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PURPOSE

The purpose of this project was to **identify the needs of researchers and patient advocates involved in research at the UNC Lineberger Comprehensive Cancer Center (UNC Lineberger), in order to expand the capability and quality of their engagement.**

INTRODUCTION

- **Key Definition:** “**Patient advocates**” may refer to those receiving care, survivors, caregivers, or other individuals with a stake in a patient’s respective health outcomes.
- Engaging patient advocates in research is a practice that identifies and prioritizes patient perspectives and needs throughout the academic or clinical research process.
- Research shows that engaging advocates in research can have a multifaceted positive impact, including better quality research, expanded applicability of research, and greater understanding of findings within the patient community.
- Most researchers report limited engagement of advocates in their research citing significant challenges in its implementation.
- UNC Lineberger recognizes the importance of understanding the current engagement structure and identifying ways to increase meaningful opportunities for advocates to participate throughout the research process.

METHODS

- Our study assessed researcher and patient advocate needs using mixed methods.
- Researchers involved in patient-engaged research (PER) were identified from a pool of active researchers at Lineberger. Their needs were assessed quantitatively using a Qualtrics survey measuring their involvement and satisfaction with incorporating advocates in research, current communication methods, and training.
- Quantitative data collected from the survey was analyzed using both Qualtrics’ internal report output and Excel.
- Our team also conducted four qualitative interviews with Lineberger-affiliated researchers, to learn more about PER, communication, and training needs.
- Patient advocate needs were assessed by conducting a focus group with five Lineberger advocates to explore their connection process with researchers, their training experience, and perceived utilization in cancer research.
- The interview and focus group recordings were reviewed internally and critical ideas were transcribed to identify themes.

Questions or comments? Please contact jpotter4@med.unc.edu.

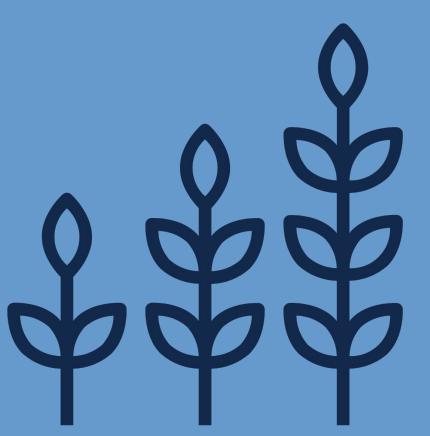
THEMES AND RECOMMENDATIONS



Training

Recommendation: Provide formal and systematic PER training for both researchers and patient advocates.

“I’m relatively new to the process and really just started this spring. Lots of acronyms were used, not necessarily medical, even UNC-related, it can be quite difficult to try to stay with the conversation and stay up to speed. I feel like I’m getting there, but to have gotten some training right up front would’ve been very helpful.”



Expansion and Diversity

Recommendation: Diversify the patient advocate pool to better represent the Lineberger patient profile. Provide adequate compensation for patient advocates involved in Lineberger PER to ensure the engagement is equitable and ethical.

“[Ideally] making sure that the pool of engaged patients are diverse. So, and that’s a challenge right..Often you get a lot of individuals who have the means and time to engage which usually means they’re more affluent. That can be true of any race, any gender, any age. So I feel like the individuals who are least likely to engage are actually some of the ones that we could really use their input, but we don’t get it.”



Communication

Recommendation: Encourage more frequent interactions between patient advocates and researchers to help identify problems as they emerge in the research process; develop a web-based communication platform for connecting patient advocates with researchers.

“I think once a month might not be enough for them [patient advocates] to fully grasp what the researchers are actually doing to be a real vital part of the process. I think a little more time spent between researchers and patient advocates would be better.”



Connection

Recommendation: Create a list of trained and vetted patient advocates that is available to all Lineberger researchers; develop and publicize a system to match patient advocates by study needs.

