Enhancing the Value of NCI Task Force and Steering Committee Patient Advocates via the NCI Patient Advocate Steering Committee: 2016-2020

CTAC Meeting
November 4, 2020
Presenters

Kim Norris
President/Co-Founder
Lung Cancer Foundation of America

Rick Bangs, MBA, PMP
Chair, SWOG Patient Advocate Committee
Agenda

- Patient Advocate Steering Committee (PASC) Background
- Improvement Actions
- Discussion and Input
- Defining Success: a PASC Leadership View
- Next Steps
The Patient Advocate Steering Committee (PASC) works to ensure that advocates involved with the Scientific Steering Committees (SCs) and their Task Forces (TFs) are effectively and consistently integrated with the evaluation and monitoring of clinical trials within those groups.

PASC membership is composed of the patient advocate members of the NCI Scientific Steering Committees and their respective Task Forces.
PASC Mission

- The PASC functions to
  - Develop and share best practices for patient advocate interactions in SCs
  - Identify common concerns and potential solutions to address the concerns
  - Identify training needs and work with appropriate bodies to develop and implement training
  - Communicate information to and from SC and TF advocates
Getting to Success: 2016-2020

- Clarified scope of role
  - NCI vs. NCTN roles
  - Task Force (TF) vs. Steering Committee (SC)
  - Research advocates vs. general advocates
  - Patient advocate skills and knowledge
SC and TF Patient Advocate
Focus Competencies* (Skills and Knowledge)

Cancer & Research Competencies

TF & SC Role Competencies

NCI Process Competencies

Effective Engagement Competencies

*Competencies can range from familiarity to expertise
Improving the PASC

Inputs
- Surveys

Methods
- Working Groups
  ✓ Orientation
  ✓ Mentoring
  ✓ Concept Review

Outputs
- TF and SC role and job spec
- New Concept Review Form
  ✓ Guiding questions
  ✓ Samples
- Onboarding
  ✓ Training/Guidance
  ✓ Videotaped review guidance
- Mentoring
- “Presentation Brief”

Materials are stored centrally, organized for ease of use, and available 24x7 in OneHub.
Clarified scope of role and relationship to NCTN

Concept Review Process

Steering Committees \textit{with} Task Forces
Concept must go through the appropriate Task Force prior to going to the Steering Committee.

Steering Committees \textit{without} Task Forces
Concept goes directly to the Steering Committee.
Created a presentation brief for speakers to guide their presentation and maximize relevance to TF and SC work; includes these questions:

- What part of their work does your content relate to?
- What new information can they apply to their work tomorrow when a new concept is provided?
- What changes in the way they work or provide input will your content trigger?
- What future concepts will the PASC likely see resulting from your content?
- What concerns might your content expose and how should the PASC approach those concerns?
- What further actions or education should the PASC consider?
- What lessons learned can the PASC apply?
Getting to Success: 2016-2020

- Developed in-depth orientation, training and development, and related mentoring programs including self-assessment

Module 1: Overview of the NCI and the NCI Steering Committees

Module 2: Biomarker, Imaging and Quality of Life Studies Funding Program (BIQSFP)

Module 3: The Concept Evaluation Process

Module 4: Patient Advocate Preparation for a Concept Review

Module 5: The Patient Advocate Steering Committee

Module 6: Resources
7. **Patient Advocacy Evaluation Questions**

7.1 How important is this trial to people who have been or will be diagnosed with this disease?

7.2 What aspects of this trial design might attract patients or be of concern to patients?

7.3 How well does this trial balance the risk, benefits, and burdens of the patient and/or the caregiver?

7.4 What effect will the eligibility/inclusion and exclusion criteria have on the target patient population?

7.5 Is this study likely to be able to meet accrual goals and retain patients through completion?

7.6 Are there other patient-related issues that should be considered?
Provide resources via one-stop shopping on a secure website (OneHub)
Defining Success of the PASC: Co-Chair View

- The PASC is successful when TF and SC Advocates:
  - Provide clarifying questions to the study team as part of the pre-meeting preparation
  - Participate in the review process of the TF or SC
  - Offer opinions and their opinions are valued
  - Provide input reflected in the documented decision to the NCTN Group Chair and the PI
The PASC is successful when TF and SC Advocates:

- Are part of a multi-disciplinary team that is interested in the perspectives of all stakeholders, including the Patient Advocates
- All advocates provide input
- Bring a familiarity and interest in research to the role
- Receive an onboarding that clarifies expectations and establishes a solid starting point for their relationship with TF or SC
Current PASC Leadership & Support Team

Annie Ellis, PCPI-UCPI  
PASC Co-Chair

Danielle Leach, MPA  
PASC Co-Chair

Deborah Jaffe, PhD  
Associate Director of NCI  
Steering Committees

Jean Lynn, MPH, RN  
PASC Facilitator

Sherill, Smallwood, MS  
PASC Coordinator

Evelyn Obot, PhD, PMP  
PASC Co-Facilitator
Next Steps

- Publish manuscript of evolution and supporting activity
- Consider how to leverage process and tools beyond PASC
“Research advocates play a vital role in shaping NCI’s work. They challenge us and ensure that we never lose sight of what we are here to do – which is to improve patient outcomes by advancing cancer research. We can’t do this without the unique perspectives research advocates bring.”

– Dr. Douglas Lowy, Principal Deputy Director, NCI