ME/CFS causes substantial morbidity, but ME/CFS both under-diagnosed and over-diagnosed in healthcare settings

Designed study to assess ME/CFS prevalence based on patient self-report in a large, integrated health system

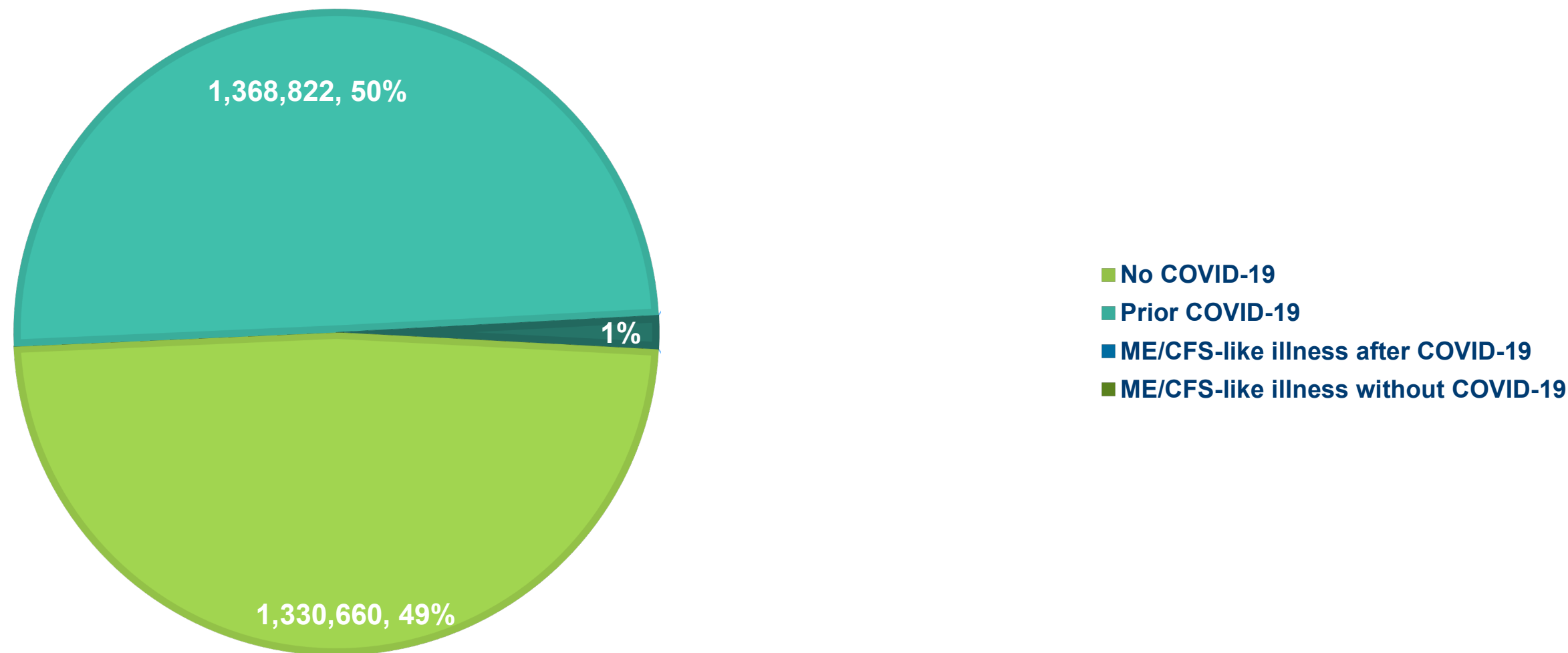Enrolled 9,825 persons using electronic survey to assess patient reported symptoms and functional status

Used 2015 Institute of Medicine diagnostic criteria for ME/CFS
- New onset profound fatigue, post-exertional malaise, and unrefreshing sleep
- Plus cognitive impairment or orthostatic intolerance

Based on self-reported symptom duration, frequency and severity identify persons with ME/CFS-like illness and stratify:
- 1) ME/CFS-like illness after COVID-19
- 2) ME/CFS-like illness without COVID-19
- 3) No ME/CFS-like illness

50% of people in our health system had COVID-19
About 1.7% overall have ME/CFS-like illness

Legend:
- No COVID-19
- Prior COVID-19
- ME/CFS-like illness after COVID-19
- ME/CFS-like illness without COVID-19

Pie chart values: 1,368,822, 50% (Prior COVID-19); 1,330,660, 49% (No COVID-19); 1%

