

Patient Research Advocates (PRAs) are patients and caregivers who have had a personal experience with cancer. They engage in activities related to cancer research, providing a patient perspective to improve research relevance, quality, participation, education, and dissemination. STARS aims to train PRAs specifically for lung cancer (LC). We do this by educating active LC advocates about the science and research related to LC screening, diagnosis, and treatment; effective ways of communicating about LC science and research; and different types of research advocacy. We also provide networking opportunities with other lung cancer PRAs and education on specific focus topics (biomarkers, clinical trials, small cell lung cancer, immunotherapy, targeted therapies, lung cancer screening).

STARS aims to train Patient Research Advocates. Research advocates bring the patient voice to research-related efforts. STARS is not intended to help patients or caregivers learn how to become patient advocates or share their personal lung cancer story.

Patient advocacy is different than research advocacy, as shown in the chart below:

|                           | Patient Advocate  | Research Advocate  |
|---------------------------|---|--|
| <b>Focus</b>              | <ul style="list-style-type: none"> <li>• Support patients and their loved ones</li> <li>• Raise awareness and/or funds</li> </ul>   | <ul style="list-style-type: none"> <li>• Provide patient perspective on research to generate better LC outcomes</li> </ul>   |
| <b>Typical Activities</b> | <ul style="list-style-type: none"> <li>• Talk with patients about their cancer experience and treatment challenges</li> <li>• Create and manage support groups</li> <li>• Act as liaison between patients, clinicians and family members</li> <li>• Share personal story to raise awareness or funds for research, support, advocacy</li> <li>• Educate local groups about cancer experience and care</li> <li>• Provide resources and services to patients and family (e.g., rides to treatment)</li> <li>• Share, moderate, curate on social media</li> <li>• Raise awareness of cancer events, treatment advancements, and the need for funding</li> </ul> | <ul style="list-style-type: none"> <li>• Learn about lung cancer science and research</li> <li>• Interact and communicate effectively and appropriately with researchers, regulators, industry, and government agencies</li> <li>• Represent and share patient perspectives for ALL lung cancer patients (not just those with your type or stage of lung cancer or personal characteristics)</li> <li>• Participate in grant reviews, Institutional Review Boards, patient advisory boards for pharma</li> <li>• Provide feedback on research questions and design</li> <li>• Know when it is NOT appropriate to share some or all of your cancer story</li> </ul> |

The role of a STARS Mentor is to help guide and encourage patients and caregivers in their efforts to become PRAs. Mentors provide support, share lived examples of research advocacy, help develop scientific understanding and skills, demonstrate effective science communication, and foster PRA comfort in interacting with scientists and clinicians.

Lung cancer patients who apply to the STARS program should have either stable disease or no evidence of disease on date of application. We want you healthy enough to complete the program and share the skills you learned afterwards!

We will evaluate STARS Mentor applicants using the seven criteria below. We do NOT expect every Mentor applicant will have skills in all these areas. Each applicant will likely have strengths and deficits--for instance, formal training in a Focus Topic but limited advocacy experience (such as a researcher), or considerable accomplishments as a research advocate in the US but no knowledge of disparities. That's OK! Lung cancer is a broad field, and no one can do everything.

We are seeking to build a pool of Mentors that will *collectively* exemplify all these characteristics:

- **Mentoring skills and experience** – Mentoring also requires good listening skills; answering PRA questions on research advocacy, science, and research accurately and clearly; providing guidance; and ability to help a PRA feel welcome and supported. At a minimum, all mentors must demonstrate empathy, patience, ability to accept differences in style and priorities, and availability before, during and after WCLC to spend several hours with PRAs (either online or in person) and attend all required STARS activities.
- **Advocacy accomplishments** – Mentors who have demonstrated dedication and experience as advocates or in working with advocates are better able to guide PRAs evolution into becoming research advocates.
- **Research advocacy accomplishments** – Mentors need to be able to share their experiences with and concrete examples of research advocacy with PRAs. We expect patient and caregiver Mentors to have at least 2 years' experience in research advocacy.
- **Communications skills and experience** – Mentors must be able to read and speak in English, which is the primary language of many oncology conferences and publications. They must demonstrate they can communicate science and research concepts confidently in an understandable and approachable way.
- **Science and research training and expertise** – We want Mentors who have previous training or demonstrated knowledge in key areas of lung cancer science and research. We seek a mix of backgrounds so that the knowledge of the collective Mentor pool covers all the STARS focus areas.
- **Interaction with scientific community** – Mentors facilitate PRAs' connection and communication with lung cancer scientists, clinicians, and key opinion leaders.
- **Knowledge of cancer care disparities** – This can be personal, professional, or research experience with national health systems, third world countries, or disparities in accessibility, affordability, and availability of lung cancer care.