

BACKGROUND

- We conducted a survey of lung cancer patients and caregivers in the United States in 2015 and 2016 that identified gaps in access to supportive care and patient education.
- An additional survey of patients and caregivers in 2016 revealed low rates of molecular testing among lung cancer patients despite being recommended by clinical guidelines.
- In order to gauge how much progress has been made in addressing these gaps, we looked at self-reported rates among participants in a lung cancer patient registry founded by a patient advocacy organization, the GO2 Foundation for Lung Cancer.

METHODS

The Lung Cancer Registry, supported by the GO₂ Foundation for Lung Cancer, and partners The American Lung Association and The International Association for the Study of Lung Cancer, collects self-reported data from lung cancer patients and caregivers through an online interface on a variety of topics related to patients' lung cancer diagnoses and care experiences. For this study, we analyzed data collected from 939 registry participants between November 2016 to December 2018 on supportive care, assistance, and molecular testing offerings to patients.

DEMOGRAPHICS

Population Level Demographics

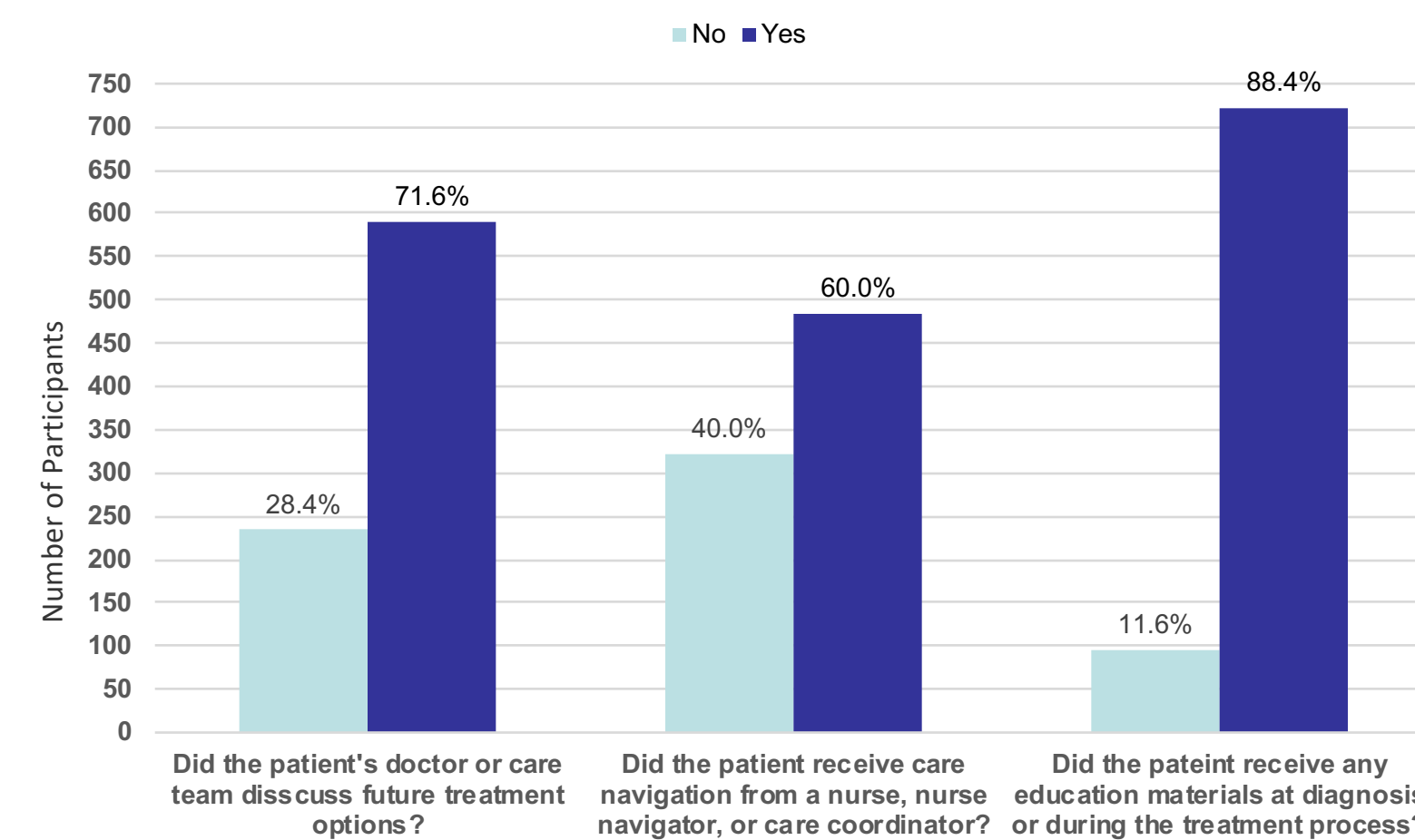
	N	%
Gender		
Female	716	76.25%
Male	223	23.75%
Age		
<40	65	6.92%
40 to 80	854	90.95%
>80	20	2.13%
Race		
White	805	87.40%
Black/African American	21	2.28%
American Indian/Alaska Native	4	0.43%
Asian	45	4.89%
Multiple	24	2.61%
Other/Unknown	22	2.39%
Ethnicity		
Hispanic/Spanish/Latino	30	5.18%
Non-Hispanic/Spanish/Latino	501	86.53%
Prefer Not To Answer/Unsure	48	8.29%
Highest Education Level		
Graduate Degree	152	25.76%
College/University Graduate	211	35.76%
Partial College or Specialized Training	146	24.75%
High School Graduate	56	9.49%
Partial High School	11	1.86%
Junior High School	2	0.34%
< 7 th Grade	2	0.34%
Prefer Not To Answer	10	1.69%

