

## BACKGROUND

- Cancer cachexia is a complex, systemic metabolic condition that impacts up to 80% of cancer patients and is characterized by significant unintended weight loss, reduction in muscle function, fatigue, and poor health-related quality of life.
- There is significant lack of understanding and communication around cancer cachexia among patients, caregivers, and healthcare providers.
- To increase knowledge and communication about cachexia, we co-created a cancer cachexia lexicon, establishing a shared set of plain language terminology for patients, caregivers, providers, and advocates.
- We evaluated the efficacy of the lexicon in increasing knowledge and communication about cancer cachexia among patients and caregivers.

## METHODS

- 191 participants (156 patients; 35 caregivers) representing diverse cancer types and stages completed the survey.
- 36% had been diagnosed with cachexia, and over 90% had experienced at least three symptoms associated with cachexia.
- The survey used a pre- and post- design in which participants: 1) reported baseline knowledge and communication around cachexia; 2) reviewed the tool; 3) rated the tool for clarity, acceptability, and resonance; and 4) re-assessed cachexia knowledge and intended communication.
- Data were analyzed using descriptive statistics, t-tests, and McNemar's tests.

## PARTICIPANTS

Participant Characteristics	n/mean	%/SD
<b>Cancer Experience</b>		
Patient	156	82%
Caregiver	35	18%
<b>Cachexia diagnosis</b>		
Diagnosed with cachexia	65	34%
Not diagnosed	90	47%
Unsure	36	19%
<b>Tumor type</b>		
Breast	66	34%
Colorectal	30	16%
Lung	25	13%
Pancreatic	15	8%
Other	55	29%
<b>Stage</b>		
0-I	46	24%
II	48	25%
III	42	22%
IV	47	25%
Unsure / Unstaged	8	4%
<b>Age, years (Range: 33-91)</b>		
	49	13
<b>Gender</b>		
Woman	152	80%
Man	36	19%
Prefer not to share	3	1.0%
<b>Race &amp; Ethnicity</b>		
Non-Hispanic White	119	62%
Non-Hispanic Black	36	19%
Hispanic / Latino	14	7%
Multiple races	11	6%
Native Hawaiian	2	1%
Prefer not to share	9	5%
<b>Level of education</b>		
High school degree	16	9%
Some college	33	17%
Associate's degree	35	18%
Bachelor's degree	69	36%
Graduate degree	38	20%