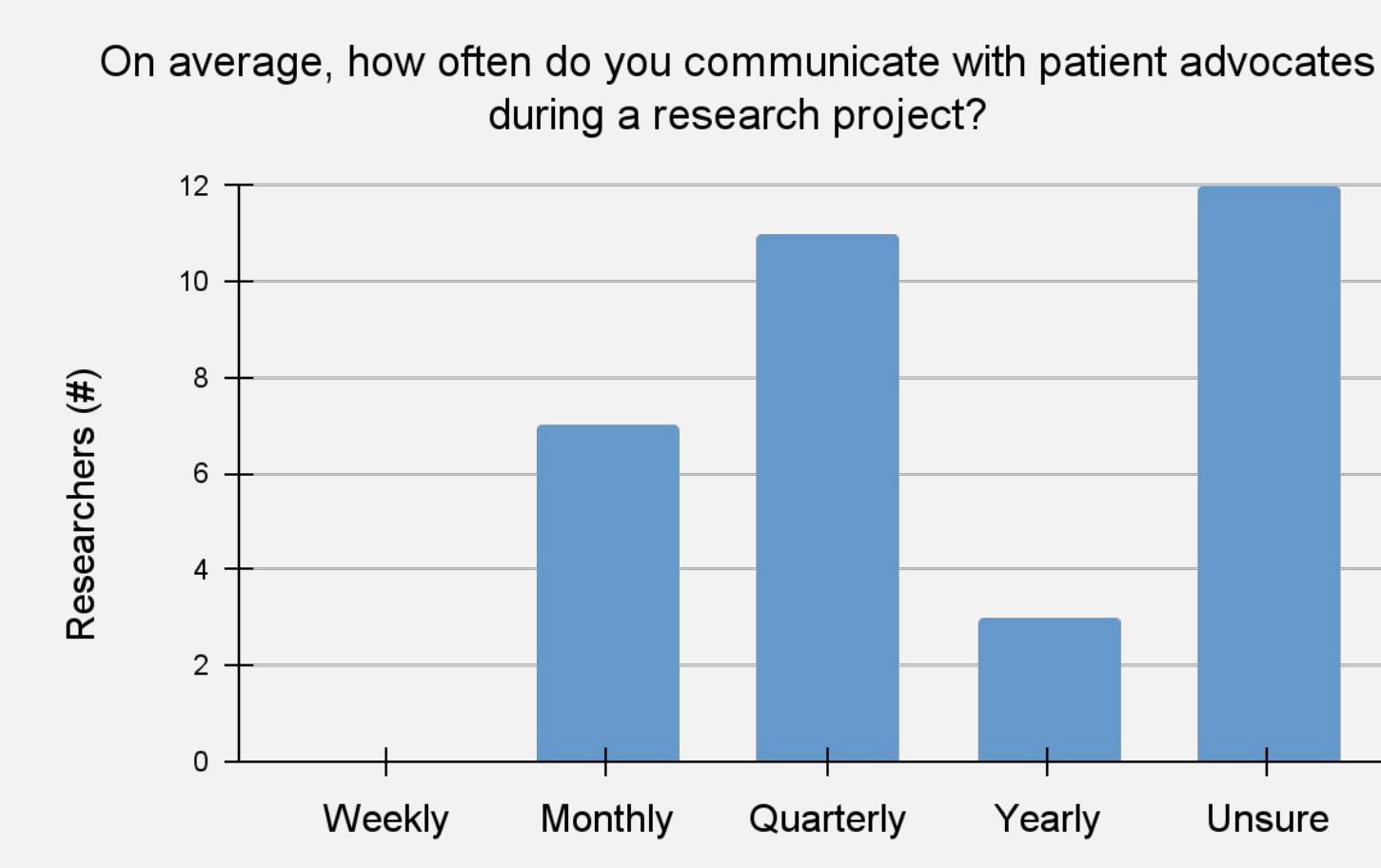
“National organizations typically have a website somewhere that you can find a point of contact to...there’s more structure, and it’s something more formalized that...helps facilitate the initial contact. It at least gives the perception that it’s easier to approach. I think when you’re talking more about the local levels, it’s like, who do I talk to? It’s unknown and you have to seek guidance...it’s very decentralized locally.”

