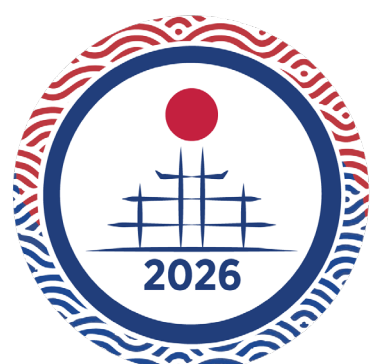


Understanding Lung Cancer Researchers' Experiences and Perspectives on Patient Research Advocate Engagement: Results from a National Survey

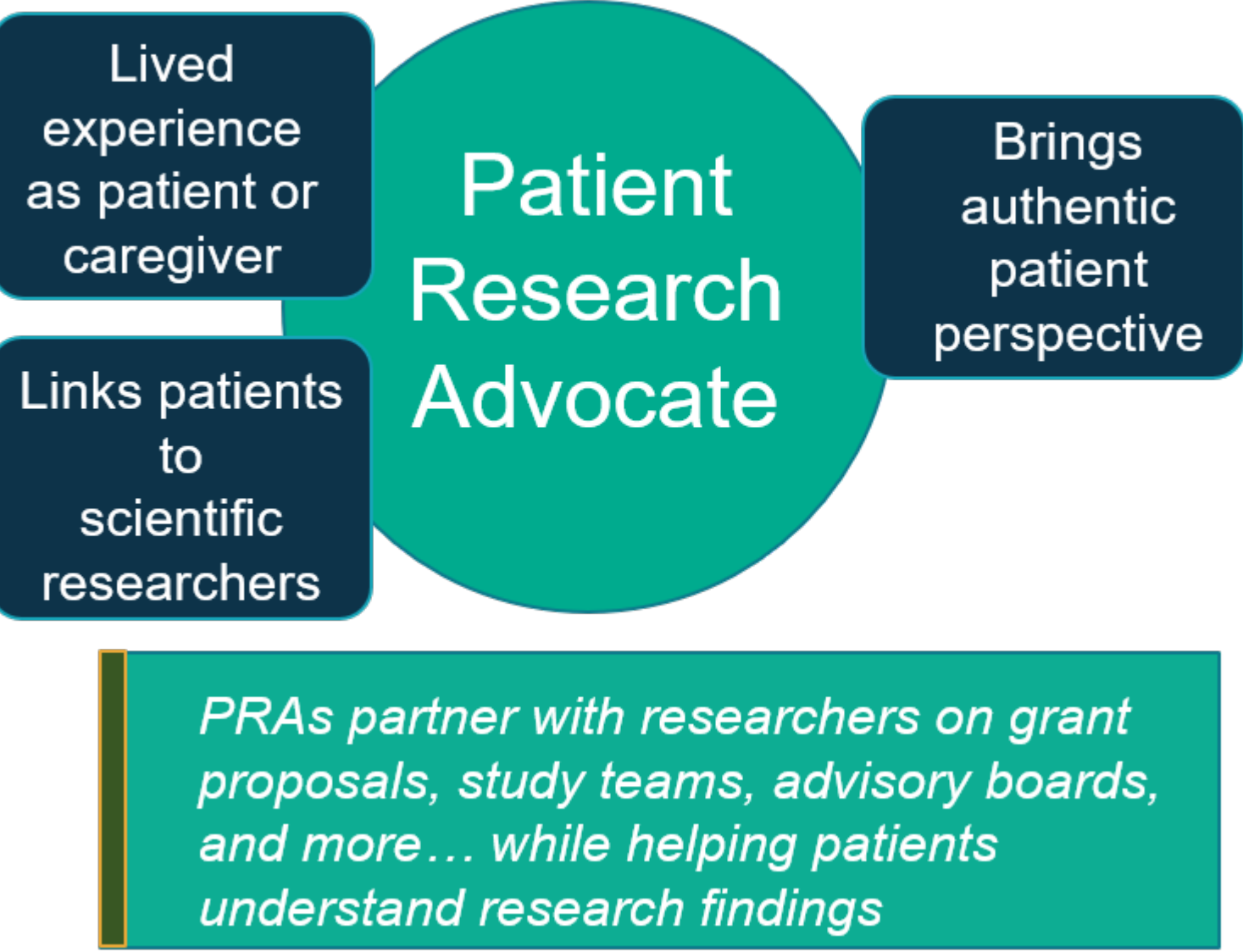
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IASLC 2026 World
Conference on Lung Cancer
SEPTEMBER 12 - 15, 2026
SEOUL, REPUBLIC OF KOREA

