

**A presentation of the National Cancer Institute (NCI), National Institutes of Health, Department of Health and Human Services**

**The NCI Advocates in Research Working Group (ARWG) Public Comment Call**

**Presented by Kelly Cotter, Chair, ARWG and Shannon Bell, Office of Advocacy Relations Director  
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### **Rationale for the Advocates in Research Working Group (ARWG)**

ARWG Charge:

To harness the knowledge, experience, and leadership of the Working Group to capture a clear picture of where and how advocates are successfully expediting advances in cancer research.

To provide NCI with recommendations for involving advocates across the spectrum of NCI activities in ways that will accelerate progress, benefit patients, and improve public health.

### **General Working Group Process**

This slide shows the process for a working group of a Federal Advisory Committee Act (or FACA) group. The working group is always formed as a subcommittee of a FACA group (in this case the NCI Director's Consumer Liaison Group). The working group then decides on a process to create a report or recommendations to the FACA group. The FACA group then votes to accept, or not, those recommendations or report. If the FACA group accepts the report, it is then forwarded to the appropriate Federal Agency leadership as a formal recommendation of the FACA group. In this case, the appropriate leadership is the NCI Director. The NCI Director then can chose to accept or reject the recommendations and instructs NCI staff on implementation of recommendations.

### **Advocates in Research Working Group Membership**

The membership of the ARWG was expanded between the group's work in its first phase and its second phase. In Phase One of its work the advocate members of the group were: Kelly Cotter, Vernal Branch, Deborah Collyar, Peggy Devine, Cindy Geoghegan, Richard Gorlick, Francine Huckaby, Paula Kim, Gerald (Buddy) Leo, Lori Monroe, Nancy Roach, and Jim Williams, Jr. The extramural members of the group were: Kirby Bland, Paul Bunn, Jr. , H. Kim Lyerly, and John Minna. The NCI staff members of the group were: Shannon Bell, James Hadley, Shamala Srinivas, and Jaye Viner.

In Phase Two of its work the membership was expanded. In Phase Two the advocate members of the group are: Syed Ahmed, Vernal Branch, Deborah Collyar, Jane Condon, Kelly Cotter, Karen Creamer, Peggy Devine, Cindy Geoghegan, Richard Gorlick, Francine Huckaby, Paula Kim, Margo Michaels, Ann-Gel Palermo\*, Jane Reese-Coulbourne, Nancy Roach, and Jim Williams, Jr. The extramural members of the group in Phase Two were the same as in Phase One. The NCI staff members in Phase Two include: Margaret Ames, Shannon Bell, Michelle Bennett, Nancy Breen\*, Jeanette Contreras\*, Jane Daye, Andrea Denicoff, Brenda Edwards, Susan Erickson, Nina Ghanem, James Hadley, LeeAnn Jensen, Jennifer

Loud, R. Allan Mufson, Kimberly Myers, Julia Rowland, Shamala Srinivas, Sudhir Srivastava, Lisa Stevens\*, Judith Swan, Anne Tatem\*, Ted Trimble\* , and Jeff White. Any member with an asterisk next to their name is an alternate member.

### **ARWG Process**

The ARWG has used a work process with four components: Introduction, Phase One, Phase Two, and Phase Three. The Introduction period was when the formal charge to the working group was developed and members were chosen. Phase One consists of analyzing background information, developing some early findings, and developing the ideal model of advocacy involvement. Phase Two consists of conducting an organizational analysis and developing initiatives. Phase Three consists of developing implementation recommendations and the final report.

### **Phase One Subgroups**

In Phase One four subgroups were formed: Review, Advise, Design, and Disseminate. Each subgroup discussed several topic areas: experience, skills and qualifications; selection process; training; information and resources; facilitating involvement; communication and feedback; evaluation and tracking; and compensation.

### **Phase Two Subgroups**

In Phase Two four different subgroups were formed: Preparation, Initiation, Activity, and Maintenance. The Preparation subgroup discussed necessary experience; skill sets and qualifications; and training. The Initiation subgroup discussed the selection process; ethics issues; and compensation. The Activity subgroup discussed the process for facilitating involvement; and information and resources. The Maintenance subgroup discussed evaluation and tracking. All four subgroups discussed communication.