PARTICIPANTS

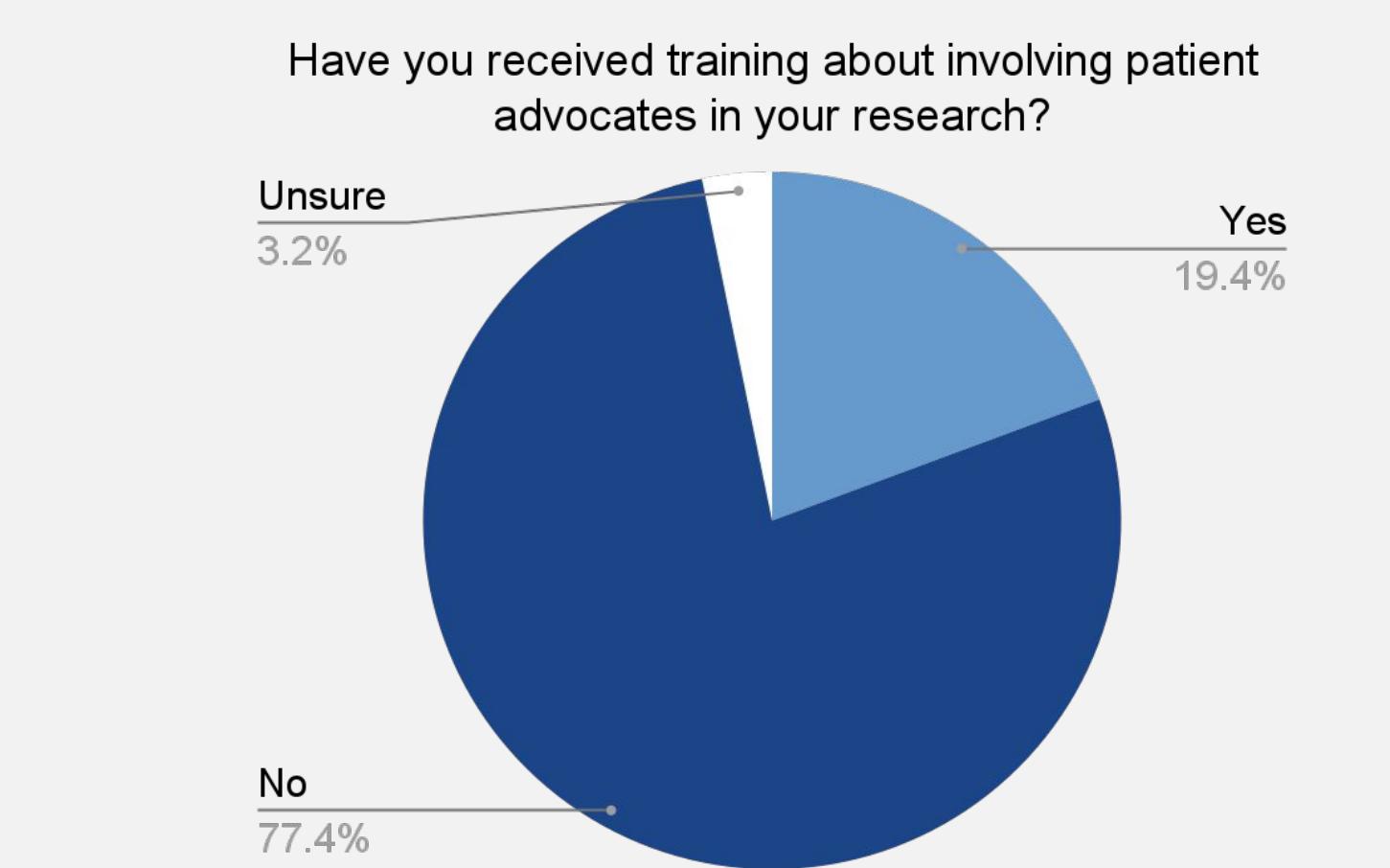
- Participants in the survey portion of the project were researchers from UNC Lineberger.
- Out of 75 active-PER researchers contacted to complete the survey, 38 responded, resulting in a 51% response rate.
- The majority of researchers have worked with current cancer patients (50%) or cancer survivors (71%).
- About half (45%) of the respondents reported having involved patient advocates in their research for more than 5 years, though 7 respondents (21%) reported less than 1 year.
- The majority (58%) reported that only 1 or 2 projects in the last 5 years involved patient advocates.