Lung Cancer Demographics

	N	%
Lung Cancer Type		
Non-Small Cell Lung Cancer (NSCLC)	716	81.0%
Small Cell Lung Cancer (SCLC)	69	7.81%
Other	82	9.28%
Unsure	17	1.92%
Stage of Lung Cancer		
0 – I	93	11.3%
II	48	5.83%
III	176	21.39%
IV	506	61.48%

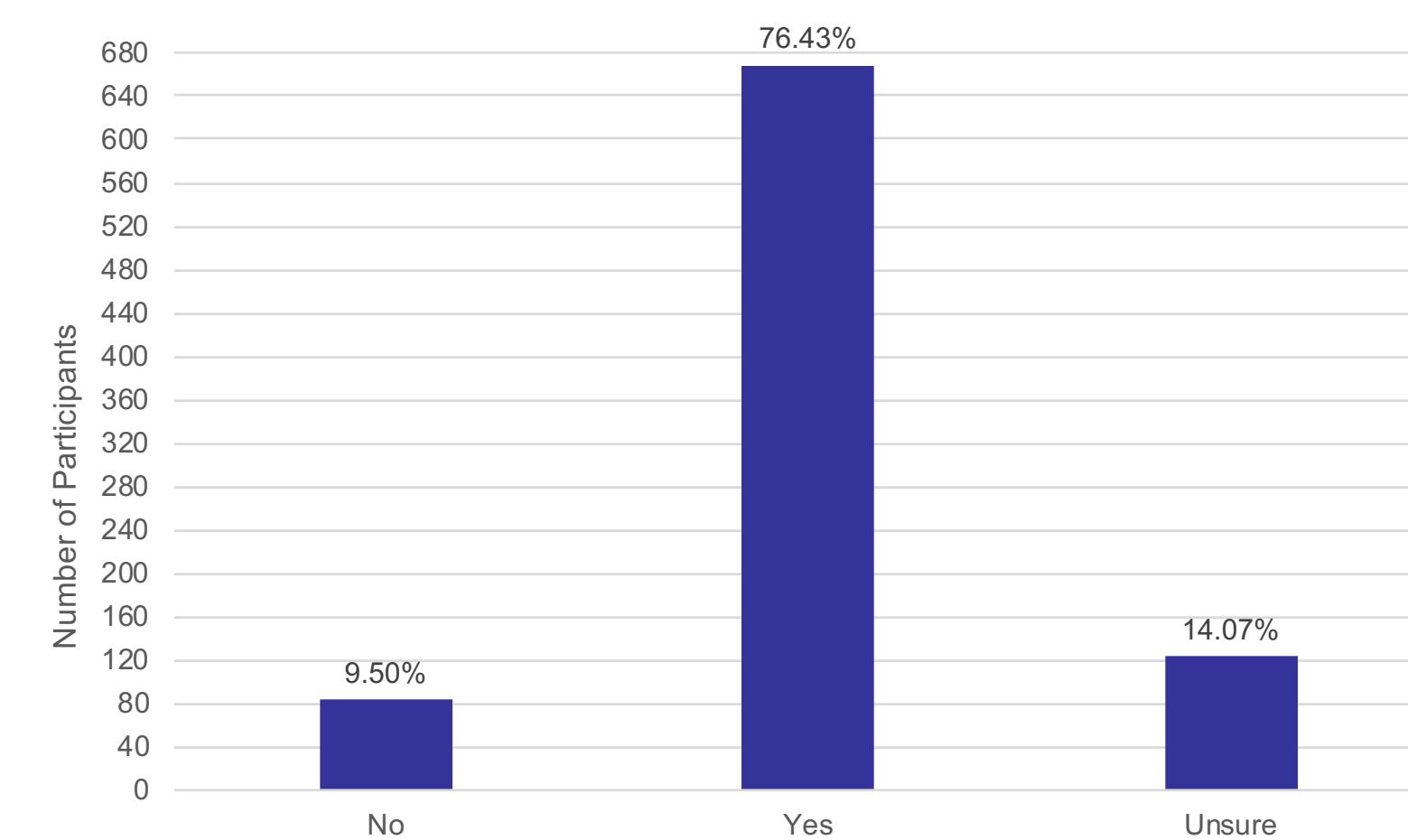
RESULTS

Supportive Care and Assistance Rates Among Registry Participants



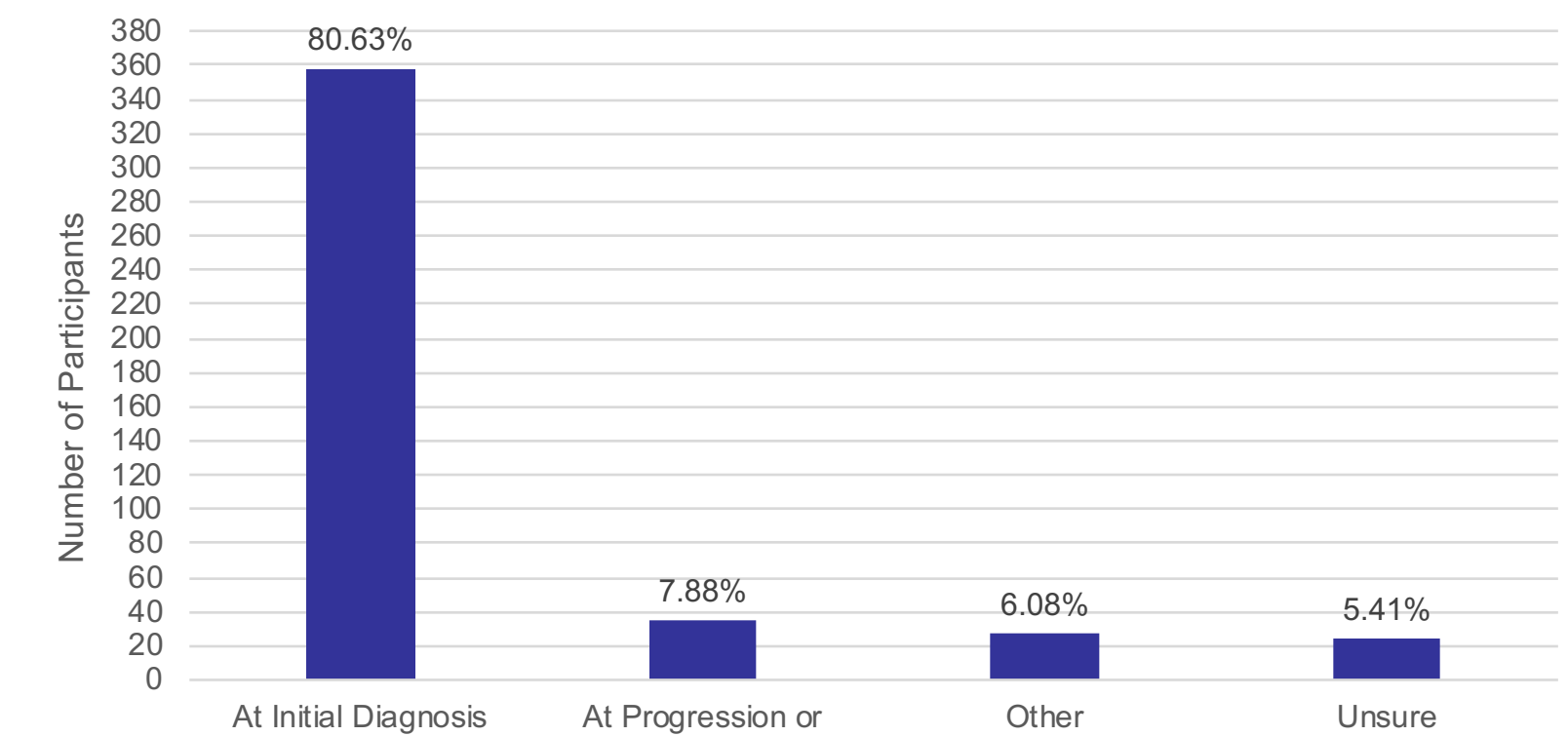
Rates of offering of various supportive care options as self reported by registry participants. Bars represent number of participants providing a given response; percent value represents portion of total participants providing a given response.

Was Molecular/Biomarker/Genetic Testing Done on the Patient's Biopsy?



Testing rates as self reported by registry participants. Bars represent number of participants providing a given response; percent value represents portion of total participants providing a given response.

When was Molecular/Biomarker Testing First Done on the Patient's Biopsy?



Timing of initial testing as self reported by registry participants. Bars represent number of participants providing a given response; percent value represents portion of total participants providing a given response.

CONCLUSIONS

- Among Registry participants rates of molecular testing were high and performed mostly at initial diagnosis
- Registry participants reported being offered care navigation and educational support at high rates

DISCUSSION

- Among the patient population represented in the registry, significant progress has been made in addressing previously identified gaps in support and care offerings
- Registry participants represent a highly educated, demographically homogeneous population; further research is needed on support and care offerings in other populations, where gaps may persist

CONTACT

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