0.01	0.07	0.01	0.01
Epileptic,Generalized,Atonic		0.1	0.04	0.03	0.02	0.07	0.02	0.05
Epileptic,Generalized,Absence,Typical	0.02	0.37	0.14	0.13	0.09	0.24	0.09	0.18
Epileptic,Generalized,Absence,Atypical		0.13	0.03	0.04	0.04	0.08	0.03	0.05
Epileptic,Focal,With impairment of consciousness, Non-Motor		0.13	0.06	0.22	0.26	0.6	0.09	0.14
Epileptic,Focal,With impairment of consciousness, Motor	0	0.21	0.1	0.23	0.34	0.97	0.18	0.19
Epileptic,Focal,To bilateral tonic-clonic	0	0.03	0.04	0.11	0.18	0.58	0.29	0.26
Epileptic,Focal,Aware,With observable motor components	0	0.02	0.01	0.03	0.05	0.07	0.04	0.04
Epileptic,Focal,Aware,Involving subjective sensory or psychic phenomena only	0	0	0.01	0.02	0.02	0.04	0.02	0.03

Legend: Seizure frequency across seizure ILAE Classification. The number in the matrix is the percent of provider-documented seizures, i.e. the number of provider-documented seizures with the corresponding seizure type and frequency out of all provider-documented seizures. Light purple indicates a lower percentage and dark purple indicates a higher percentage. N = 14,755. We removed 24,716 rows missing seizure type and seizure frequency

Reported Seizure Frequency Group Legend	Description
A	Innumerable ( $\geq 10$ per day on most days)
B	Multiple per day (4 days per week with $\geq 2$ seizures)
C	Daily (4 or more days in the past week)
D	Weekly but not daily (1 - 3 in the past week)
E	Monthly but not weekly (1 - 3 in the past month)
F	At least once per year, but not every month ( $\leq 10$ in past 12 months)
G	Less than once per year
H	Frequency not well defined

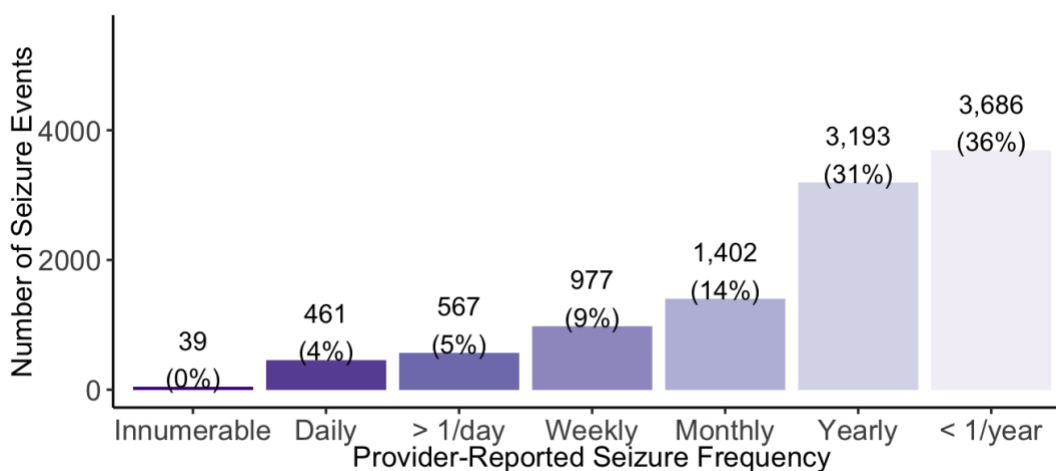


## 6 Provider Reported Seizure Control

### 6.1 Provider-Reported Seizure Frequency

More Frequent

Less Frequent



Seizure Frequency Category	Number of Seizure Events (all forms) (N = 27,346 unique patients)	Number of Seizure Events (using forms from most recent visit)
Innumerable ( $\geq 10$ per day on most days)	391	39
Multiple per day (i.e., 4 days per week with $\geq 2$ seizures)	3386	567
Daily (i.e., 4 or more days in the past week)	3029	461
Weekly but not daily (i.e., 1 - 3 in the past week)	5672	977
Monthly but not weekly (i.e., 1 - 3 in the past month)	7302	1402
At least once per year, but not every month (i.e., 10 or fewer in past 12 months)	12052	3193
Less than once per year	11868	3686
Frequency not well defined	8574	2686
Unknown	9645	1990
Missing	28331	3646
<b>Total</b>	<b>90,250</b>	<b>18,647 (excluding Frequency not well defined, unknown and missing N = 10,325)</b>

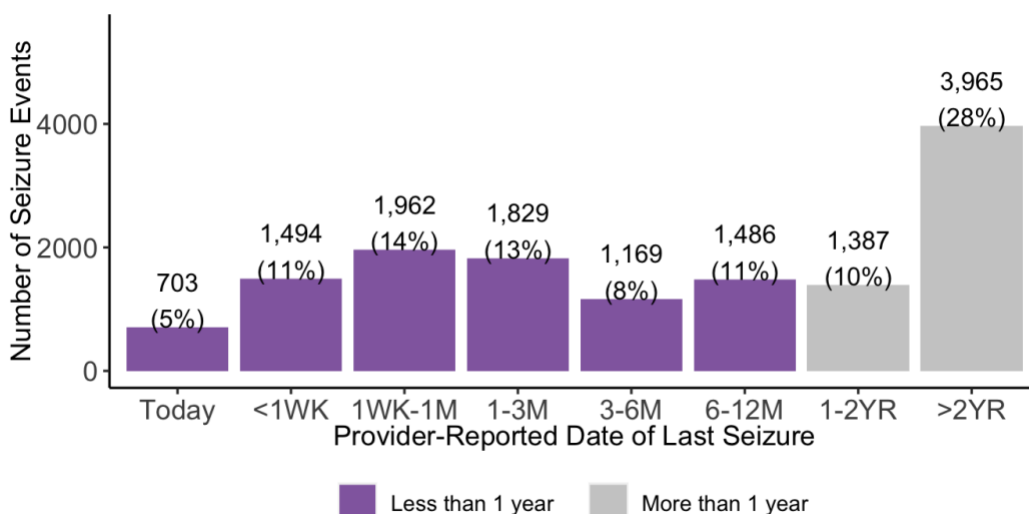




## 6.2 Provider-Reported Date of Last Seizure

More Recent

Less Recent



Legend: Provider-Reported Date of Last Seizure. 2 = More than 1 to 6 days ago, 3 = More than 1 week to 4 weeks ago, 5 = More than 3 months to 6 months ago, 6 = More than 6 months to 12 months ago, 7 = More than 1 year to 2 years ago, 8 = More than 2 years ago. A total of 4,652 individuals had responses “Unknown”, “Decline to Answer” or were missing response to data of last seizure.

Seizure Frequency Category	Number of Seizure Events (all forms) (N = 27,346 unique patients)	Number of Seizure Events (using forms from most recent visit)
Today	4616	703
More than 1 day to 6 days ago	9893	1494
More than 1 week to 4 weeks ago	10825	1962
More than 1 month to 3 months ago	8908	1829
More than 3 months to 6 months ago	6094	1169
More than 6 months to 12 months ago	6950	1486
More than 1 year to 2 years ago	6569	1387
More than 2 years ago	15502	3965
Decline to answer	181	25
Unknown	7000	1180
Missing	13712	3447
Total	<b>90,250</b>	<b>18,647 (excluding Frequency not well defined, unknown and missing N = 13,995)</b>



## 6.3 Provider-Reported Seizure Control by ILAE Classification

### 6.3.1 Adults >= 18

ILAE Classification	Percent	Less than 1 Year Ago	More than 1 Year Ago	Unknown/Decline to Answer	Total
<b>Focal Onset</b>					
Focal aware, without impairment of consciousness	22%	1,036	295	22	1,353
Focal with impairment of consciousness	30%	1,323	567	45	1,935
Focal to bilateral tonic-clonic	47%	1,093	963	16	2,072
No sub-classification	12%	76	10	30	116
<b>Generalized Onset</b>					
Absence, atypical	19%	108	25	0	133
Absence, typical	39%	228	148	17	393
Atonic	7%	13	1	2	16
Clonic	6%	62	4	0	66
Epileptic spasms	40%	3	2	0	5
Eyelid myoclonia	21%	23	6	0	29
Myoclonic	24%	284	92	9	385
Myoclonic absence	33%	6	3	0	9
Myoclonic atonic	31%	25	11	0	36
Myoclonic-tonic-clonic	40%	12	8	0	20
Tonic	22%	136	38	4	178
Tonic-clonic	40%	1,182	775	30	1,987
No sub-classification	33%	30	15	9	54
<b>Unknown Onset</b>					
Unknown Onset, Non-motor	40%	32	21	6	59
Unknown Onset Motor tonic-clonic	41%	140	96	8	244
Unknown Onset, Other motor	45%	45	37	5	87
Unknown Onset, Epileptic Spasms	30%	7	3	0	10
No sub-classification	21%	84	23	10	117

Legend: Number of Patients with and without a seizure in the past 12 months for each ILAE classification. Using only provider-reported information from the patient's most recent visit. Patients may have more than 1 documented seizure sub type and therefore may be counted more than 1 time.



