**Title:** Identifying Unique Challenges and Opportunities in Incorporating Patient Advocates into the Lung Cancer SPORE Program

**Authors:** Elda Railey, Marcia Horn, Merel Mountain-Grey, Lisa Spain

**Abstract:**

Incorporating advocates into the Lung Cancer SPORE program has been a top priority since its inception. While there has been progress in achieving meaningful involvement, qualitative research conducted by the Research Advocacy Network Advocate Institute has identified some unique challenges for both the patient advocates and the SPORE scientific research team members.

**Patient Advocate Challenges:**

- Understanding the science, methodology and statistical approaches used in translational studies involving preclinical models, patient biospecimens, and early/late phase clinical trials.

- Learning how to apply critical thinking to analyze the presented science to understand and evaluate the validity, significance, quantitative impact of the findings and likelihood of eventual translation into patients

- Learning how to provide and communicate a patient's perspective that applies to translational science settings, including team members of variable degrees of experience and expertise, and that actually can help scientific team members improve and extend their findings.

**Scientific Team Challenges:**

- Understanding how to collaborate with patient advocates – learning what constitutes different types of interaction (learning from patients, teaching advocates, information sharing, joint decision-making)

- Addressing communication and terminology challenges to improve communication between advocates and scientists

- Teaching young, clinical translational research inexperienced scientific team members how to interact beneficially with patient advocates (Career Enhancement, Developmental Projects)

- For non-clinical scientific team members how to appreciate dealing with lung cancer from a patient and family’s perspective

**Resources Developed:** To address these challenges, the Research Advocacy Network has developed several resources ( <https://researchadvocacy.org/pdf-resources> ):

- Piloted a training with virtual Learning Labs with topic expert and online curriculum covering translational science-specific topics, such as an overview of translational science, biomarkers, cell biology, correlative research, as well as a skill-building session on critical thinking.

- A video for researchers to explain how to collaborate with advocates <https://vimeo.com/790243746?share=copy>

The UT Southwestern/MD Anderson Lung SPORE (P50 CA070907) members played a significant role in contributing to the qualitative research, curriculum development, and delivery. Plans to offer the Translational Science curriculum for Advocates to all SPORES and expand the distribution of the video are underway. Evaluating the program's impact will be essential to its success.

(Abstract =350 words)