1 in 211 people who had COVID-19 have ME/CFS-like illness after COVID-19
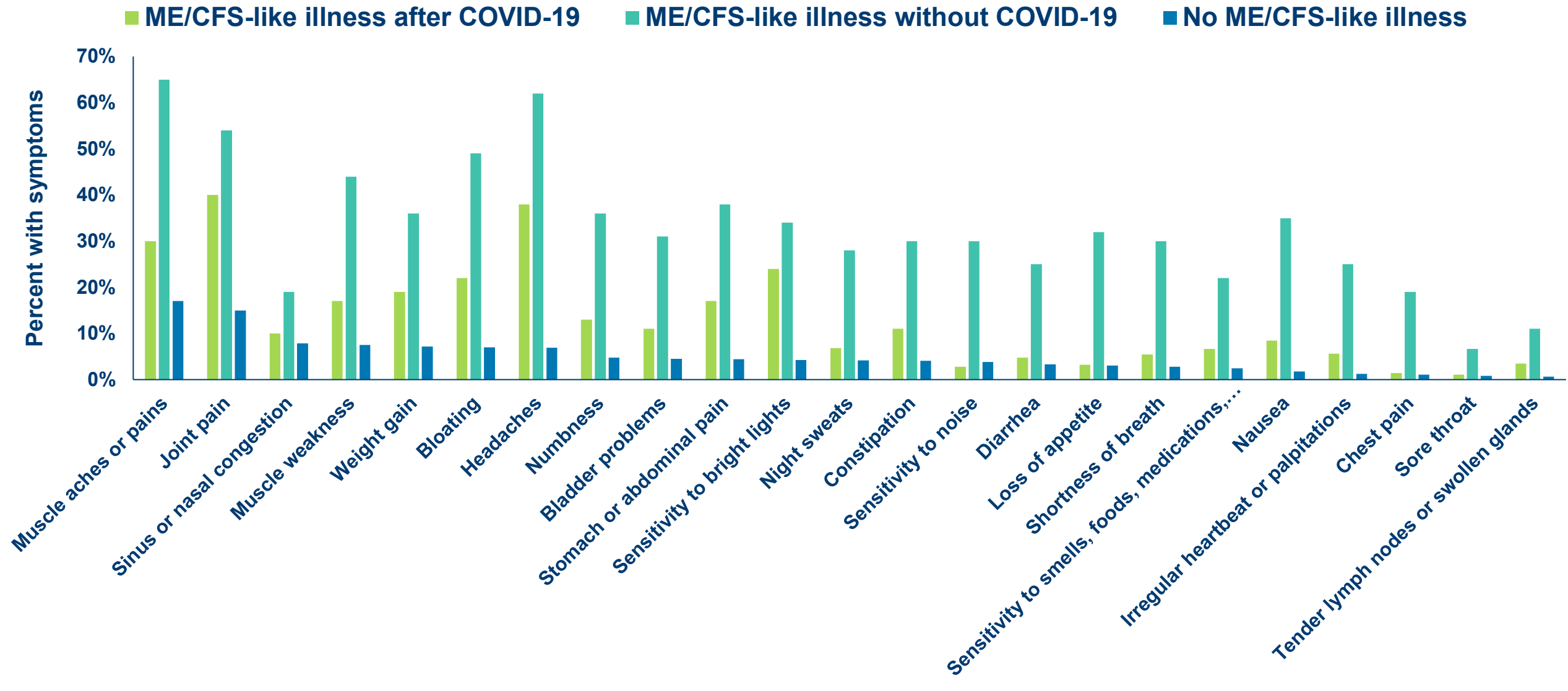# 1 in 70 people have ME/CFS-like illness without COVID-19
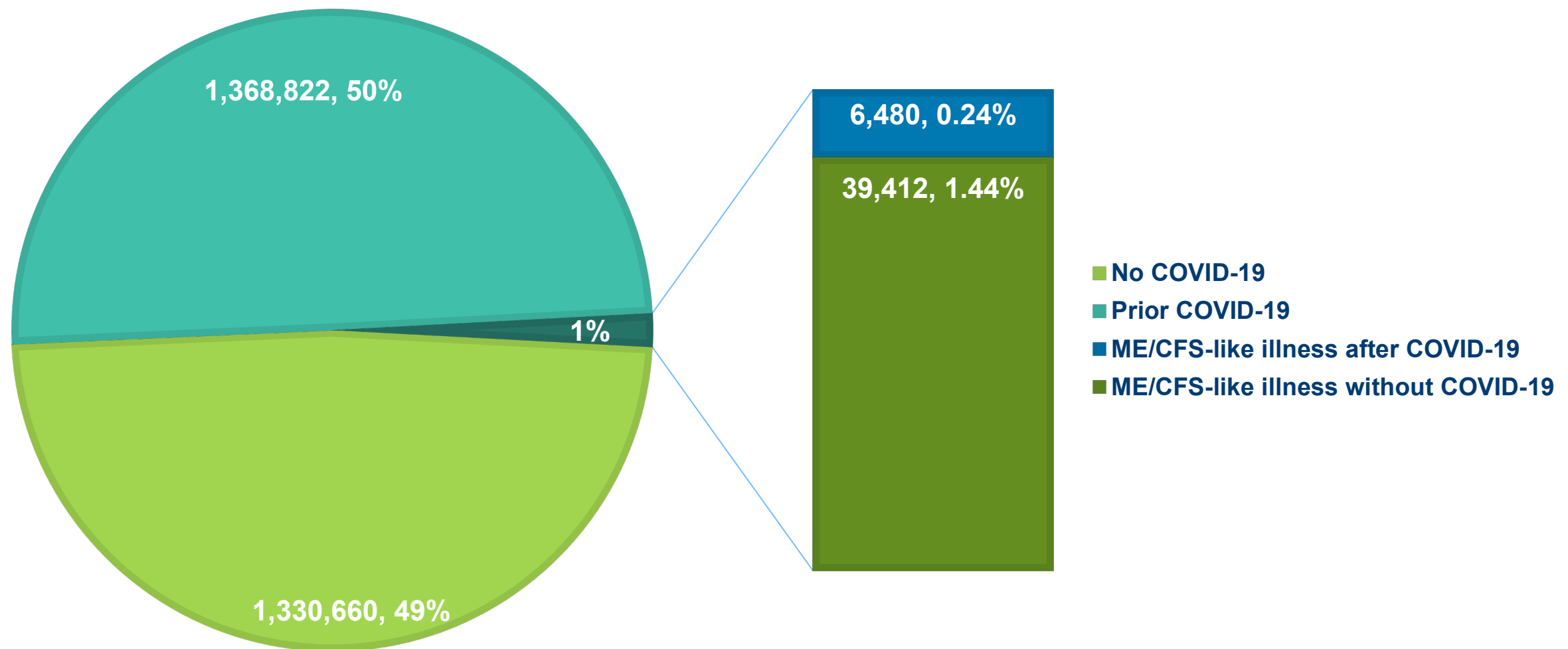
Persons with ME/CFS-like illness after COVID-19 have shorter duration of symptoms, are younger, more likely to be LatinX/Hispanic, and more likely to be obese