### 6.3.2 Pediatric Patients <18

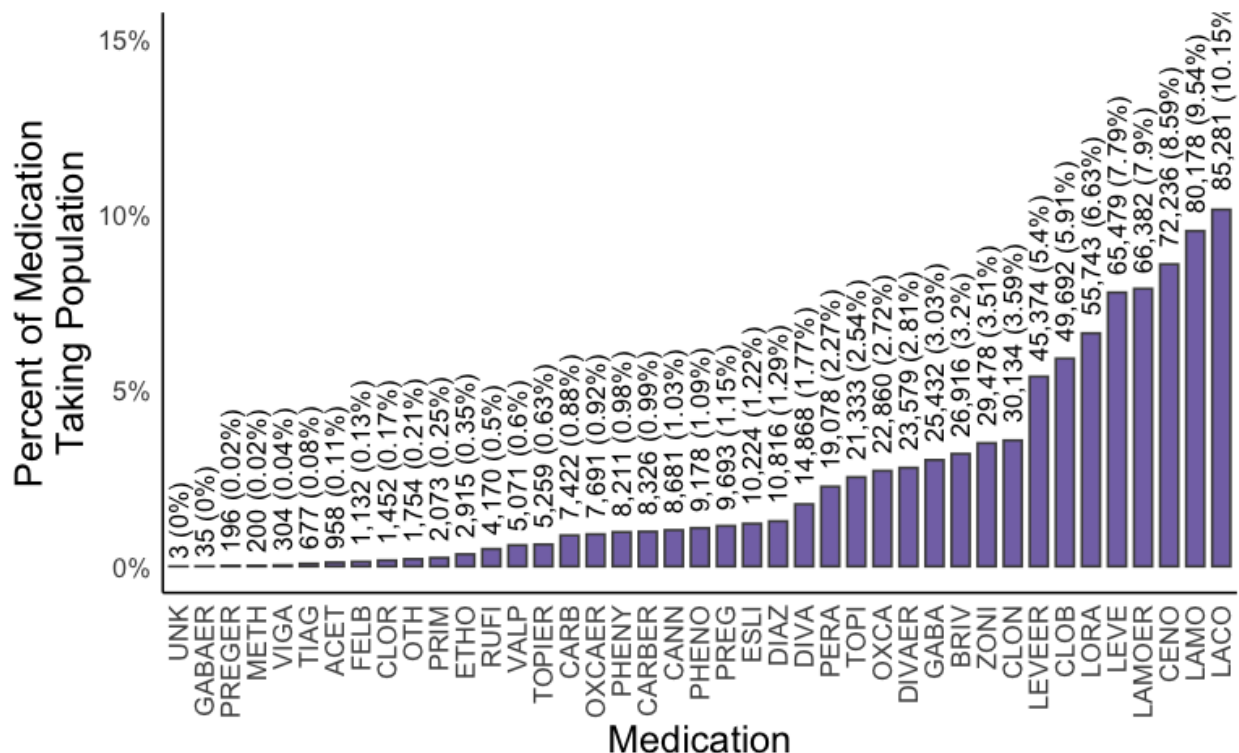
ILAE Classification	Percent	Less than 1 Year Ago	More than 1 Year Ago	Unknown/Decline to Answer	Total
<b>Focal Onset</b>					
Focal aware, without impairment of consciousness	28%	171	68	3	242
Focal with impairment of consciousness	28%	845	335	98	1,278
Focal to bilateral tonic-clonic	35%	431	232	2	665
No sub-classification	22%	113	32	268	413
<b>Generalized Onset</b>					
Absence, atypical	23%	150	44	24	218
Absence, typical	27%	422	160	62	644
Atonic	21%	106	29	10	145
Clonic	23%	37	11	3	51
Epileptic spasms	17%	97	20	7	124
Eyelid myoclonia	4%	71	3	5	79
Myoclonic	17%	273	55	11	339
Myoclonic absence	16%	27	5	1	33
Myoclonic atonic	30%	30	13	1	44
Myoclonic-tonic-clonic	25%	15	5	2	22
Tonic	17%	196	40	6	242
Tonic-clonic	31%	1,404	618	208	2,230
No sub-classification	50%	2	2	51	55
<b>Unknown Onset</b>					
Unknown Onset, Non-motor	27%	154	57	17	228
Unknown Onset Motor tonic-clonic	20%	487	119	48	654
Unknown Onset, Other motor	23%	191	56	29	276
Unknown Onset, Epileptic Spasms	36%	49	27	4	80
No sub-classification	14%	18	3	52	73

Legend: Number of Patients with and without a seizure in the past 12 months for each ILAE classification. Using only provider-reported information from the patient's most recent visit. Patients may have more than 1 documented seizure sub type and therefore may be counted more than 1 time.

## 7 Medications

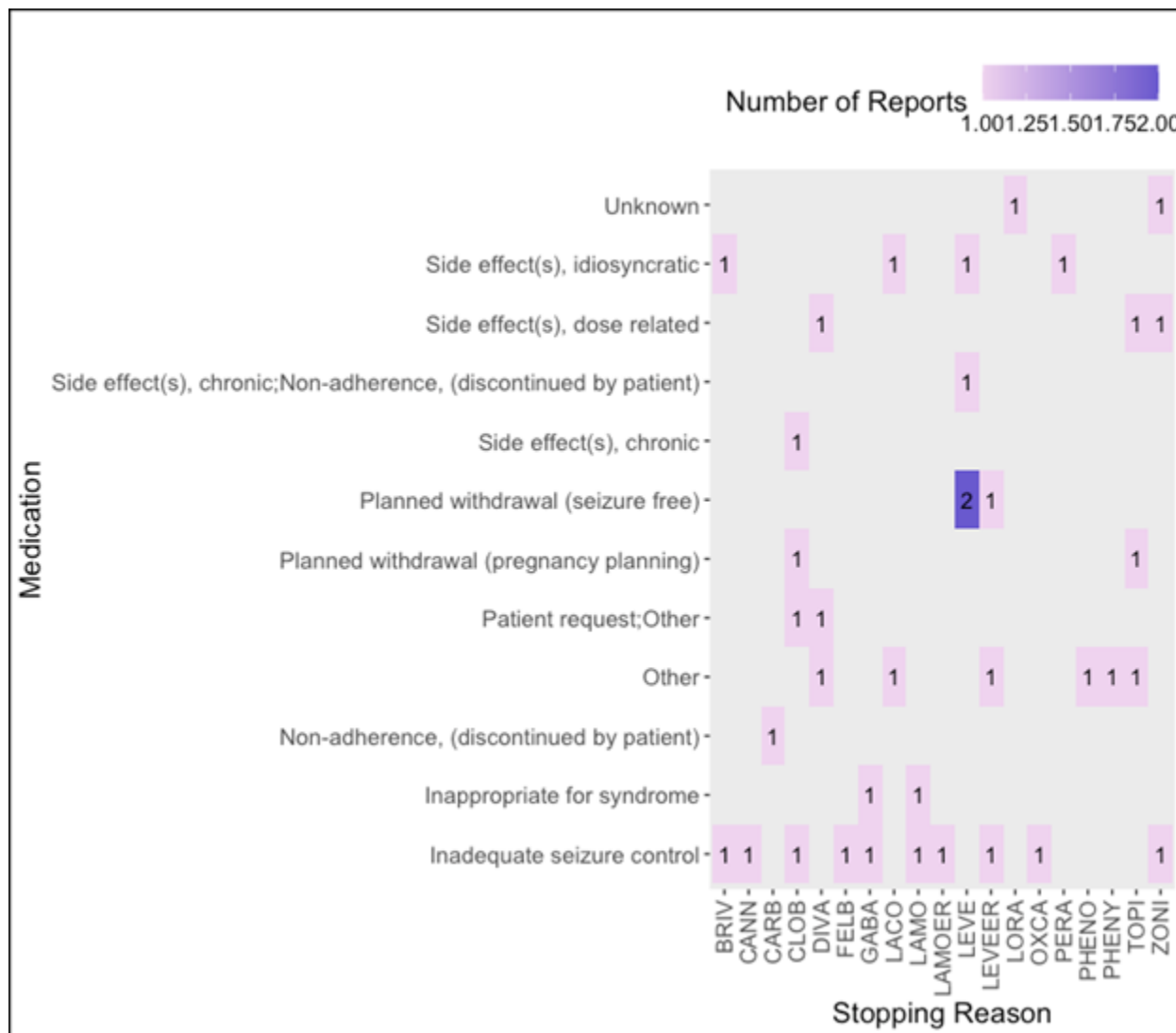
Of the 840,484 instances of medication noted, how often was each medication prescribed