N=200

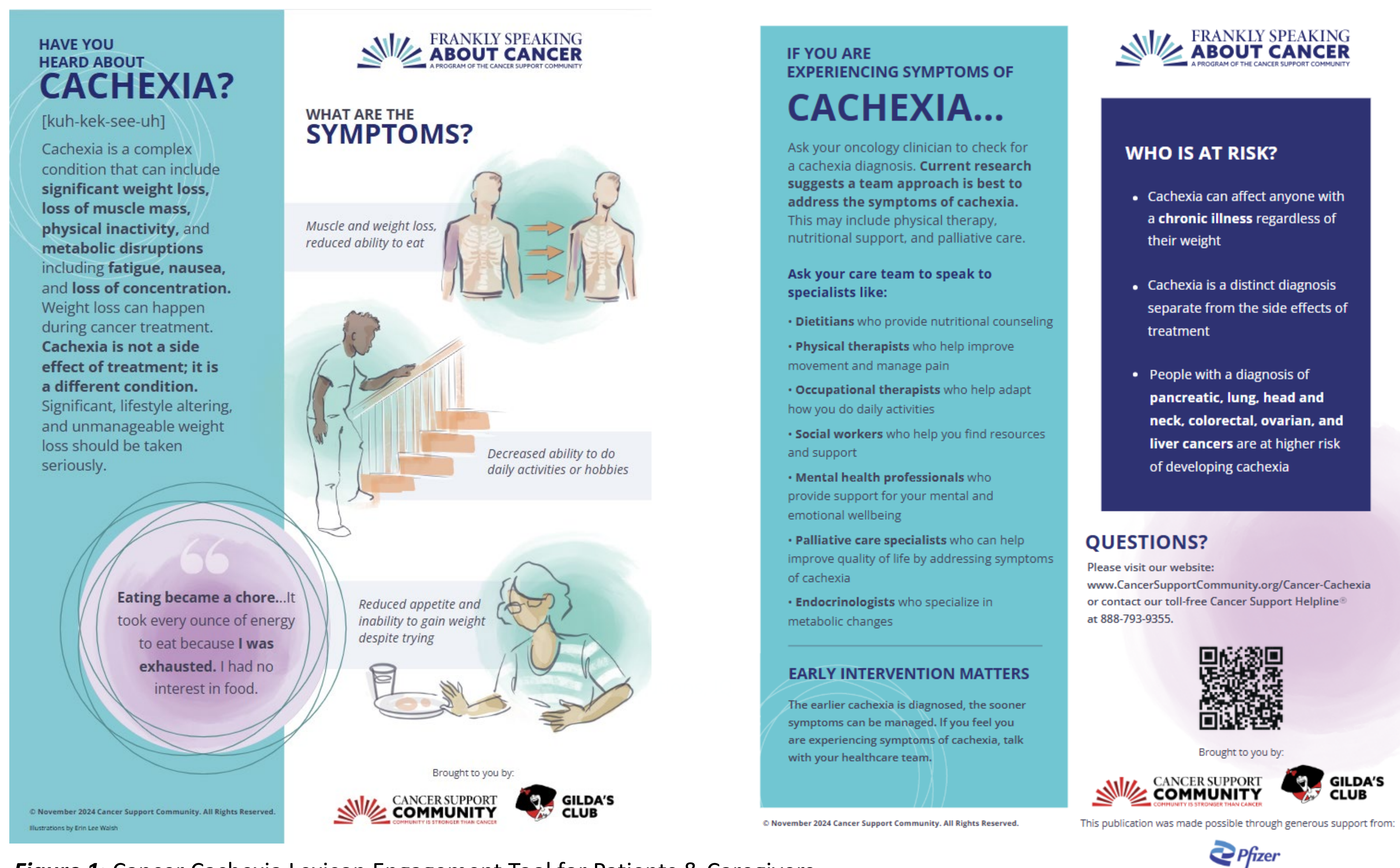
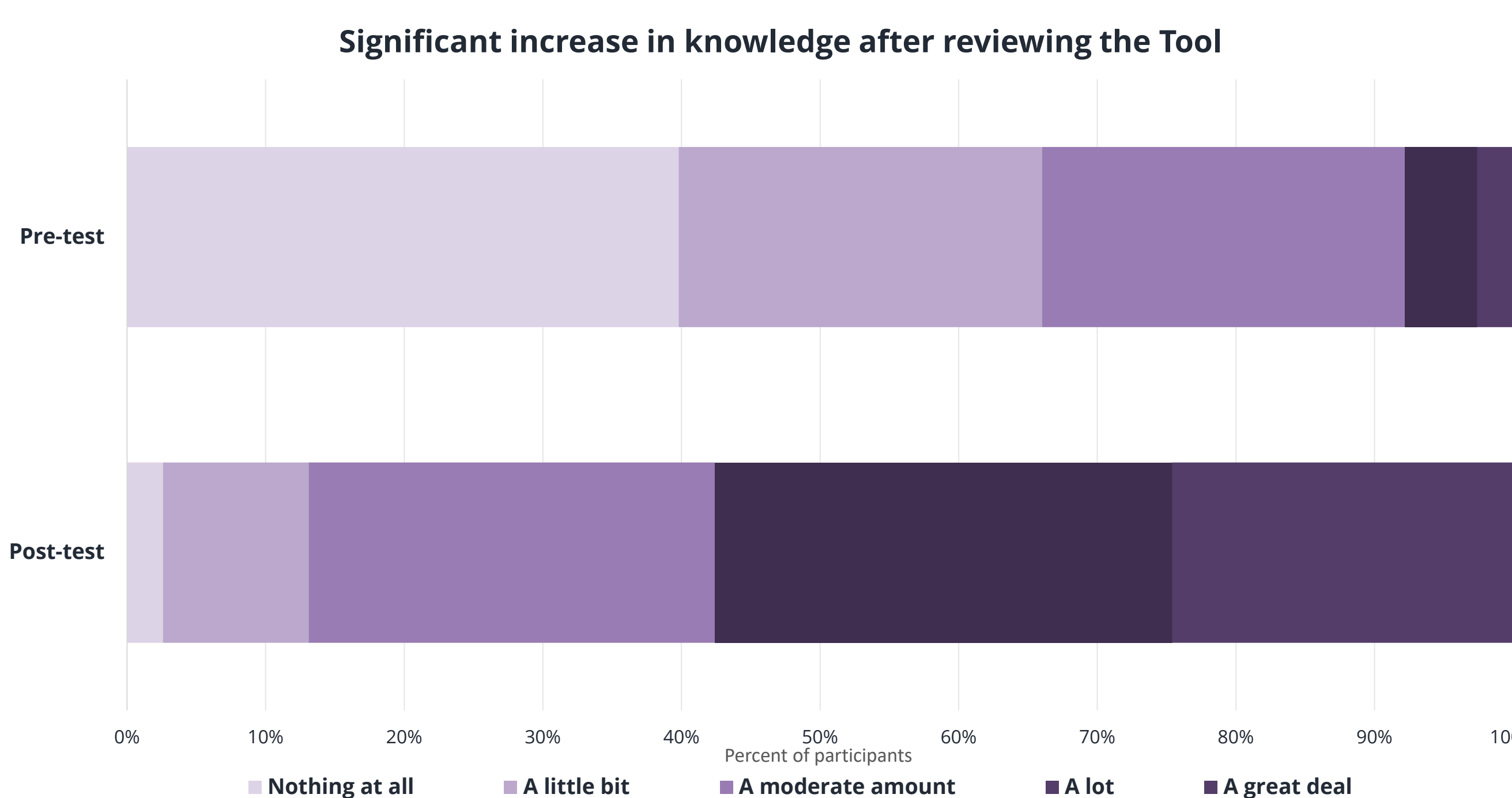