INTRODUCTION

WHO IS A PATIENT RESEARCH ADVOCATE?



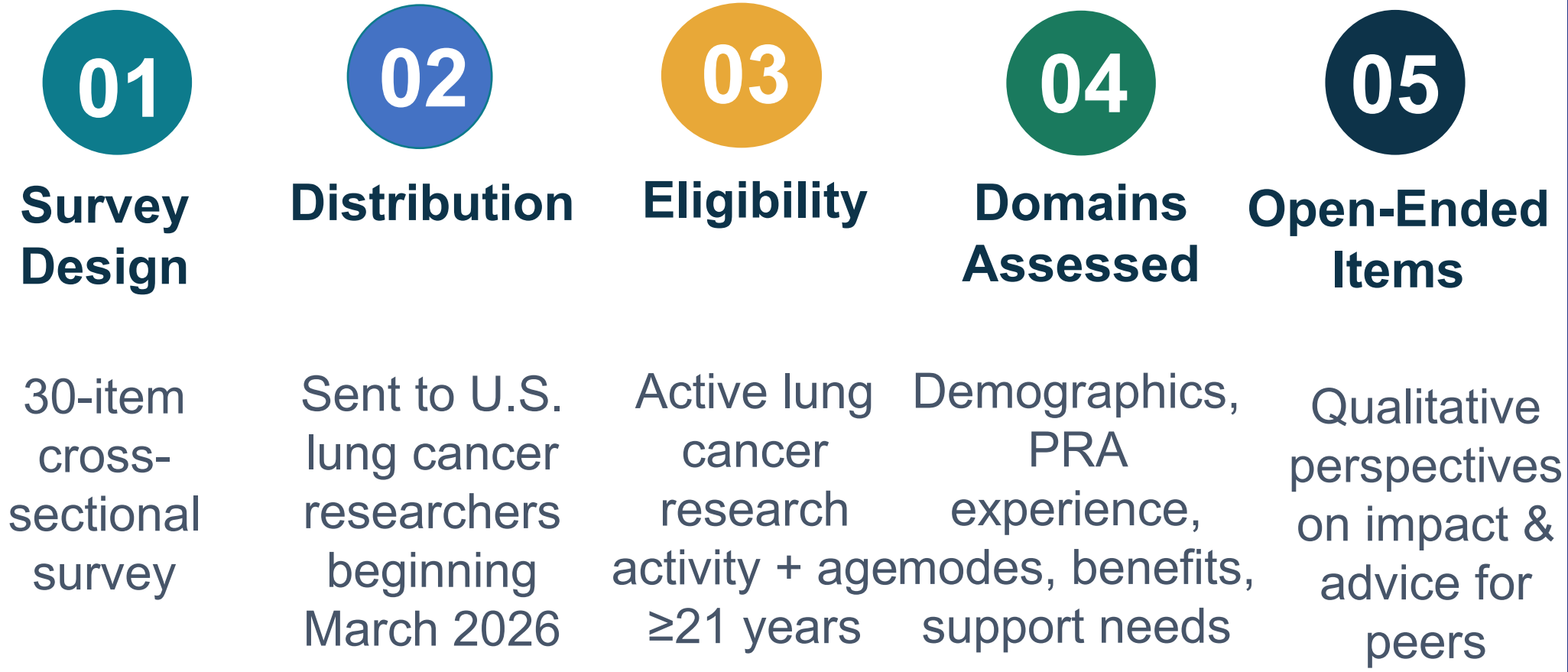
The Research Gap

- Barriers to why patients do not participate in research are well-documented in the literature.
- Little is known about how researchers themselves experience PRA engagement, especially in lung cancer.