### 7.1 Population Distribution of Medications



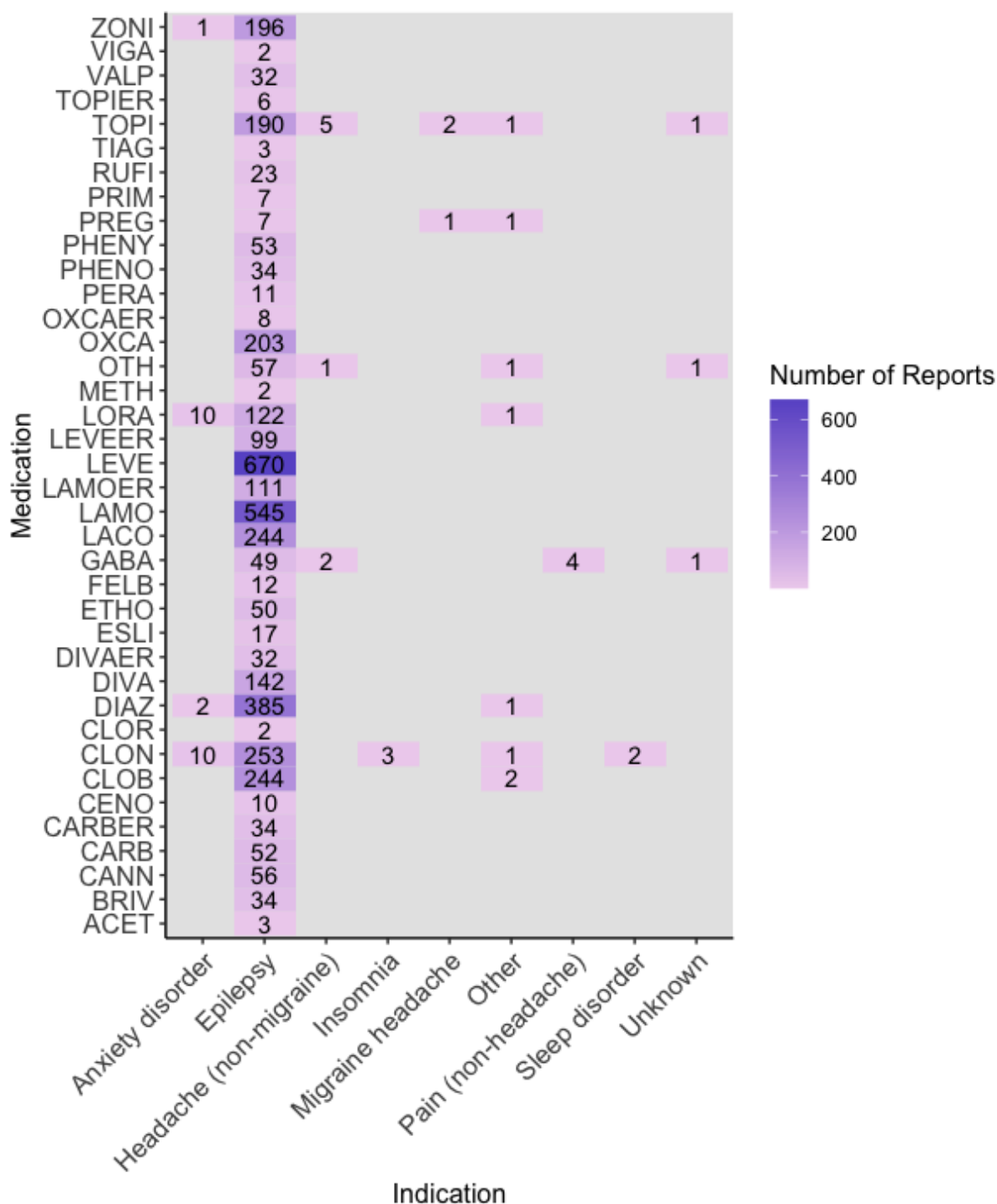
Legend: This graph shows the distribution of medication by collecting prescription data from each visit. Note that the same patient may appear multiple times across different visits records. The graph displays the total number of prescriptions and the percentage for each medication

## 7.2 Medications stopped due to adverse effects



Legend: Reason why Anti-seizure Medications was stopped stratified by medicine. The text in the box shows the number of reports for the corresponding stopping reason and medication. Darker purple indicates a higher number of reports.

### 7.3 Indication for Starting Medication

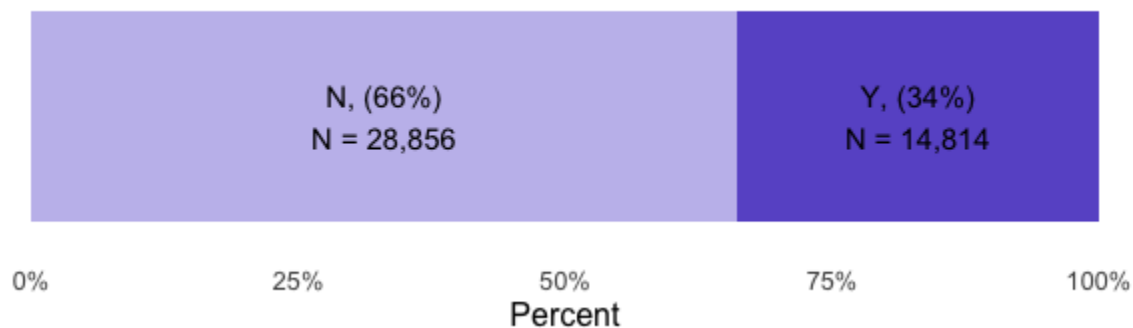


Legend: Indication for Anti-seizure Medications stratified by medicine. The text in the box shows the number of reports for the corresponding indication and medication. Darker purple indicates a higher number of reports.



## 8 Patient-Reported Seizure Documentation Completion

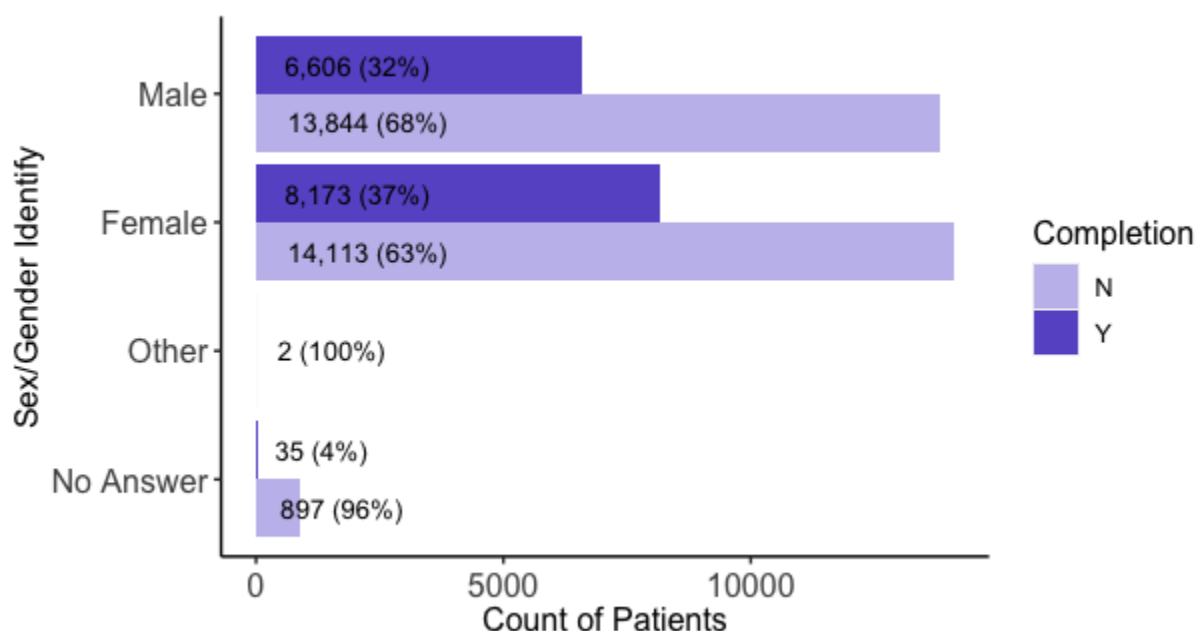
### 8.1 Patients with completed seizure documentation



Legend: Number of patients with completed patient-reported seizure documentation for at least 1 visit. Completed seizure documentation is defined as having patient-reported seizure frequency or patient-reported date of last typical seizure.