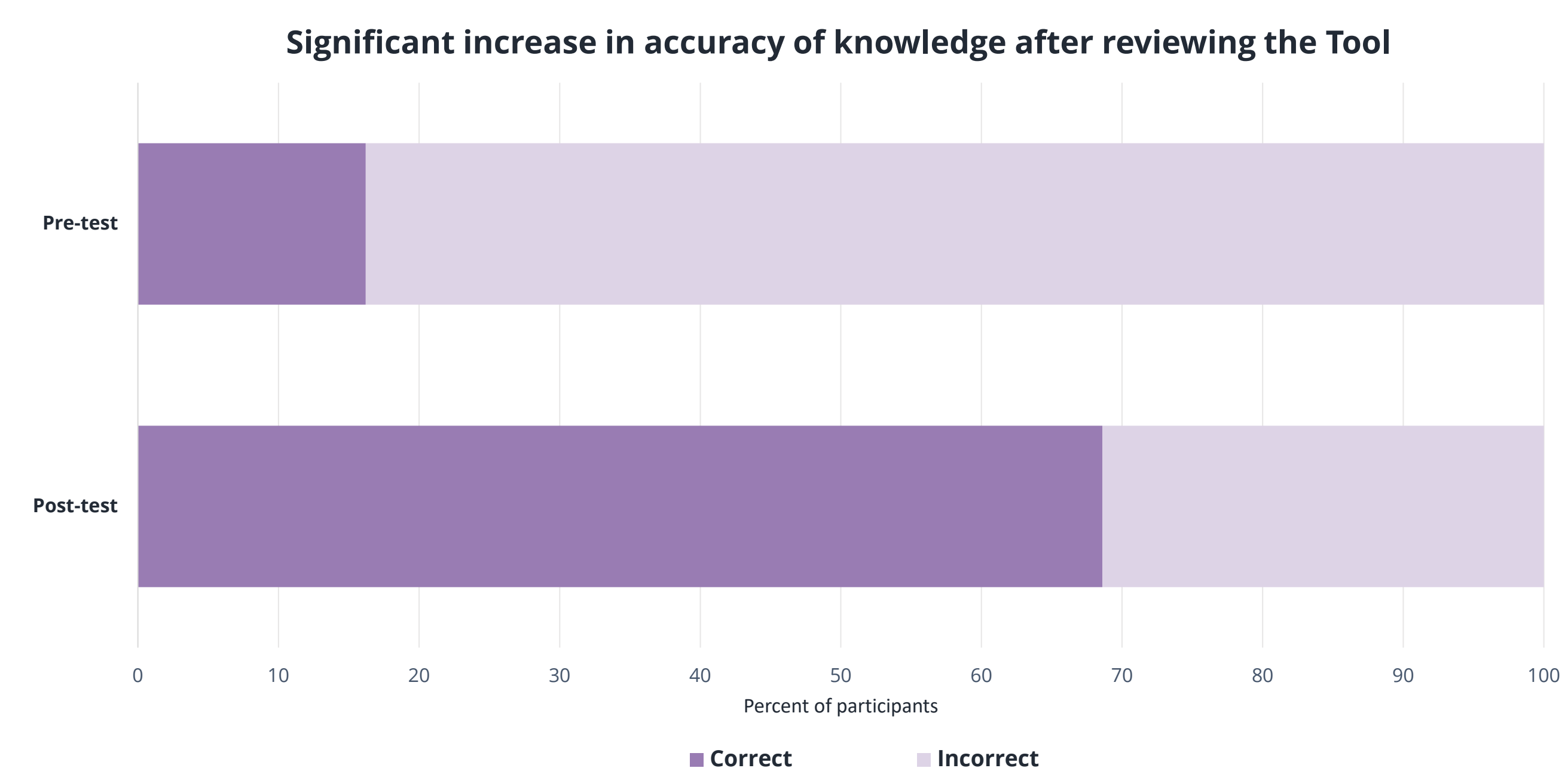
Figure 1: Cancer Cachexia Lexicon Engagement Tool for Patients & Caregivers

