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## BACKGROUND

- Huntington's disease (HD) is a rare, and ultimately fatal, hereditary neurodegenerative disorder affecting approximately 41,000 patients in the United States (US) and has no cure.<sup>1,4</sup>
- Chorea is commonly the first symptom of HD that leads to a diagnosis; it is characterized by sudden, irregular, and non-stereotyped involuntary movements.<sup>1,4</sup>
- HD results in a significant burden of disease and healthcare resource utilization (HCRU).<sup>5,6</sup>
- The recommended care model for patients with HD involves a team of healthcare providers. However, patients with HD are diagnosed and managed by a variety of provider types, and it is unclear what the most common diagnosing provider type is for patients with HD in the real world. Further, it is unclear how diagnosing provider type may affect HCRU, cost, or treatment pathways.

## OBJECTIVE

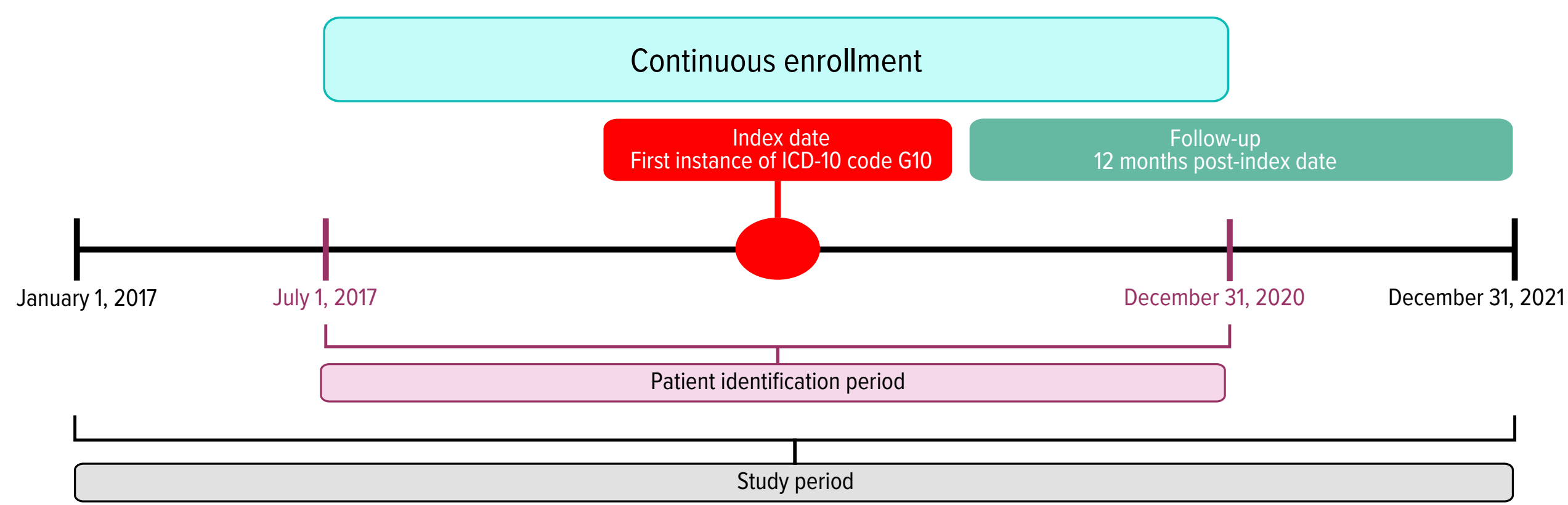
- To understand the association between type of provider of diagnosing patients with newly diagnosed HD and HCRU, cost, and treatment patterns.

## METHODS

### Study design and data source

- We performed a retrospective, cross-sectional analysis of data from the Merative MarketScan<sup>®</sup> Commercial Claims database.
  - Study period: January 1, 2017, to December 31, 2021 (Figure 1)
- Index date: The first date of an outpatient or inpatient ICD-10 code for HD (G10) in any diagnosis variable during the patient identification period