Study Purpose: To characterize U.S. lung cancer researchers' experiences, perceived benefits, barriers, and support needs surrounding PRA engagement in research.

METHODS

Design: A 30-item, cross-sectional online survey was co-developed by patient research advocates and lung cancer researchers, and distributed beginning March 2026.

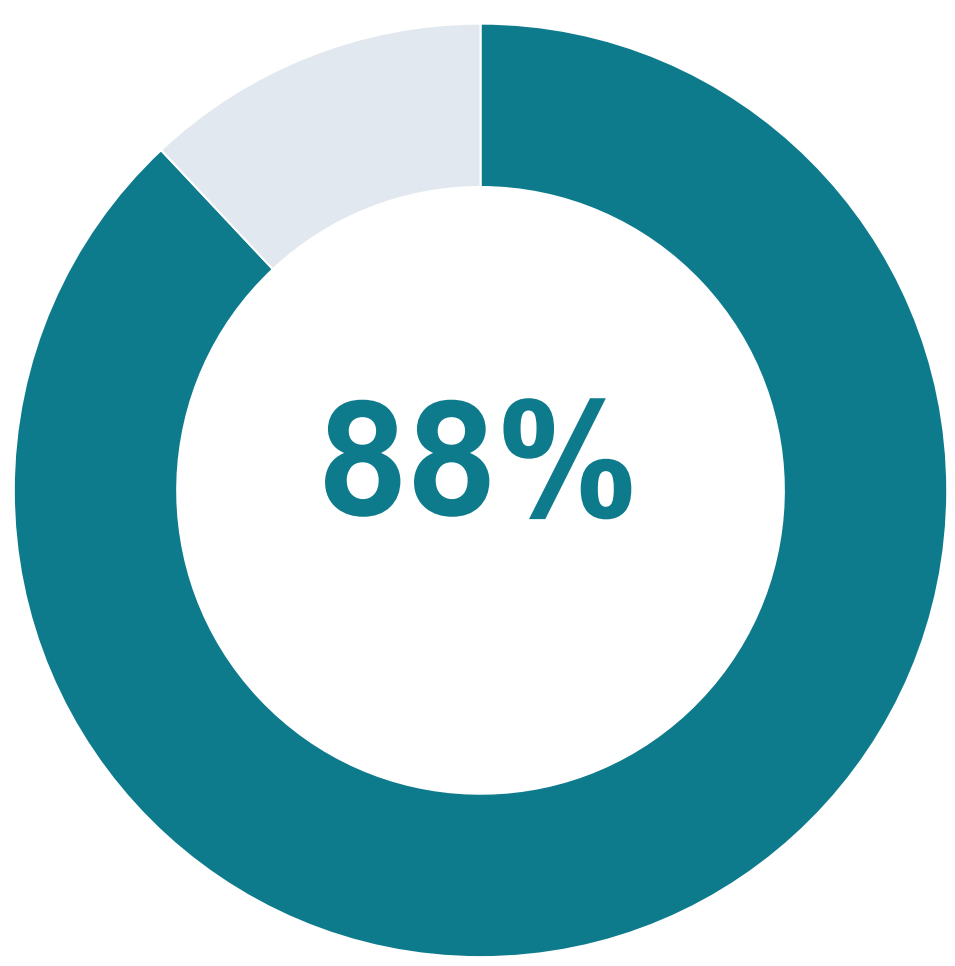
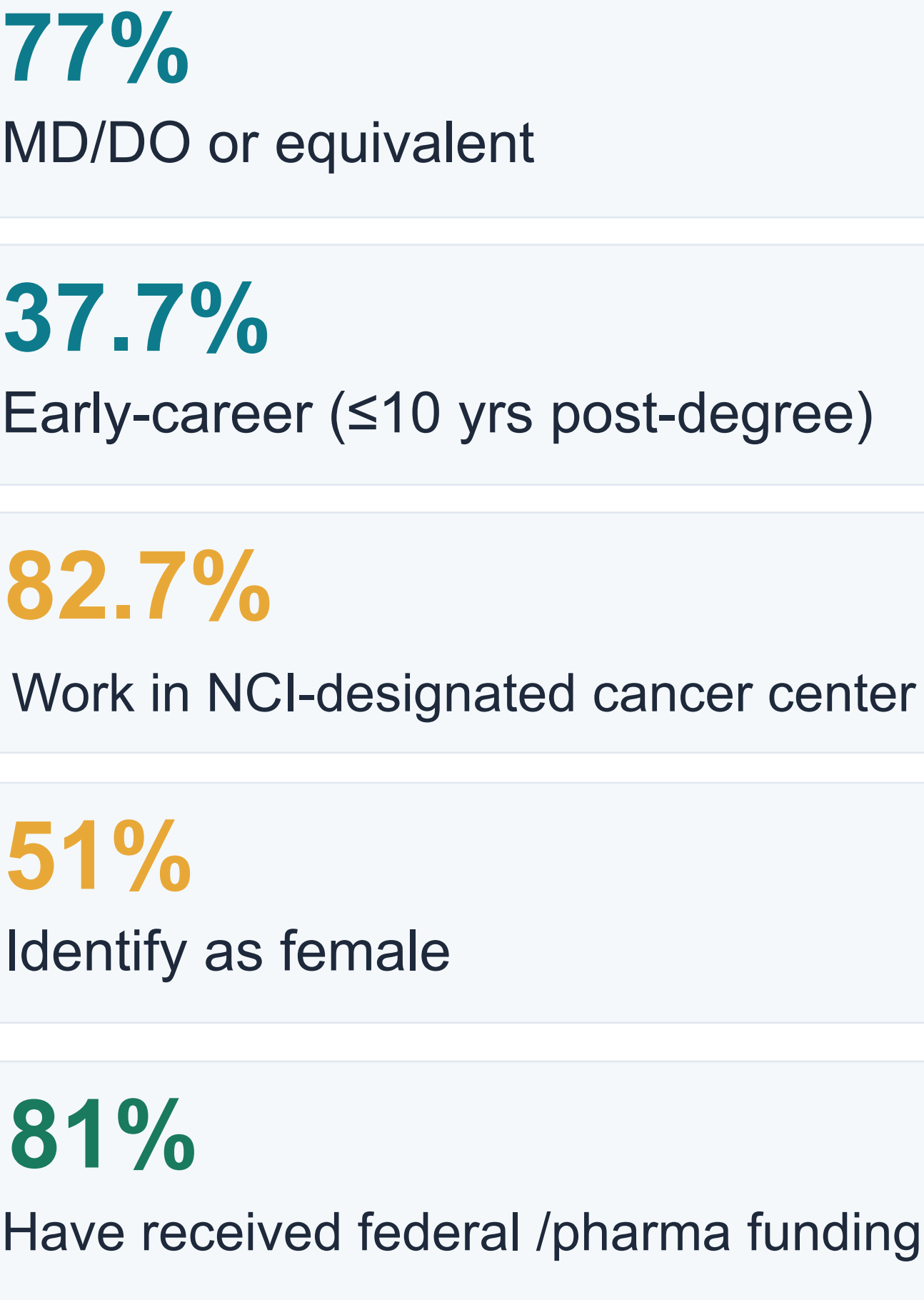


Analysis: Responses were summarized using descriptive statistics (%; n); open-ended items were summarized thematically. Denominators vary by item due to skip logic and optional questions. Multi-select items permit totals over 100%.