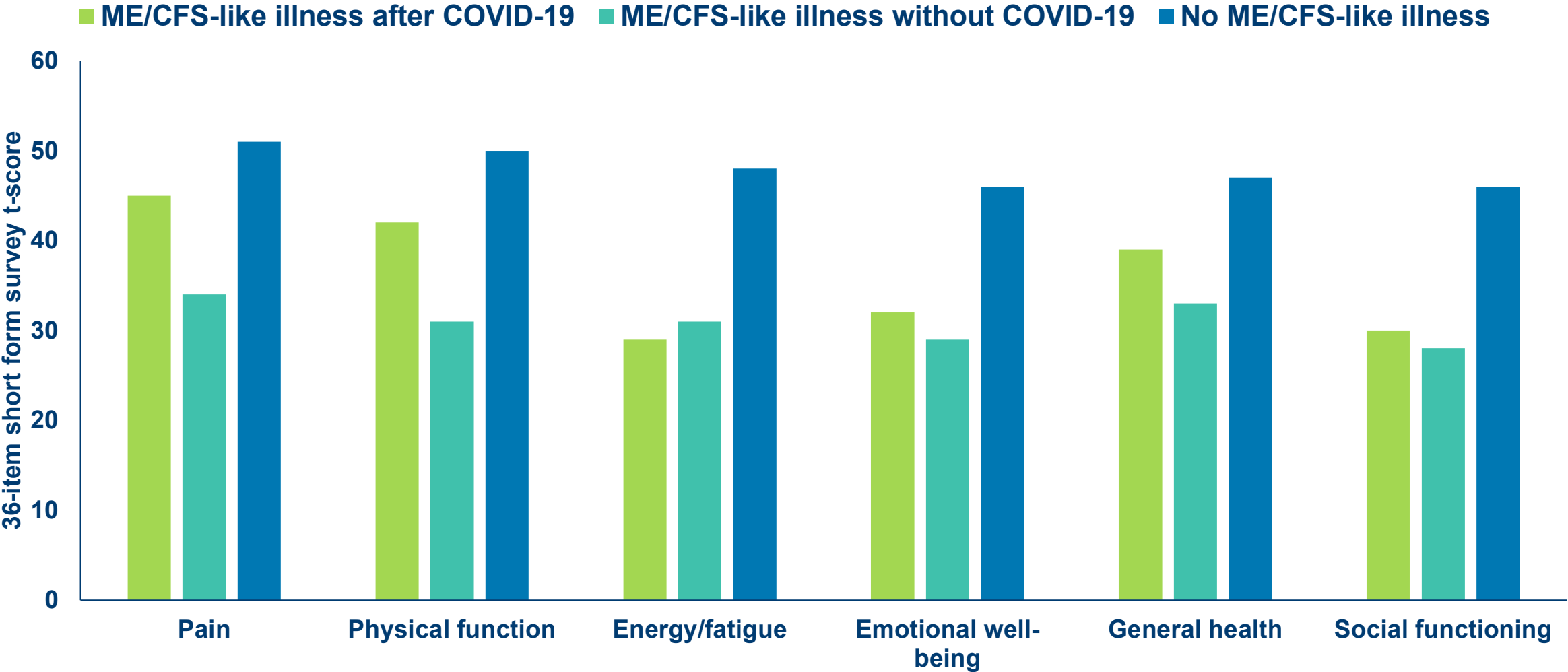| Characteristic	ME/CFS-like illness after COVID-19 % (CI)	ME/CFS-like illness without COVID-19 % (CI)	No ME/CFS-like illness % (CI)
Years since fatigue onset (mean)	2 (1.5, 2.0)	9 (5.4, 12)	
Age, years (mean)	36 (33, 39)	45 (40, 50)	50 (49, 50)
Race/ethnicity			
LatinX/Hispanic	41 (11, 79)	27 (15, 43)	17 (16, 19)
Black	4.0 (0.65, 21)	11 (3.5, 30)	5.5 (4.6, 6.6)
Asian	0.4 (0.09, 1.5)	14 (6.4, 29)	22 (20, 24)
White	53 (18, 85)	44 (30, 59)	50 (48, 52)
Female sex	60 (21, 89)	75 (57, 86)	58 (56, 60)
Body mass index $\geq$ 30 kg/m^2	40 (11, 79)	45 (31, 60)	26 (24, 27)