Figure 1. Study design



## Patient and provider identification

### Patient population

- Inclusion criteria:**
  - Continuous enrollment 6 months before and 12 months after the index date
  - Newly diagnosed HD (ICD-10 code: G10)
  - Age ≥18 years
- Exclusion criteria**
  - Prescriptions for vesicular monoamine transporter 2 inhibitors (VMAT2is) or antipsychotics (APs) in the 6-month pre-index period as a proxy to eliminate undiagnosed patients
  - Patients with late-stage HD, defined by use of nursing home care, feeding tube, or hospice care or incontinence, bedsores, ≥2 falls within 1 month, or dysphagia after the index date<sup>5</sup>

### Diagnosing and managing provider types

- The 3 most common provider types for HD patients: (1) Primary care physicians (PCPs), (2) neurologists, and (3) psychiatrists were included
  - Additional provider types were grouped as “other”
- Diagnosing provider: Provider type for the visit on the patient’s index date
- Managing providers: Providers associated with any claim during the 12-month follow-up period post-index date
- Missing or uninterpretable provider type information such as facility providers (acute care hospital, urgent care facility, etc) or service providers (radiology, laboratory, etc) were not included

### Outcomes

- Outcomes included baseline demographics, frequency of diagnosing and managing providers for HD patients, all-cause HCRU and costs, HD-related HCRU and costs, and AP and VMAT2i use (regardless of indication).
- HCRU, costs, and VMAT2i and AP use were assessed in the 12-month follow-up period.
- Total healthcare costs included inpatient and outpatient costs, and outpatient pharmaceutical costs; costs were reported per-patient-per-year (PPPY) in 2022 US dollars (USD).

### Statistical analysis

- Continuous variables were summarized with means and standard deviations (SD) and categorical variables with counts and percentages.
- Associations between diagnosing provider type and HCRU outcomes and also healthcare costs were evaluated using multivariable generalized linear regressions
- Statistical analyses were performed using R 4.2.2 (R Core Team, 2022).

## RESULTS

### Baseline demographics

- 340 patients were identified for inclusion (Table 1). The mean age at index date was 49 years (11.1), and 56.5% patients were female.
- 165 (48.5%) patients were diagnosed by neurologists, 121 (35.6%) by PCPs, 12 (3.5%) by psychiatrists, and 42 (12.4%) by other provider types.