QUANTITATIVE RESULTS

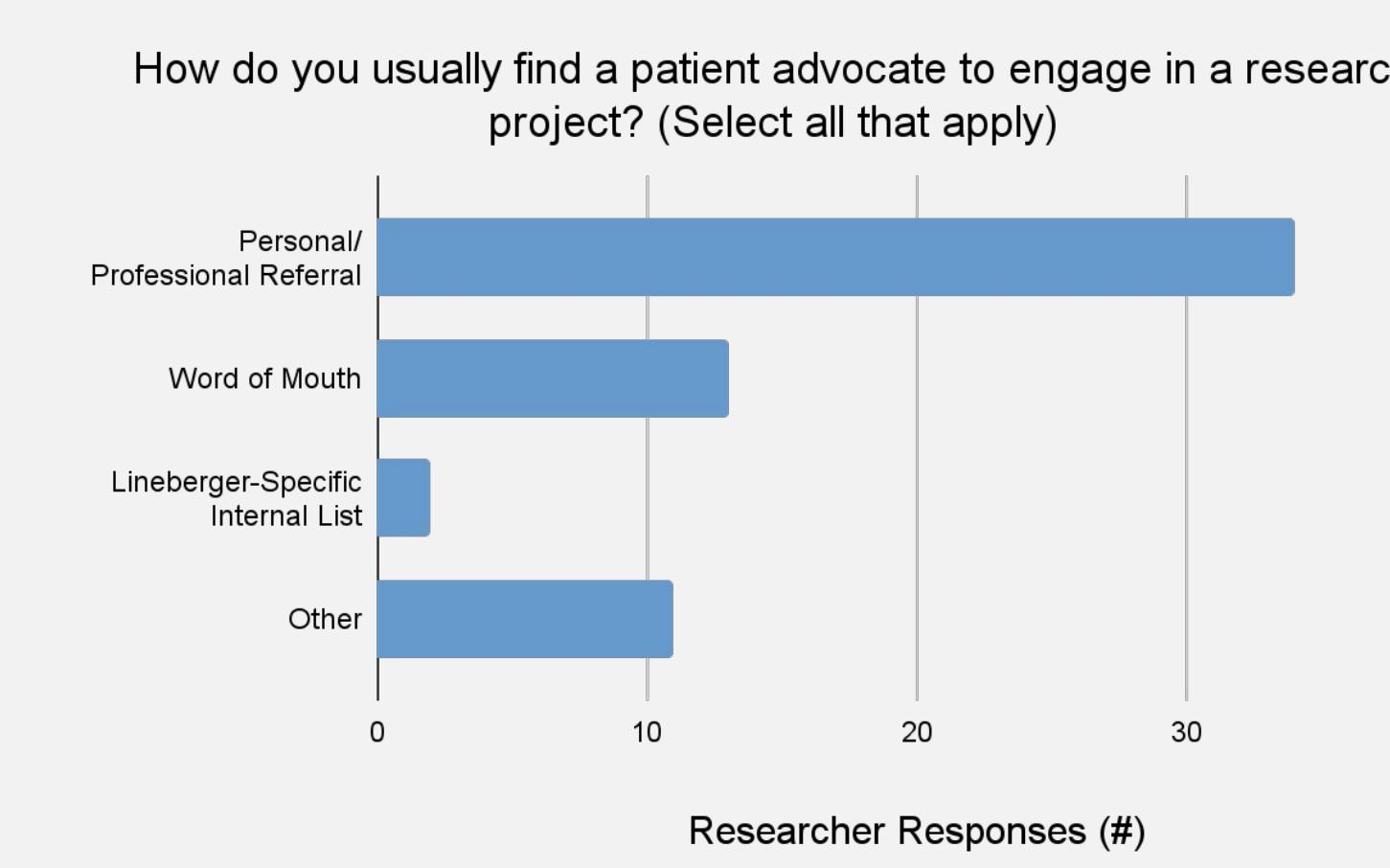
The amount of communication between researchers and patient advocates varied, but most researchers indicated communication was quarterly or unknown.



The majority of participating researchers reported not having ever received formal training on involving patient advocates in research projects.



The most common way researchers found patient advocates to work with was through informal processes (word of mouth or reference-based).



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