

# Advocates in Research

WORKING GROUP



## Executive Summary

### **Photo Captions**

Advocates and researchers at NCI interact in varied ways, including participation in advisory board meetings, special conferences, and educational tours. In these photos (clockwise from top center):

- Donald Johnsey, Program Manager, Phase I/II Chemoprevention Consortia Program, NCI Division of Cancer Prevention
- NCI Director's Consumer Liaison Group members Wendy Selig, President and Chief Executive Officer, Melanoma Research Alliance, and Max Wallace, Chief Executive Officer, Accelerate Brain Cancer Cure
- Maria Merino, Principal Investigator, Laboratory of Pathology, NCI Center for Cancer Research
- Lee Helman, Scientific Director for Clinical Science, NCI Center for Cancer Research, with congressional staff member Dipti Chhajwani
- J. Carl Oberholtzer, Chief, Laboratory of Pathology, NCI Center for Cancer Research
- Barbara Duffy Stewart, Association of American Cancer Institutes, and Mark Pascu, Leukemia and Lymphoma Society

*The findings and conclusions in this report are those of the Advocates in Research Working Group and do not necessarily represent the official position of the National Institutes of Health or the U.S. Department of Health and Human Services.*

# Executive Summary

Since the late 1990s, the National Cancer Institute (NCI) has facilitated the engagement of individual advocates in its research activities through what is currently known as the Office of Advocacy Relations (OAR). This engagement has taken many different forms and resulted in varying levels of success. In September 2007, NCI Director Dr. John E. Niederhuber asked the NCI Director's Consumer Liaison Group (DCLG), a federal advisory committee, to consider how to most effectively and consistently engage individual advocates in the research process to accelerate progress and benefit patients. To this end, the Advocates in Research Working Group (ARWG) was established under the auspices of the DCLG.

This report outlines the ARWG's process, findings, and recommendations. The ARWG comprised an array of stakeholders in the cancer research process, including research advocates, a broad range of NCI staff, and extramural researchers. The group's dialogue was informed by the extensive expertise of its members as well as a scan of the advocacy landscape, a review of current literature, the collection and review of numerous case studies, and interviews with advocates and the researchers who engage them.

Early on the term *research advocate* was defined and provided context for the work of the ARWG:

- A **research advocate** brings a nonscientific viewpoint to the research process and communicates a collective patient perspective.
- A **collective patient perspective** is created when a person has knowledge of multiple disease experiences and conveys this collective perspective rather than his or her own exclusive experience.

The ARWG also analyzed information about current advocate engagement practices and identified four primary ways advocates engage in the research process. These roles included advising, designing,

reviewing, and disseminating. The group defined the scope of each role and identified examples to further clarify each one:

1. Advocates engaged in **advisory roles** help develop recommendations or advise on strategic directions or broad policy issues. Advisory activities include participation on a formal advisory board or providing a critical perspective as part of a panel discussion at a scientific meeting.
2. Advocates engaged in **design roles** develop new or enhance existing programs or activities. Design activities include serving on a committee or panel involved in development of a new program or oversight of an existing program to provide the patient perspective or to identify patient barriers to implementation.
3. Advocates engaged in **review roles** evaluate and analyze research proposals and ongoing research activities. Review activities include participating in peer or concept review panels.
4. Advocates engaged in **dissemination roles** interpret and communicate scientific information for nonscientific audiences. Dissemination activities include using scientific content to develop, edit, and/or distribute research findings to such audiences.

The ARWG identified outcomes associated with engaging advocates in research. These outcomes fit into two broad areas: enhanced research and increased public understanding and support of research.

### 1. **Enhancing research**

- a. Advocate involvement improves clinical research feasibility by providing experiential knowledge of protocols' impacts on patients.
- b. Advocate involvement provides a perspective that can stimulate innovation and expand the scope of inquiry.
- c. Advocate involvement serves as an immediate reminder of the need for research focused on patient benefit and outcomes.

### 2. **Increasing public understanding and support of research**

- a. Advocate involvement increases public trust through enhanced transparency and accountability.
- b. Advocate involvement helps break down barriers between the public and researchers.
- c. Advocate involvement establishes a conduit for regular communication between the public and researchers.
- d. Advocate involvement assists in disseminating research findings in clear and understandable ways.
- e. Advocate involvement helps other advocates understand and effectively communicate about science and research institutions.

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Numerous NCI offices currently engage advocates. Some do so through a formal process, working with OAR, whereas others work with advocates independently. To support an effective, centralized, and transparent process for advocate engagement, the ARWG identified seven broad recommendations. The ARWG understood the varying needs and interests of investigators across NCI and the broader research enterprise. As such, the recommendations are intended to provide support, clarity, and guidance but not necessarily to restrict or limit current effective practices.

1. **Recruit:** Proactively recruit experienced and diverse research advocates and encourage NCI investigators and staff to engage advocates.
2. **Assess:** Develop a robust application process that generates a cadre of highly qualified research advocates who can meet the scientific needs of NCI.
3. **Match:** Develop a matching process that identifies program needs and effectively engages the right advocate in the right activity at the right time.
4. **Train:** Provide training, coaching, and informational resources to advocates and NCI staff to ensure all participants have the knowledge and tools they need to be effective.
5. **Facilitate:** Leverage NCI's centralized resources and expertise to better inform and support the advocate engagement process.
6. **Monitor:** Track and evaluate the advocate engagement process to implement continuous improvements and develop an evidence base around engaging advocates in research.
7. **Promote:** Develop a process to retain and recognize advocates and staff who successfully work together and communicate these successes across the community.

Detailed descriptions and examples of each of these recommendations are provided in the full report. These recommendations build on the prior success of NCI and identify new opportunities to enhance that success. The ARWG noted that without a centralized system of implementation and process of evaluation, these recommendations are likely to be less effective.

Below are examples of the ARWG's specific recommendations for implementation at NCI:

- **Ongoing, online application process:** Having well-qualified research advocates available to engage in NCI activities requires accurate eligibility criteria and an effective application process. In the past,

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NCI's advocate engagement programs have had application periods to fill gaps created by natural attrition. However, no ongoing application process exists at NCI. As such, the ARWG recommended an online application module that would consider advocates' skills and experiences to ensure research advocates engaging with NCI are well prepared to meet the needs of the Institute's scientific programs.

- **Additional diversity among NCI research advocates:** Advocates inherently bring a diverse perspective to science and the research process. The way in which NCI engages research advocates should maximize this benefit. The ARWG recommended that research advocates should not only represent the demographic diversity of the nation and those affected by cancer, but also be diverse across additional measures, such as area of expertise, specialization, and professional skill set.
- **Open, online training resources:** For advocates to add value and offer informed opinions on how scientific discovery affects the patient community, they must have access to relevant training and information. Previously, NCI research advocates were trained in specific topics on an as-needed basis. The ARWG recommended development of an online repository of community-wide training resources, open to all advocates, to support their ability to contribute to the research process.

The ARWG recommendations are primarily intended to meet the specific needs of NCI. As such, they are based on the culture, practice, and structure of NCI. Although some of the recommendations are limited in scope, the ARWG hopes that its report will be applicable across multiple research environments, thus serving as a guide for how the broader research community can engage research advocates. ■



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