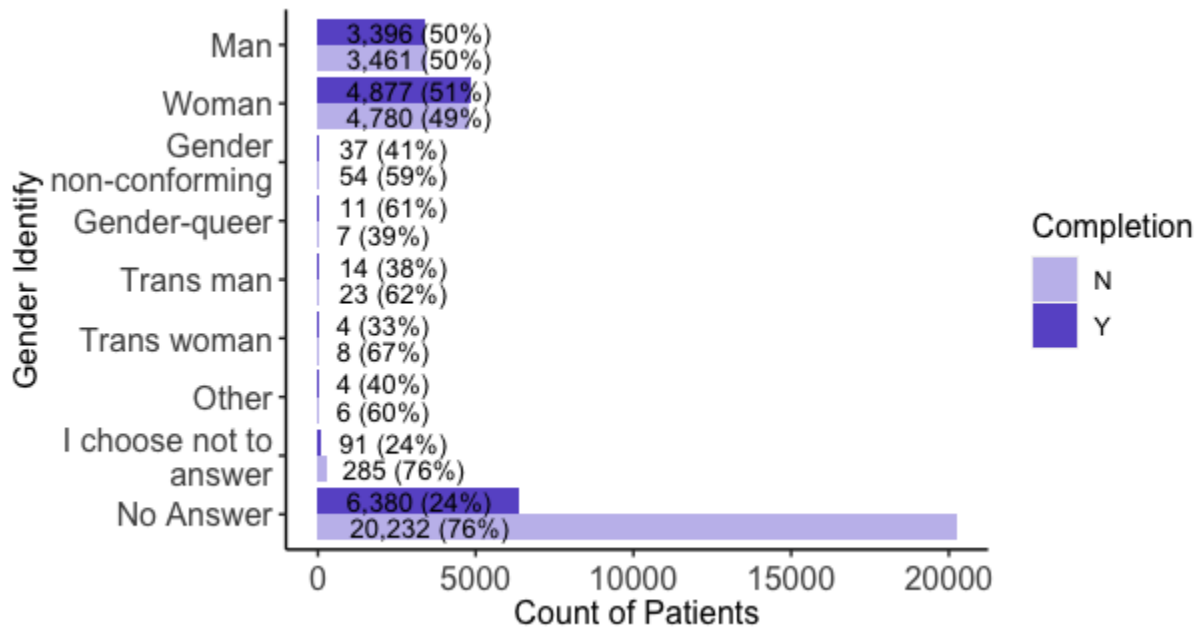
## 8.2 Patient Seizure Frequency Form Completion: Stratified by Sex



Legend: Number of patients with completed patient seizure documentation for at least 1 visit. Completed seizure documentation is defined as having completed patient-reported seizure frequency and patient-reported date of last typical seizure. Numerator is the count of patients with a complete (all fields completed) patient seizure frequency form on any visit and denominator is the number of unique patients in the given category of sex assigned at birth; Overall N = 43,670; Female N = 22,286, Male N = 20,450, Other N = 2, and Missing N = 932. This chart indicates the number of patients with at least one complete provider seizure frequency form.



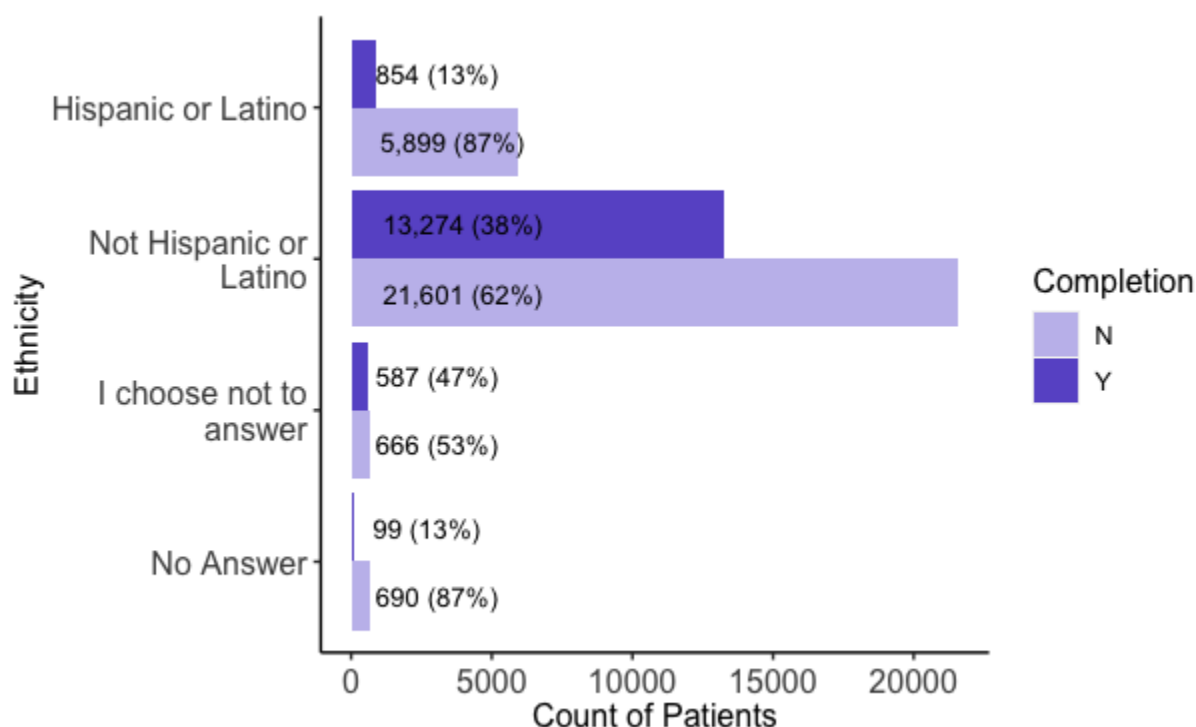
### 8.3 Patient Seizure Frequency Form Completion: Stratified by Gender Identity/Sex



Legend: Number of patients with completed patient seizure documentation for at least 1 visit. Completed seizure documentation is defined as having completed patient-reported seizure frequency and patient-reported date of last typical seizure. Numerator is the count of patients with a complete (all fields completed) patient seizure frequency form on any visit and denominator is the number of unique patients in the given category of sex assigned at birth; Overall N = 43,670; Woman N = 9,657, Man N = 6,857, Gender non-conforming N = 91, Gender queer N = 18, Transgender man N = 37, Transgender female N = 12, Other N = 10, I choose not to answer N = 376 and Missing N = 26,612. This chart indicates the number of patients with at least one complete provider seizure frequency form.



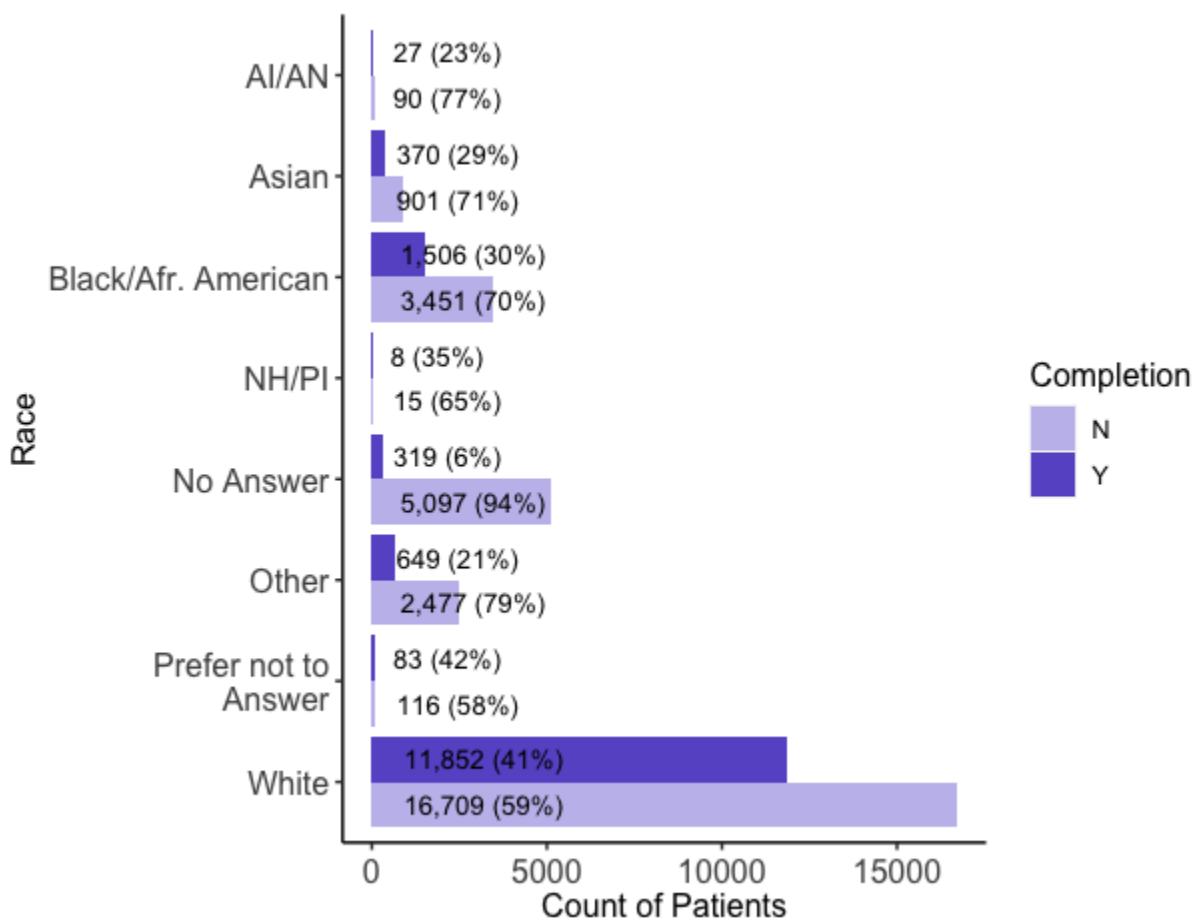
#### 8.4 Patient Seizure Frequency Form Completion: Stratified by Ethnicity