## RESULTS



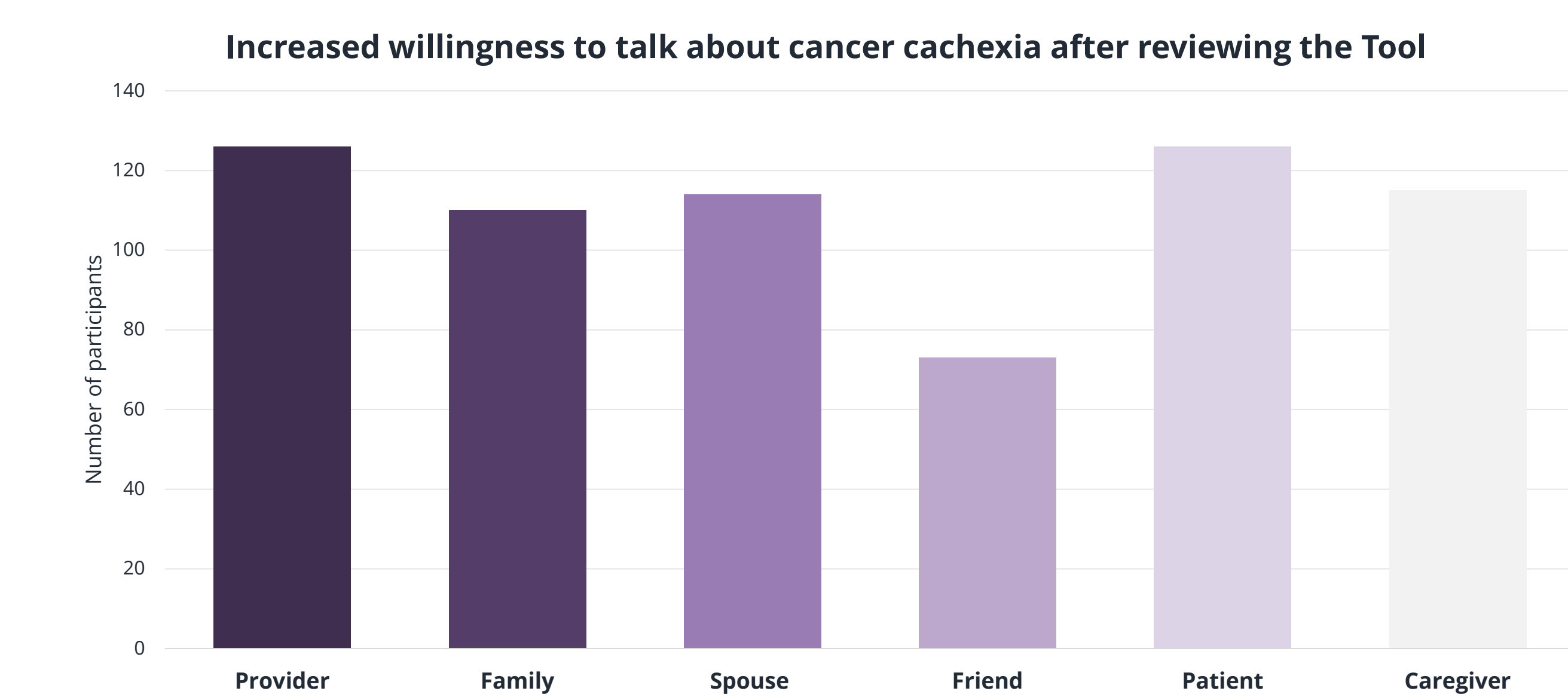
- Self-rated **knowledge increased among 85% of participants.**

- Average self-rated **knowledge increased significantly** from pre-test (M=2.05, SD=1.04) to post-test (M=3.66, SD=1.04),  $t(4.83)$ ,  $p<.001$ , with a large effect size of **1.5 points.**



- Before reviewing the Engagement Tool, **only 16%** of participants accurately identified the symptoms associated with cachexia, compared to **69% of participants** at post-test.

- A significant proportion of participants **increased the accuracy of their knowledge** around cachexia symptoms between pre and post-test based on McNemar's test ( $p<.001$ ).



- After reviewing the Engagement Tool, **77% of participants** were willing to talk to their provider about cachexia, compared to only **38% at pre-test.**

- Most participants were willing to share the Tool with their **providers**, as well as **other patients, caregivers, and friends.**

## CONCLUSIONS AND IMPLICATIONS

- Reviewing the Engagement Tool was associated with **increased self-rated knowledge, increased accuracy of knowledge, and increased willingness to communicate** about cancer cachexia.
- Coordinated dissemination of the tool in diverse venues and formats may encourage communication around the condition, **increase diagnosis**, and connect patients and caregivers with **supportive care.**
- Educational interventions around cancer cachexia are essential in **raising awareness** around the condition, increasing patient-provider communication, and increase **the rate of diagnosis and support.**

ACKNOWLEDGMENTS Funding support for this study was provided by Pfizer