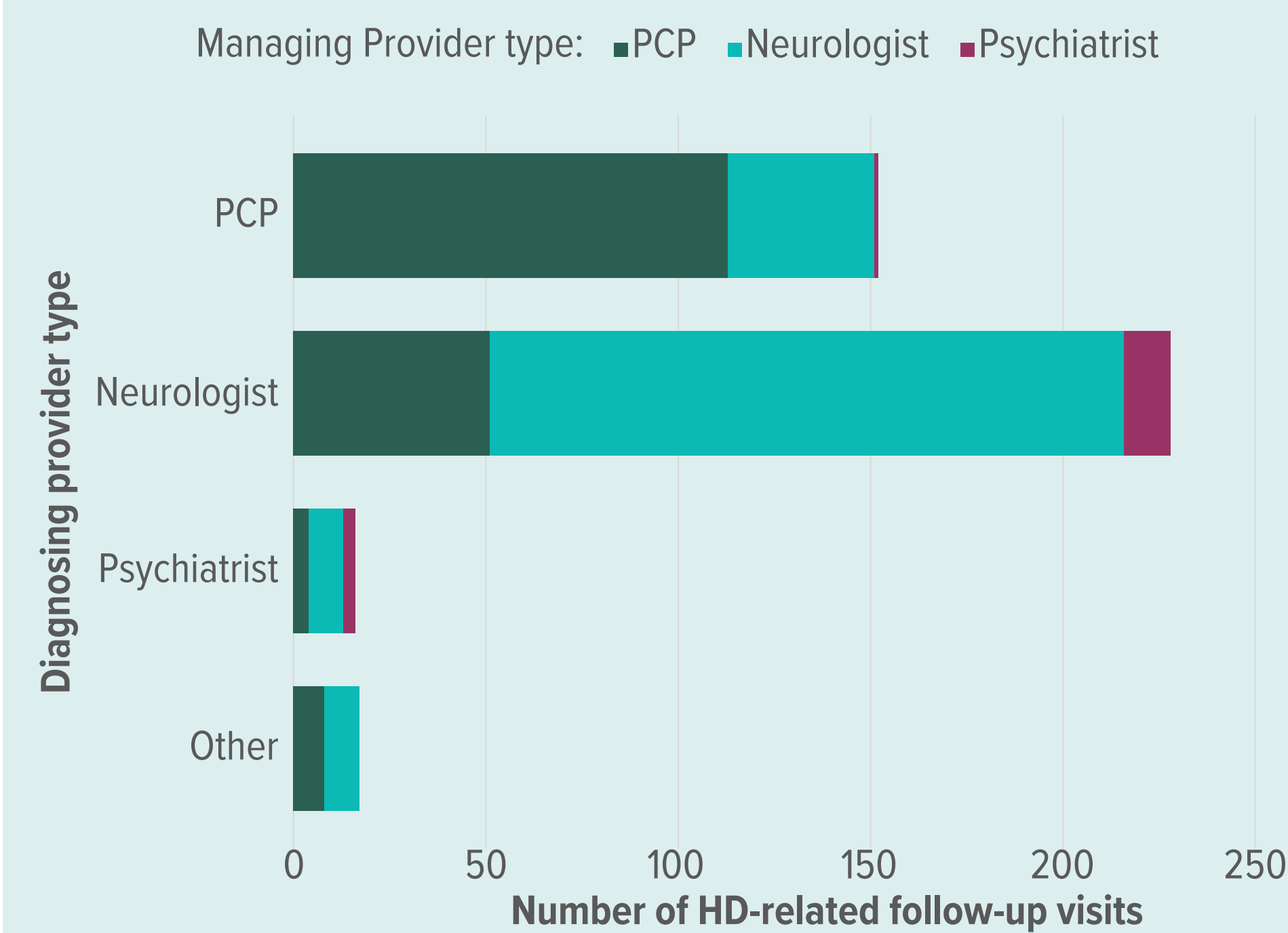
Table 1. Patient baseline demographics

	All HD patients N=340	Diagnosing provider type			
		PCP n=121	Neurologist n=165	Psychiatrist n=12	Other <sup>a</sup> n=42
Age (years), mean (SD)	49.2 (11.1)	48.4 (11.0)	51.0 (10.3)	45.1 (12.8)	45.8 (12.7)
Female, n (%)	192 (56.5)	66 (54.5)	92 (55.8)	7 (58.3)	27 (64.3)
Region, n (%)					
South	142 (41.8)	62 (51.2)	55 (33.3)	5 (41.7)	20 (47.6)
North-central	113 (33.2)	24 (19.8)	76 (46.1)	5 (41.7)	8 (19.0)
Northeast	56 (16.5)	20 (16.5)	22 (13.3)	1 (8.3)	13 (31.0)
West	29 (8.5)	15 (12.4)	12 (7.3)	1 (8.3)	1 (2.4)
Health plan <sup>b</sup> , n (%)					
PCP referral required	53 (15.6)	23 (19.0)	22 (13.3)	2 (16.7)	6 (14.3)
PCP referral not required	287 (84.4)	98 (81.0)	143 (86.7)	10 (83.3)	36 (85.7)
Diagnosing settings, n (%)					
Inpatient	33 (9.7)	10 (8.3)	18 (10.9)	1 (8.3)	4 (9.5)
Outpatient	307 (90.3)	111 (91.7)	147 (89.1)	11 (91.7)	38 (90.5)
Charlson Comorbidity Index n (%)					
0	243 (71.5)	88 (72.7)	116 (70.3)	10 (83.3)	29 (69.0)
1	45 (13.2)	17 (14.0)	22 (13.3)	0 (0.0)	6 (14.3)
2	26 (7.6)	6 (5.0)	15 (9.1)	1 (8.3)	4 (9.5)
3+	26 (7.6)	10 (8.3)	12 (7.3)	1 (0.6)	3 (7.1)

<sup>a</sup> Other providers include various specialists like hematologists, pulmonologists, nephrologists, gynecologists, etc.  
<sup>b</sup> Health plans that required PCP referral: Health maintenance organization/exclusive provider organization, point-of-service. Health plans that did not require PCP referral: Basic/comprehensive, preferred provider organization, high-deductible health plan.  
 Key: HD – Huntington's disease; PCP – primary care provider; PPPY – per patient per-year; SD – standard deviation.

- Patients diagnosed by PCPs or neurologists were significantly more likely to be managed by those types of providers during follow-up ( $P<0.05$ ) (Figure 2).