Legend: Number of patients with completed patient seizure documentation for at least 1 visit. Completed seizure documentation is defined as having completed patient-reported seizure frequency and patient-reported date of last typical seizure. Numerator is the count of patients with a complete (all fields completed) patient seizure frequency form on any visit and denominator is the number of unique patients in the given category of sex assigned at birth; Overall N = 43,670; Not Hispanic or Latino N = 34,875; Hispanic or Latino N = 6,753; I choose not to answer N = 1,253; Missing N = 789.



## 8.5 Patient Seizure Frequency Form Completion: Stratified by Race

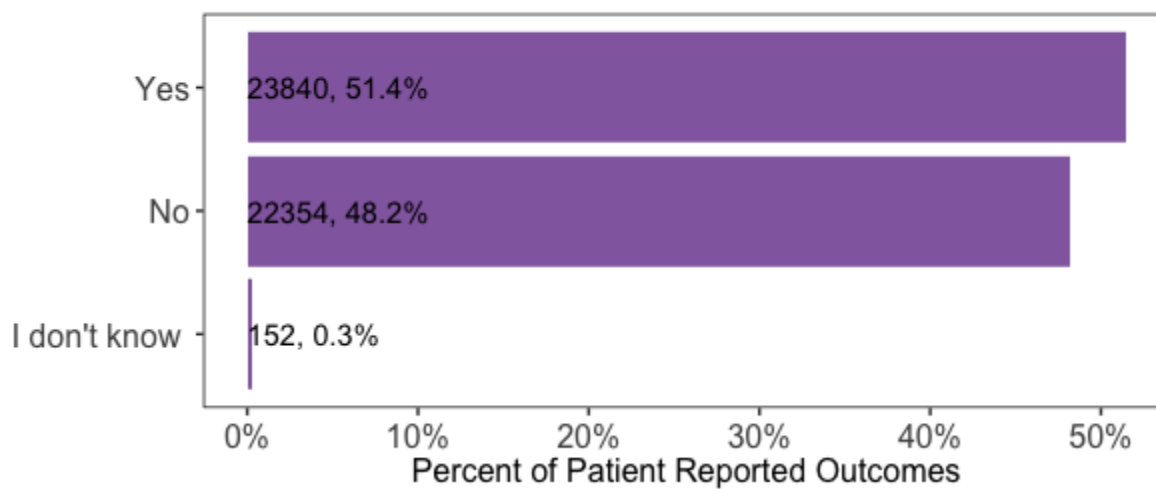


Legend: Number of patients with completed patient seizure documentation for at least 1 visit. Completed seizure documentation is defined as having completed patient-reported seizure frequency and patient-reported date of last typical seizure. Numerator is the count of patients with a complete (all fields completed) patient seizure frequency form on any visit and denominator is the number of unique patients in the given category of sex assigned at birth; Overall N = 43,670; American Indian or Alaskan Native N = 117; Asian N = 1,271; Black N = 4,957; Native Hawaiian or other Pacific Islander N = 23; Other N = 3,126; Prefer not to answer N = 199; White N = 28,561.



## 9 Patient Reported Outcomes

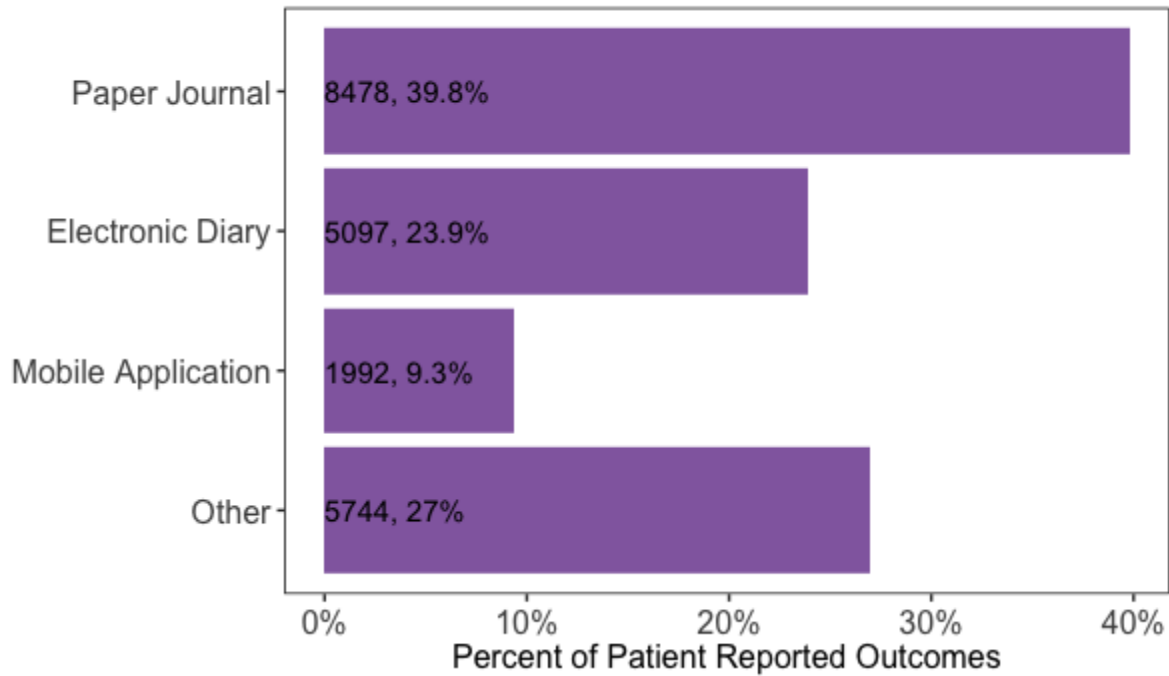
### 9.1 Patient Reported Seizure Documentation (Yes/No/IDK)



N = 46,346. There were 20,242 out of 66,588 patient reported outcomes forms missing responses.



