

Slide 1

Outreach to Patient and Consumer Representatives

October 13, 2011

Carolyn Branson, Manager

Consumer Reviewer Administration

Slide 2

Topics

- Who are they?
- What characteristics do they share?
- How can you identify the “right” person for your needs?
- What selection techniques are effective?
- What has worked for SRA International?

Slide 3

Who Are Patient Representatives/Consultants?

- Patients/survivors/thrivers
- Patient advocacy group members
- Community advocacy group members
- Family members and/or caregivers
- Healthcare providers

Slide 4

Characteristics of Patient Representatives

- Have personal experience with the disease
- Are knowledgeable about treatment options and/or the science of the disease
- Are able to be objective and move beyond their own personal experience to represent others
- Are able to speak extemporaneously in public

Slide 5

Characteristics of Patient Representatives

- Are engaged with other patients and advocates (involved with or affiliated with a patient or consumer advocacy organization)
- Have no conflicts of interest that would significantly impact the research process

Slide 6

Identifying the “Right” Consumer Representative

- Allow adequate time for recruiting patient/consumer representatives.
- Clearly establish objectives, roles, and expectations before beginning the recruitment process.
- Develop relationships with advocacy organizations.
- Support groups and online groups may offer an opportunity to identify patients who might be underrepresented (such as for rare diseases).

Slide 7

Identifying the “Right” Consumer Representative

- Include patient and consumer representatives on selection committees to help recruit and retain representatives.
- Multiple recruitment methods should be employed in order to identify a broader demographic, including older patients, minorities, and the underserved.

Slide 8

Techniques for Selecting Patient Representatives

- Determine specific information needed:
 - Patient/caregiver experience
 - Advocacy experience
 - Ability to represent other patients/survivors
 - Knowledge and skills related to disease area
 - Alternate disease experience
 - Work experience
 - Education
- Interview representatives.

Slide 9

Techniques for Selecting Patient Representatives

- Include more than one patient/consumer representative in any activity:
 - Provides a broader perspective of the individual experience
 - Provides the patient/consumer representative with a colleague in the experience

Slide 10

SRA International and Consumers/Advocates

Slide 11

About SRA International, Inc.

- Founded in 1978, SRA is dedicated to solving complex problems of global significance for clients in national security, civil government, and global health.
- Within SRA, the vision of the Center for Peer Review and Science Management (PRSM) is enhancing human health around the world through innovative science, knowledge, and technology solutions.
- PRSM supports clients, including the DOD Congressionally Directed Medical Research Programs (CDMRP) under the U.S. Army Medical Research and Materiel Command (USAMRMC) and the Cancer Prevention and Research Institute of Texas Research Programs for which we recruit, train, and support consumer advocates (and scientists) for peer reviews. We have overseen the scientific peer review of nearly 70,000 research applications.

Slide 12

Successful Partnerships

Build strong partnerships with the advocacy/support community:

- Base all interactions on respect and acknowledged value of the consumer/advocates to the process.
- Maintain regular contact.
- Clearly define needs.
- Offer a “unique opportunity.”
- Set the standards high.

Slide 13

Successful Processes

- Follow detailed formal processes for
 - Recruitment
 - Support
 - Evaluation

Slide 14

Successful Processes

- Recruitment
 - More than 440 organization/agency contacts in the last 3 years alone
 - Includes nomination by organization
 - Nomination letter
 - Consumer/Patient resume
 - Essay
 - Includes assessment and telephone interviews

Slide 15

Successful Processes

- Support
 - Nearly 1,400 consumer reviewers in the pool for 18 programs over the years)
 - Training
 - Peer mentorship
 - Personnel support

Slide 16

Successful Processes

- Evaluation
 - Obtain feedback throughout the process.
 - Obtain feedback in a timely manner.
 - Debrief with all participants involved.
 - Modify/improve the process.

Slide 17

Successful Support

- Develop and provide easily accessible, appropriate training.

- Provide time immediately after their contribution for one-on-one or small group debriefing.
- Take all suggestions seriously.
- Quickly make suggested changes (“turning on a dime”) where feasible.
- Provide a written evaluation tool for consumers/advocates to provide input.
- Provide compassionate, passionate, and knowledgeable points of contact.

Slide 18

Summary

- Dedicate resources for recruitment.
- Develop partnerships for recruitment:
 - National and local advocacy organizations
 - Patient/consumer representatives
- Provide clear descriptions of the activity and expectations of involvement.