Among persons who had COVID-19, those with ME/CFS-like illness after COVID-19 are more likely to be unvaccinated and infected in pre-Delta period

	ME/CFS-like illness after COVID-19	ME/CFS-like illness without COVID-19	No ME/CFS-like illness
Characteristic	% (CI)	% (CI)	% (CI)
No COVID-19 vaccination at time of first COVID-19 episode	96 (87, 99)	22 (14, 34)	21 (19, 22)
Variant at time of first COVID-19 episode			
Pre-Delta (before June 1, 2021)	74 (34, 94)	17 (10, 28)	14 (13, 16)
Delta	5.4 (1.9, 15)	25 (11, 47)	11 (9.3, 12)
Omicron	1.2 (0.39, 3.5)	57 (38, 74)	67 (65, 70)
Unknown	19 (2.7, 66)	0.9 (0.49, 1.6)	7.5 (6.1, 9.3)

Persons with ME/CFS-like illness experience many severe, frequent symptoms

Legend:
- ME/CFS-like illness after COVID-19
- ME/CFS-like illness without COVID-19
- No ME/CFS-like illness

Y-axis: Percent with symptoms (0% to 70%)

Categories: Muscle aches or pains, Joint pain, Sinus or nasal congestion, Muscle weakness, Weight gain, Bloating, Headaches, Numbness, Bladder problems, Stomach or abdominal pain, Sensitivity to bright lights, Night sweats, Constipation, Sensitivity to noise, Diarrhea, Loss of appetite, Shortness of breath, Sensitivity to smells, foods, medications,..., Nausea, Irregular heartbeat or palpitations, Chest pain, Sore throat, Tender lymph nodes or swollen glands