## 9.2 Patient Reported Seizure Documentation Type

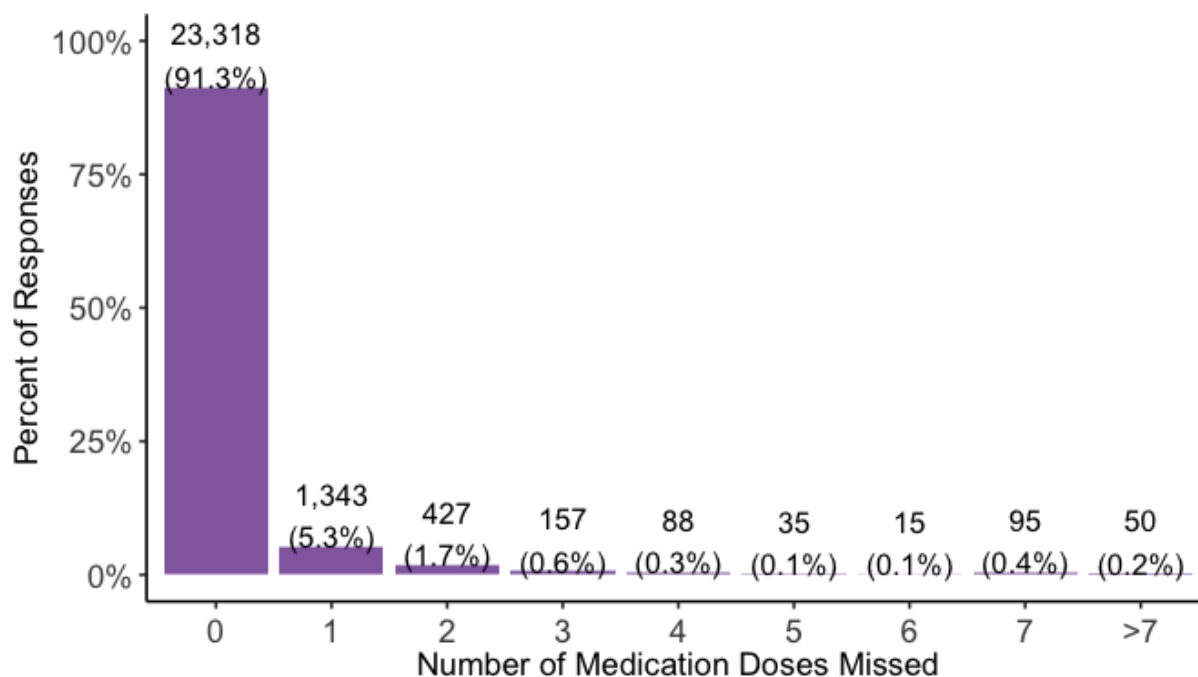


N = 21,311. There were 45,277 out of 66,588 patient reported outcomes forms missing responses.



### 9.3 Patient Reported Medication Adherence

In the past week, I/(my child) has missed \_\_\_\_\_ doses of the anti-seizure medicine

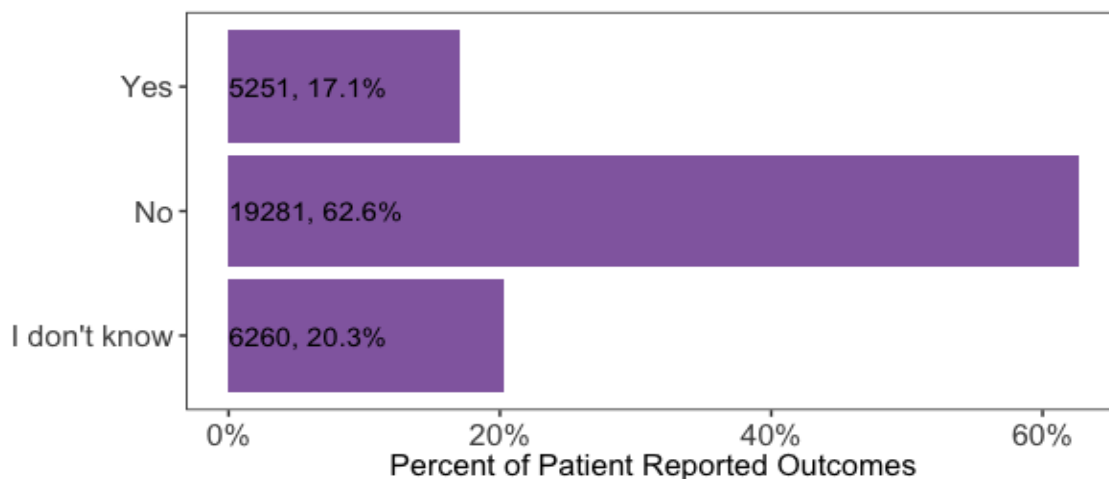


N = 25,528. There were 41,060 out of 66,588 patient reported outcomes forms missing responses.



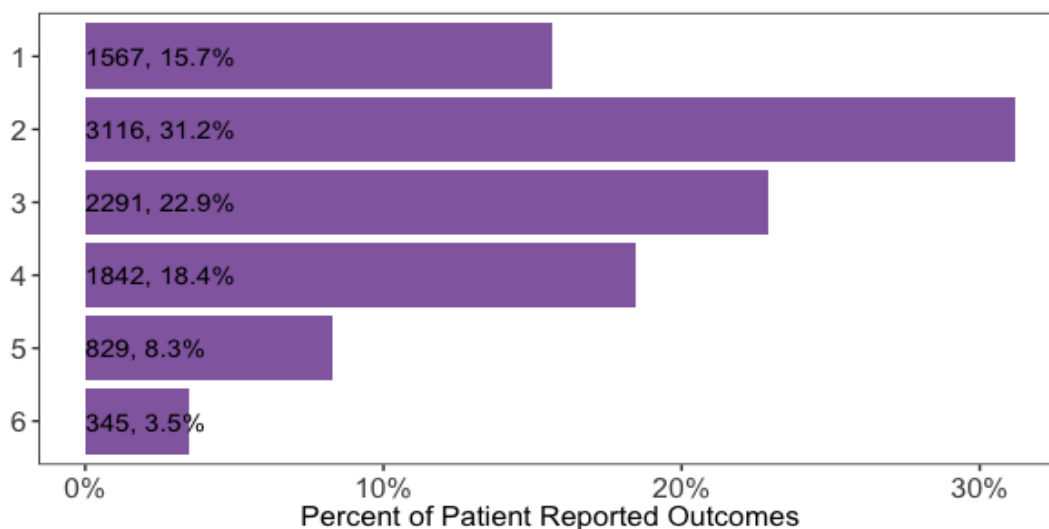
## 9.4 Patient-Report Medication Side Effects

Are you having any problems that you think are side effects of your medication?



N = 30,792. There were 35,796 out of 66,588 patient reported outcomes forms missing responses.

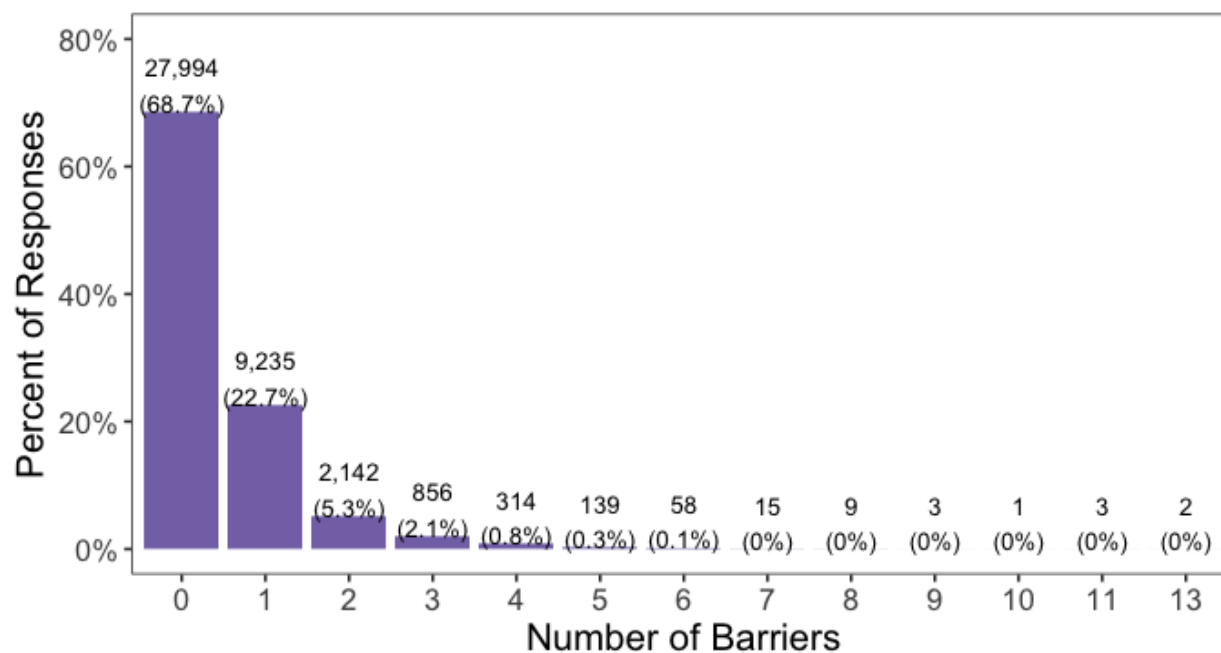
Please rate the severity of the side effects you/your child have experienced from your epilepsy medicine in the past month.



Legend: N = 9,990. There were 56,598 out of 66,588 patient reported outcomes forms missing responses.