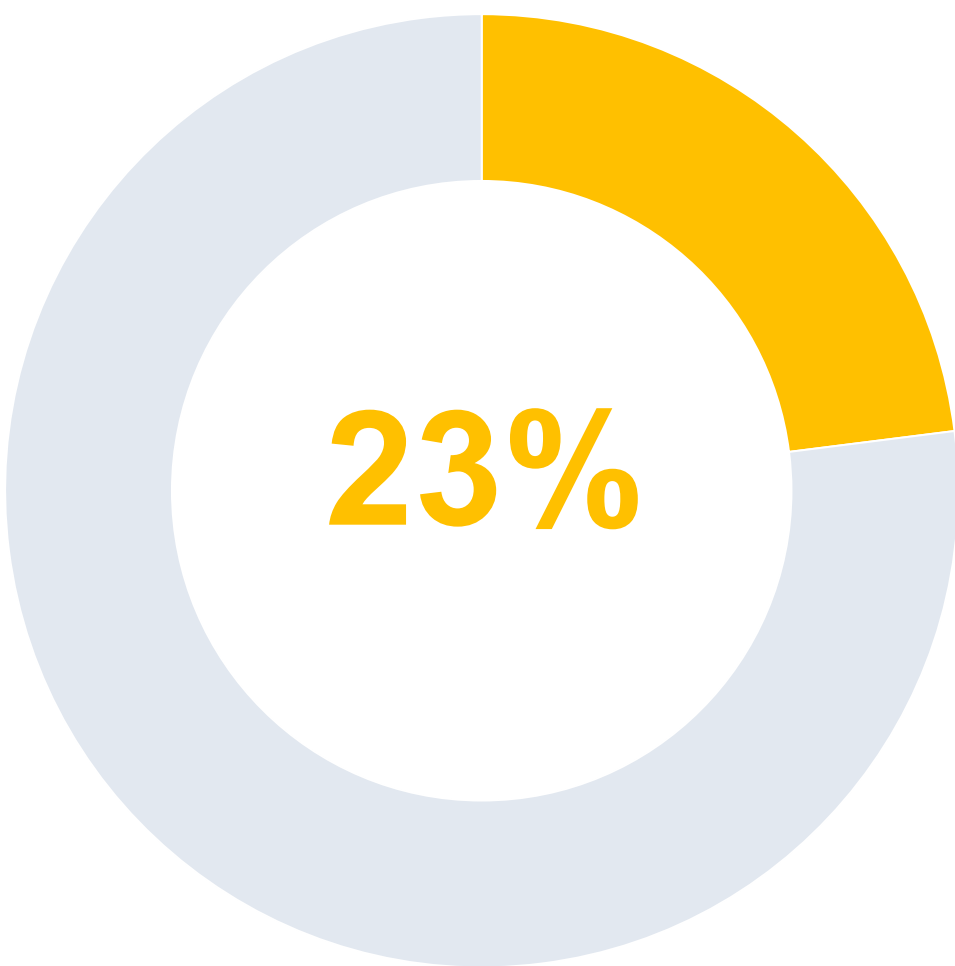
n = 103 researchers responded; 95 met eligibility criteria (active U.S. lung cancer research, age ≥21 years).

RESULTS

Experience Working with Patient Research Advocates (n = 95)



