

Advocacy Relations

Shannon K. Bell, MSW, Director, Office of Advocacy Relations, NCI Bldg 31 Rm 10A28 would like to present a seminar on Patient Advocacy Relations at this years FYI symposium

Here is her overview of her proposed advocacy presentation. Please let me know if the steering committee thinks that this should be added to the meeting or if there are any questions or concerns. She is willing to modify the plan/outline if we believe that a different approach might be more useful.

EMAIL FROM SHANNON:

I am hoping to introduce the concept of Research Advocacy, ie: the idea of engaging advocates in the research process:

- Is it a good idea?
- If so, why?
- How can benefit the research - and therefore patient outcomes
- How can benefit the researcher

Here is an outline:

- The goal of involving advocates in research
- Models of Advocacy
- Advocacy Continuum
- Five Types of Advocacy
- Definition of a research advocate
- A framework for Research Advocacy at NIH
- How OAR can support you

I have attached an overview of advocacy to give you some context. Please let me know if you have any questions or concerns. I'm happy to modify the plan /outline if you feel a different approach might be more useful.

Shannon K. Bell, MSW

Director, Office of Advocacy Relations, NCI Bldg 31 Rm 10A28, 301-451-3393 Key info about NCI: <http://www.cancer.gov/aboutNCI/servingpeople>

Advocacy Background from the National Cancer Institute (NCI)

The goal of involving advocates in research is to enhance the scientific process and improve patient outcomes by providing diverse perspectives. Advocates have become increasingly involved in the research process over the last several decades. Within the last decade, the involvement of patient advocates in the research process, particularly in the cancer research process, has been made a priority by the governments of the United States and the United Kingdom. At the National Cancer Institute (NCI) the Office of Advocacy Relations (OAR) coordinates advocate involvement in NCI activities. **Models of Advocacy** Advocacy Continuum (developed by the National Coalition for Cancer Survivorship, found at <http://www.canceradvocacy.org>):

- Personal Advocacy – finding information, getting a second opinion, working for rights around privacy, employment, health insurance, etc.
 - Community Advocacy – speaking to others in the community, participating in support groups, engaging in community-based fundraising, etc.
 - National Advocacy – lobbying Congress around cancer concerns, telling one's story in the national media, participating in federal peer review
- Five Types of Advocacy (developed by Jane Perlmutter, Ph.D., Consultant and Cancer Research Advocate, found at <http://www.gemini-grp.com>):
1. Research - Ensure high quality research that is sensitive to the priorities of patients
 2. Support - Help people who are facing cancer
 3. Fundraising - Raise and distribute money worthy organizations involved in patient support, research and public outreach/education
 4. Outreach and Education - Increase public awareness of risks and realities of cancer as well as methods and progress of research
 5. Political - Impact public policy through lobbying **Advocacy at the National Cancer Institute**

The NCI's OAR works primarily with those who are in a research advocacy capacity at the national level. OAR defines a research advocate as:

- Someone who brings a non-scientific viewpoint to the research process and communicates a collective patient perspective.

Note: A *patient* perspective is created when a person goes through personal or professional experience with the disease. A *collective* patient perspective is created when the person has knowledge of others' disease experiences and conveys this collective patient perspective rather than their singular experience.