## 9.5 Patient-Reported Barriers to Medication Adherence

### 9.5.1 Number of Barriers Reported per Patient

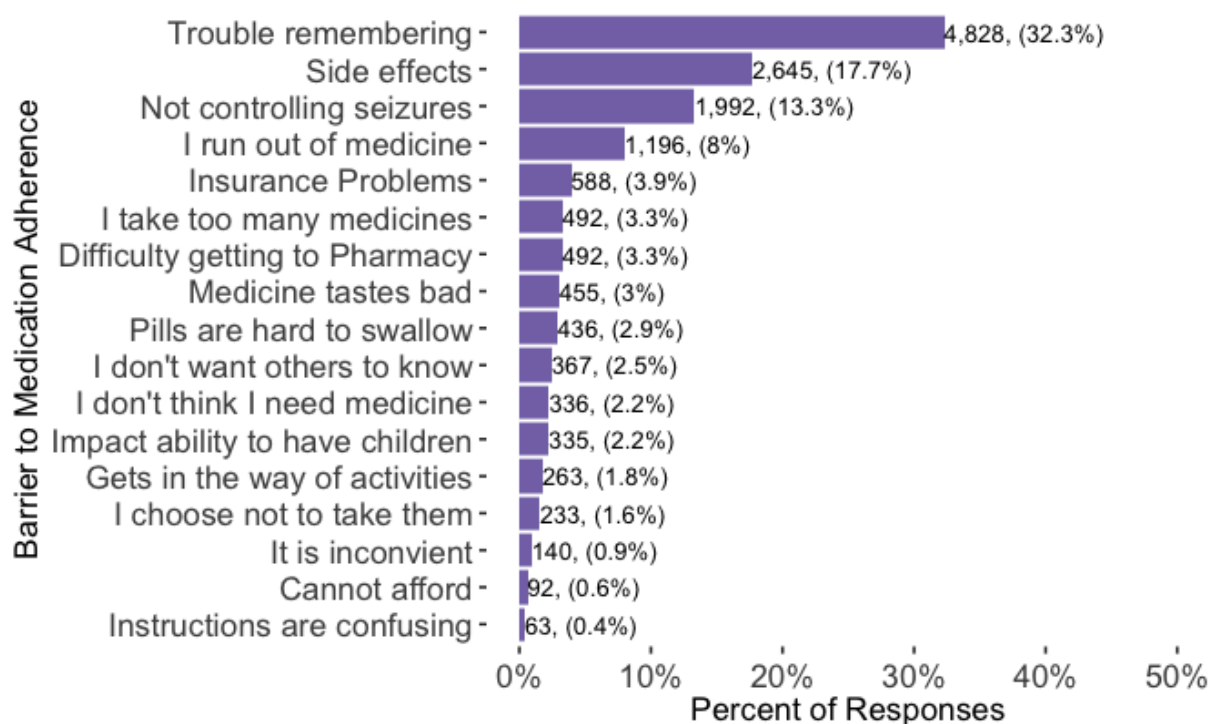


N = 40,771





### 9.5.2 Frequency of Barriers Reported



Legend: N = 14,953, note that patients can report more than one barrier per form



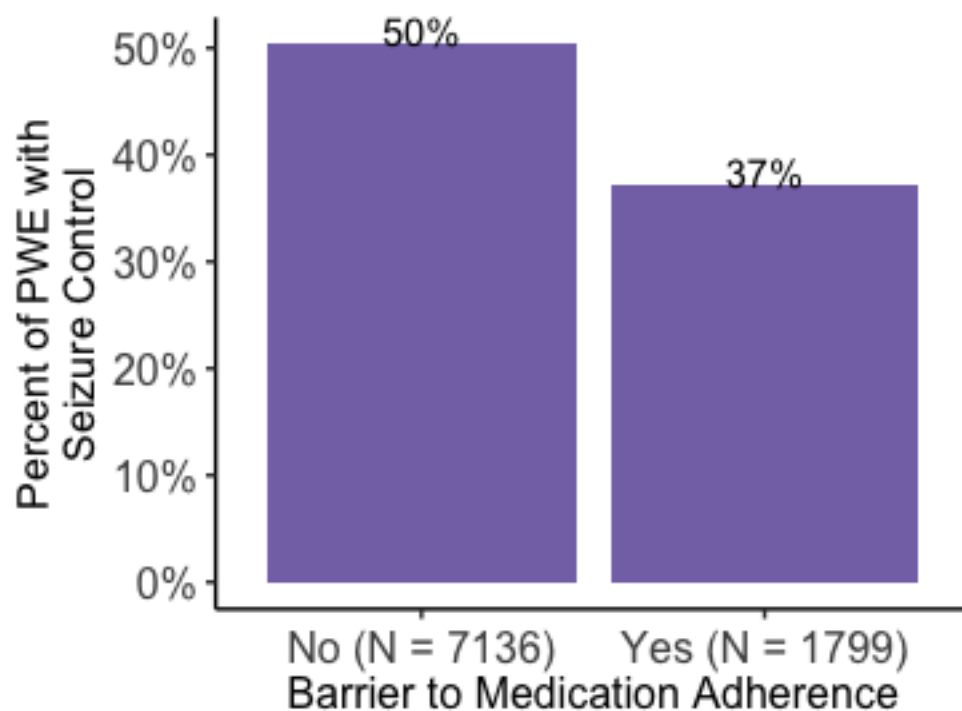
### 9.5.3 Medication Side Effects and Barriers to Medication Adherence x Seizure Control

	Less than 1 Year Ago (N=7008)	More than 1 Year Ago (N=5270)	I dont know/Decline to Answer (N=1504)	No Answer (N=11664)	Overall (N=25446)
<b>Experiencing Medication Side Effects</b>					
Yes	742 (10.6%)	257 (4.9%)	95 (6.3%)	75 (0.6%)	1169 (4.6%)
No	1651 (23.6%)	1756 (33.3%)	388 (25.8%)	1827 (15.7%)	5622 (22.1%)
I don't know	755 (10.8%)	413 (7.8%)	152 (10.1%)	86 (0.7%)	1406 (5.5%)
No Answer	3858 (55.1%)	2844 (54.0%)	869 (57.8%)	9676 (83.0%)	17247 (67.8%)
Missing	2 (0.0%)	0 (0%)	0 (0%)	0 (0%)	2 (0.0%)
<b>Barriers in Taking Seizures Medication</b>					
Yes	1132 (16.2%)	667 (12.7%)	163 (10.8%)	2528 (21.7%)	4490 (17.6%)
None	3543 (50.6%)	3593 (68.2%)	728 (48.4%)	3373 (28.9%)	11237 (44.2%)
Missing	2333 (33.3%)	1010 (19.2%)	613 (40.8%)	5763 (49.4%)	9719 (38.2%)

Legend: Using Patient Reported Outcome's from Patients Last Visit



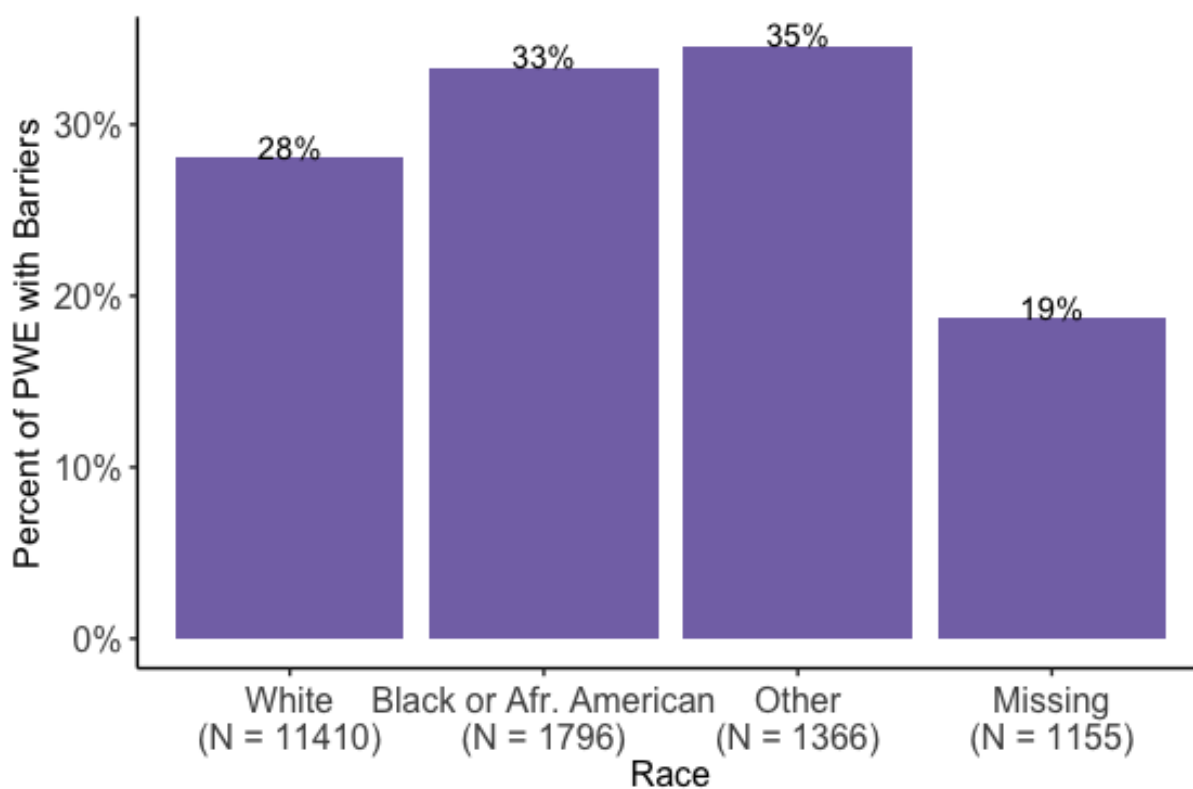
#### 9.5.4 Patient Reported Seizure Control by Barriers to Medication Adherence