Have worked with a PRA



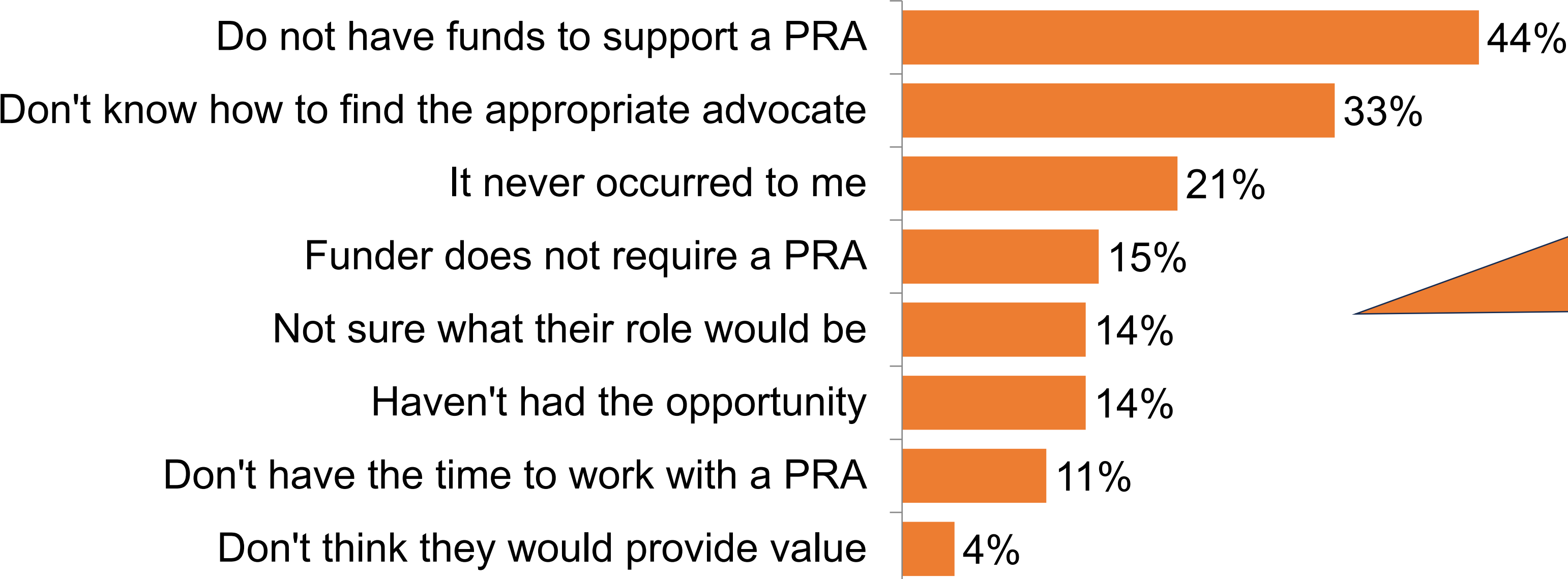
Included a budget to compensate PRA time



Rated the experience very/somewhat beneficial

"Lack of patient perspective would have impacted the development of study protocol and consent. The study was a lot more practical for both the patients and physicians"

Barriers to Engaging a PRA (n = 72)



"I don't know how or where to find the appropriate advocate"
"I don't have the funds to support a patient research advocate"
"I'm not sure what their role should be"
"Clear guidance, policies, funding and resources are needed."

What Would Facilitate Greater PRA Engagement (n = 94)



TAKEAWAYS

- Lung cancer researchers who have worked with PRAs report near-universal benefit, including more patient-centered research and improved incorporation of the patient perspective.
- However, many researchers have never engaged a PRA. Rather than lack of interest, it's often due to lack of dedicated funding (44%), difficulty finding an advocate (33%), time constraints, or lack of training/guidelines.

FUTURE CONSIDERATIONS

- Dedicated funding:** Build advocate compensation into grant budgets and institutional support
- Matching resources:** Accessible advocate contact lists and advocacy-organization partnerships
- Formal training & guidelines:** Clear institutional/funder standards for PRA engagement
- Expanded outreach:** Build capacity among underrepresented lung cancer communities
- Global framework:** A partnership model that reflects diverse international contexts

THANK YOU

We thank the 103 lung cancer researchers who completed this survey, and AACR, ASCO, SWOG, ECOG-ACRIN, NRG, IASLC, LUNgevity, and the EGFR Resisters community for supporting distribution.