Figure 2. Managing provider types during 12-month follow-up by diagnosing provider



Key: HD – Huntington's disease; PCP – primary care physician.  
 Note: “Other” managing providers are not shown in Figure 2 as the category encompasses a wide variety of provider types.

### All-cause and HD-related HCRU and costs

- All-cause and HD-related outpatient visits were numerically higher in patients diagnosed by PCPs (23.9; 5.1 PPPY) than neurologists (18.0; 2.4), psychiatrists (16.7; 1.67), or others (15.3; 2.4).
  - Only patients diagnosed by neurologists had a statistically significantly lower number of HD-related outpatient visits PPPY than those diagnosed by PCPs (0.57;  $P<0.05$ ).
- HD-related total cost PPPY was \$2,489 (\$11,053), with \$1,179 (\$8,727) inpatient and \$1,310 (\$4,858) outpatient (Table 2).
  - Patients diagnosed by neurologists had a significantly lower HD-related total non-medication cost than PCPs (-\$2,256;  $P<0.05$ ).
- There were no other significant associations between diagnosing provider type and other HCRU outcomes.

Table 2. HCRU and cost during 12-month follow-up by diagnosing provider type, PPPY

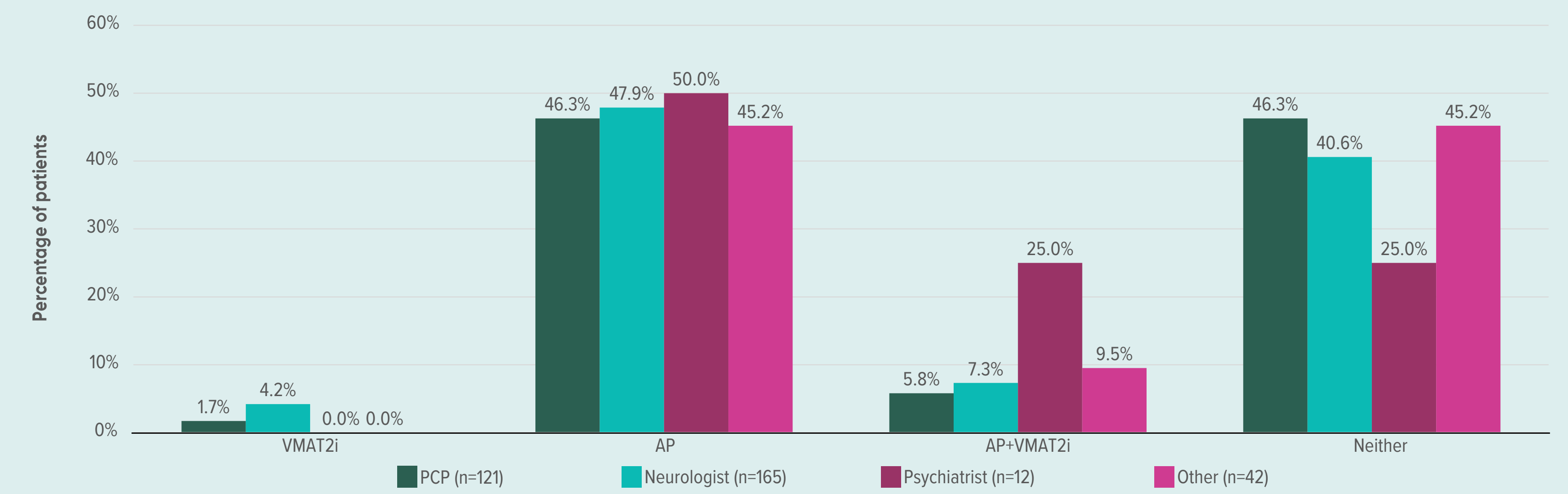
	All HD patients N=340	Diagnosing provider type			
		PCP n=121	Neurologist n=165	Psychiatrist n=12	Others n=42
<b>All-cause HCRU</b>					
Inpatient length of stay (days), mean (SD)	1.03 (4.26)	0.71 (3.31)	1.19 (4.90)	1.42 (3.37)	1.17 (4.32)
Unique hospitalizations, (counts), mean (SD)	0.14 (0.47)	0.11 (0.38)	0.18 (0.55)	0.17 (0.39)	0.12 (0.40)
Unique outpatient visits (counts), mean (SD)	19.70 (19.40)	23.90 (59.10)	18.00 (22.90)	16.70 (13.90)	15.30 (18.90)
<b>All-cause costs</b>					
Total costs (\$), mean (SD)	18,379 (60,503)	23,085 (88,029)	13,674 (31,187)	22,812 (37,649)	22,039 (56,057)
Inpatient service	8,729 (32,860)	7,851 (30,824)	6,984 (25,358)	12,997 (32,373)	16,893 (56,616)
Outpatient service	9,650 (40,158)	15,234 (65,380)	6,690 (11,476)	9,814 (19,752)	5,145 (6,588)
<b>Paid body (\$), mean (SD)</b>					
Out-of-pocket	1,177 (1,703)	1,221 (1,717)	1,090 (1,605)	2,312 (3,371)	1,068 (1,256)
Health plan	17,233 (60,215)	21,869 (87,630)	12,608 (31,051)	20,500 (34,755)	21,113 (56,173)
<b>HD-related HCRU</b>					
Inpatient length of stay (days), mean (SD)	0.26 (1.49)	0.26 (1.82)	0.55 (1.22)	0.58 (2.02)	0.19 (1.23)
Unique hospitalizations, (counts), mean (SD)	0.05 (0.24)	0.04 (0.20)	0.07 (0.27)	0.08 (0.29)	0.02 (0.15)
Unique outpatient visits (counts), mean (SD)	3.33 (18.80)	5.12 (30.90)	2.37 (4.90)	1.67 (2.53)	2.40 (5.29)
<b>HD-related costs</b>					
Total costs (\$), mean (SD)	2,489 (11,053)	3,641 (12,668)	1,807 (10,887)	5,617 (14,156)	954 (1,248)
Inpatient service	1,179 (8,727)	1,572 (7,852)	1,090 (6,984)	4,777 (13,369)	133 (663)
Outpatient service	1,310 (4,858)	2,070 (7,722)	912 (2,018)	840 (1,010)	821 (1,159)
<b>Paid body (\$), mean (SD)</b>					
Out-of-pocket	303 (623)	378 (873)	270 (445)	221 (194)	243 (384)
Health plan	2,185 (10,894)	3,264 (12,348)	1,535 (10,842)	5,396 (14,105)	715 (1,049)