Persons with ME/CFS-like illness have lower physical, emotional, and social functioning

Legend:
- ME/CFS-like illness after COVID-19 (green)
- ME/CFS-like illness without COVID-19 (teal)
- No ME/CFS-like illness (blue)

Y-axis: 36-item short form survey t-score

Categories: Pain, Physical function, Energy/fatigue, Emotional well-being, General health, Social functioning

Persons with ME/CFS-like illness are more likely to have depression or anxiety
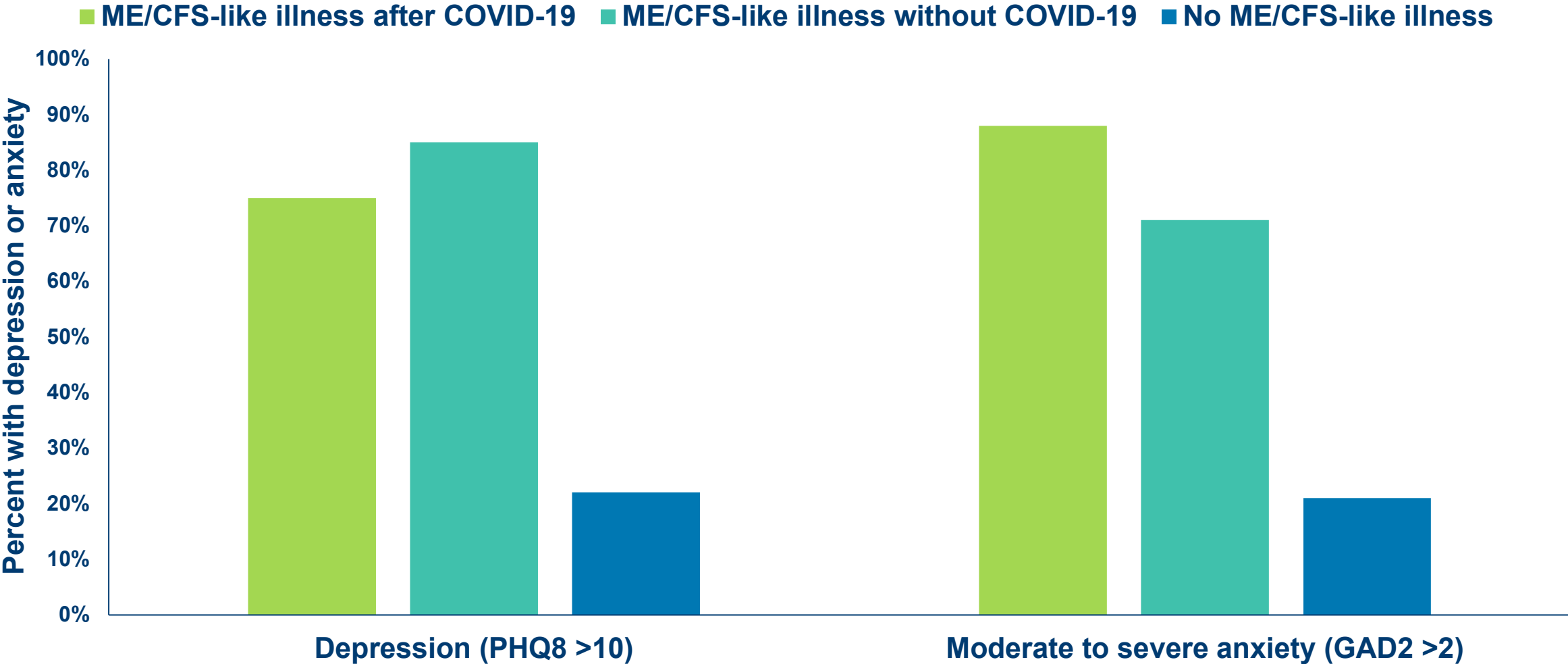
Burden of ME/CFS-like illness after COVID-19 might be very large

Our study
2,745,374 adults × 50% had COVID-19 × 1 in 211 with ME/CFS-like illness after COVID-19 =
6,480 (95% confidence interval 1,244–11,715)

United States
258,327,312 adults × 50% had COVID-19 × 1 in 211 with ME/CFS-like illness after COVID-19 =
609,973 (95% confidence interval 117,054–1,102,329)

Persons with ME/CFS-like illness after COVID-19

↑ **Symptoms**

↓ **Physical, emotional, and social functioning**

↑**Depression and anxiety**

Thank you!!!

This work was supported by