### **Organizational Analysis (A Step in Phase Two)**

The goal of the organizational analysis is to gain a better understanding of where and how advocates are being utilized across NCI and throughout NCI-funded activities. The rationale for this analysis is that the comprehensive and relevant information from the organizational analysis will help NCI identify best practices, potential barriers, and future opportunities for advocate involvement. The analysis will provide us with vital baseline information that will help us develop effective implementation plans.

### **Phase Two – Initiatives**

1. Assess and Qualify Advocate Experience & Skills
2. Create a Code of Conduct
3. Create a Transparent Environment
4. Create a Process for Advocate Involvement
5. Identify Training Opportunities
6. Provide Information and Resources

7. Track and Evaluate
8. Recognize and Promote Successes

### **1. Assess and Qualify Advocate Experience and Skills**

Rationale:

Developing metrics to assess and qualify research advocate experience and skills will:

- Improve alignment between each activity and the advocate selected.
- Enable transparent communication between NCI and advocates.
- Capture the depth and breadth of advocate experience.

### **2. Create a Code of Conduct**

Rationale:

Developing a Code of Conduct or Operating Principles for involving advocates in research will:

- Create shared expectations in support of productive relationships.
- Create guidelines around issues such as ethics, confidentiality, conflict of interest, compensation, etc.
- Provide a reference point for the community.

### **3. Create a Transparent Environment**

Rationale:

Increasing transparency and public accountability will:

- Increase public trust in cancer research activities.
- Maximize understanding of NCI activities.
- Identify opportunities for advocate involvement.

### **4. Create a Process for Advocate Involvement**

Rationale:

Creating a common process for advocate involvement will:

- Increase support for NCI Divisions, Offices and Centers who involve advocates by designing user-friendly customizable tools and resources.
- Enhance the opportunity to identify where, how, and when to most effectively engage advocates.
- Create a foundation for roles, expectations and desired outcomes.
- Improve efficiency.

## 5. Identify Training Opportunities

Rationale:

Building on existing resources to identify and address gaps in knowledge and experience will:

- Prepare researchers and program staff to effectively engage advocates.
- Ensure advocates have the knowledge necessary to fully participate.
- Provide a blueprint to keep advocates informed regarding cutting-edge science and advocate opportunities.

## 6. Provide Information and Resources

Rationale:

Building on existing resources to identify and address gaps in knowledge and experience will:

- Prepare researchers and program staff to effectively engage advocates.
- Ensure advocates have the knowledge necessary to fully participate.
- Provide a blueprint to keep advocates informed and able to fully participate as partners.

## 7. Track and Evaluate

Rationale:

Building on existing systems to track and evaluate advocate involvement will:

- Establish parameters and milestones for success.
- Allow NCI to report on advocate involvement.
- Allow for identification of additional opportunities for advocate engagement.
- Allow for the identification of specific recruitment needs.
- Measure the effect of advocate involvement in order to facilitate continuous improvement.

## 8. Recognize and Promote Successes

Rationale:

Recognizing advocates and the researchers who successfully involve them will:

- Encourage greater collaboration and exchange.
- Demonstrate appreciation for advocates and researchers.
- Provide greater awareness.

### Relationship Between Phase One Focus Areas and Phase Two Initiatives

Initiative one, Assess and Qualify Advocate Experience & Skills, is related to: experience, skills and qualifications; selection process; facilitating involvement; evaluation; and tracking.

Initiative two, Create a Code of Conduct, is related to: training; information and resources; facilitating involvement; and ethics and compensation.

Initiative three, Create a Transparent Environment, is related to: experience, skills and qualifications; selection process; training; information and resources; facilitating involvement; evaluation; tracking; and ethics and compensation.

Initiative four, Create a Process for Advocate Involvement, is related to: experience, skills and qualifications; selection process; training; information and resources; facilitating involvement; evaluation; tracking; and ethics and compensation.

Initiative five, Identify Training Opportunities, is related to: experience, skills and qualifications; training; information and resources; and facilitating involvement.

Initiative six, Provide Information and Resources, is related to: training; information and resources; and facilitating involvement.

Initiative seven, Track and Evaluate, is related to: experience, skills and qualifications; selection process; facilitating involvement; evaluation; and tracking.

Initiative eight, Recognize and Promote Successes, is related to: facilitating involvement; evaluation; and tracking.

### **ARWG Process – Next Steps**

Phase three comes next and that includes developing implementation recommendations and writing the final report.