Key – HCRU – healthcare resource utilization; HD – Huntington's disease; PCP – primary care provider; PPPY – per patient per-year; SD – standard deviation.

### HD medication use

- 57% (n=195) of patients received an AP, VMAT2i, or combination AP+VMAT2i prescription within the first year of HD diagnosis (Figure 4).
  - A similar proportion of patients diagnosed by neurologists and by PCPs received APs within the first year (55% vs 52%, respectively).
  - A numerically larger proportion of patients diagnosed by neurologists received VMAT2i (12%) vs 7% diagnosed by PCPs.

Figure 3. Percentage of patients on HD medication<sup>a</sup> during 12-month follow-up by diagnosing provider type



<sup>a</sup> Medication classes were mutually exclusive.  
 Key: AP – antipsychotic; HD – Huntington's disease; PCP – primary care physician; VMAT2i – vesicular monoamine transporter 2 inhibitor.

## LIMITATIONS

- Our study includes limitations inherent to retrospective claims studies, such as lack of generalizability to a broader population, missing/miscoded claims data, and short length of follow-up.
- AP prescriptions were captured, but it is unknown whether those prescriptions were specifically for HD, as they can be used for a wide variety of indications or chosen over guideline-recommended treatments, such as VMAT2i, to treat both HD chorea and a comorbid condition.
- As only newly diagnosed patients were included to understand the impact of the diagnosing provider on outcomes, results may be different for patients who were previously diagnosed and received treatment.

## CONCLUSIONS

- HD patients are most often diagnosed by neurologists or PCPs. The same type of provider who diagnosed the patient typically manages their HD during the first year after diagnosis.
- Patients diagnosed by neurologists had significantly fewer HD-related outpatient visits and lower HD-related non-drug costs vs those diagnosed by PCPs.
- An integrated care team approach is important for patients with newly diagnosed HD to ensure patients are receiving consistent, guideline-based, and personalized care for their HD symptoms.

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