Legend: N = 8,935, Using Patient Reported Outcome's from Patients Last Visit



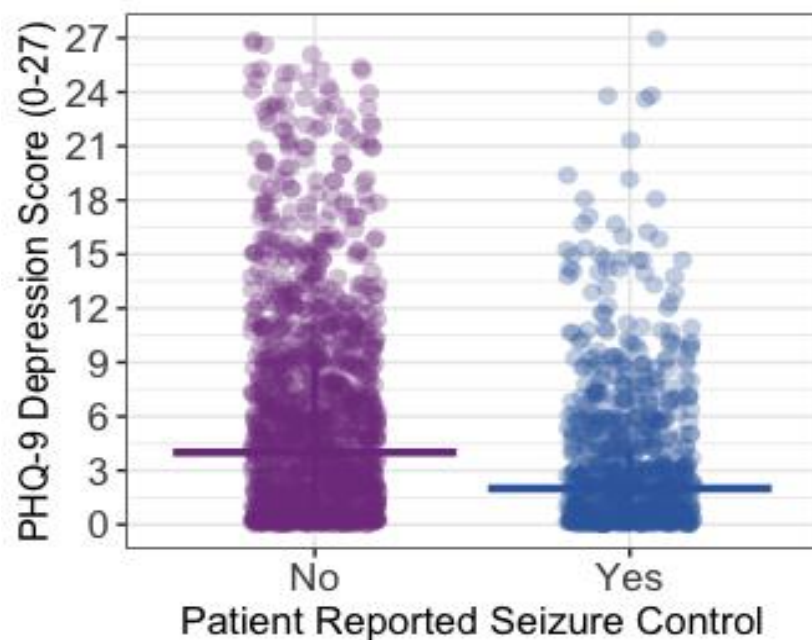
### 9.5.5 Patient Reported Barriers to Medication Adherence by Race



Legend: N = 15,727 Using Patient Reported Outcome's from Patients Last Visit

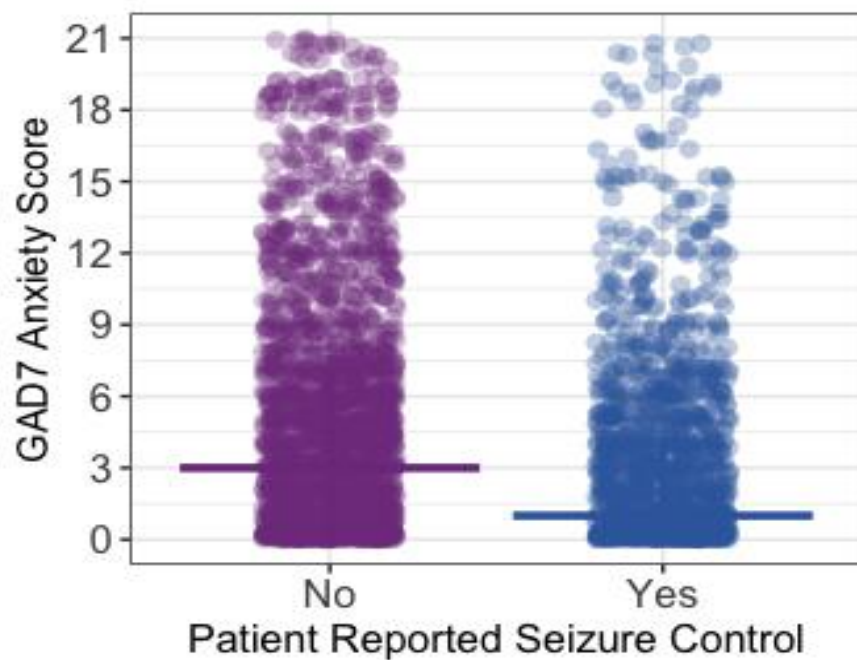
## 10 Patient Reported Mental Health

### 10.0.1 Patient Reported PHQ-9 Depression Score by Seizure Control



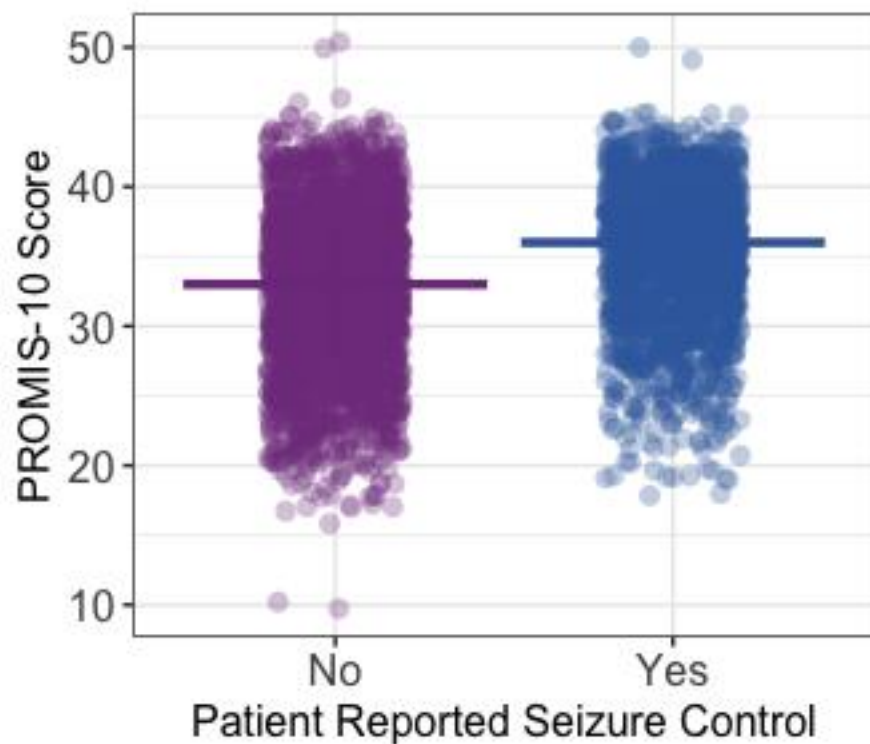
Legend: Scores 0-4 = None to Minimal, score 5-9 = Mild, score 10-14 = Moderate, score 15-19 = Moderately Severe, score 20-27 = Severe

### 10.0.2 Patient Reported GAD-7 Anxiety Score by Seizure Control



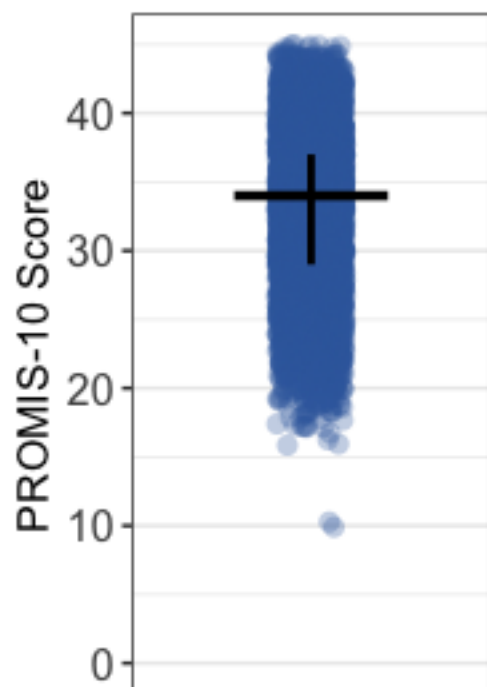
Legend: Scores 0-4 = Minimal, score 5-9 = Mild, score 10-14 = Moderate, score greater than 15 = Severe

### 10.0.3 Patient Reported PROMIS-10 Score by Seizure Control



Legend: Scores 16-30 = Severe, score 30-40 = Moderate, score 40-45 = Mild; 45-68 = Within normal limits

#### 10.0.4 Patient Reported PROMIS-10 (Adults $\geq 18$ ) Score



#### 10.0.5 Patient Reported NDDI-E Score by Seizure Control

