

Creating a Culture of Advocate Engagement

*Office of Advocacy Relations
National Cancer Institute*



NATIONAL CANCER INSTITUTE
Office of Advocacy Relations

The Value of Advocacy

“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*

Introduction

NCI's Office of Advocacy Relations (OAR) engages cancer research advocates and **serves as a link for advocate stakeholders to collaborate with NCI.**

OAR works with individual research advocates, local and national advocacy groups, and professional societies to ensure the collective patient perspective is included in NCI efforts to advance cancer research and improve patient outcomes.

One aspect of OAR's work involves **facilitating specific engagements among various stakeholders**, including internal program staff, external grantees, contract staff and the cancer advocacy community.

In this document, we're sharing a few of the ways in which advocate engagement **enhances NCI's work**, as well as some of the principles that we've found support successful engagements among scientists, individual research advocates and the cancer advocacy community as a whole.

How Advocacy Supports NCI's Work

In addition to their personal connection to cancer (either as a caregiver or survivor), advocates often work with large patient communities, which helps bring a collective patient perspective to NCI's research enterprise. This perspective, unique to advocate communities, helps by:

- providing NCI leadership and staff with advice and strategic insights from the community's perspective
- advising programs and initiatives (such as the Cancer Moonshot)
- creating urgency around scientific needs that are a priority to patients
- disseminating research findings
- translating science to the patient community and the public
- participating in peer review
- ensuring that the research being funded supports efforts that will ultimately help patients, as opposed to interesting science for its own sake
- collaborating to bring patient and research communities together

Supporting a Culture of Advocate Engagement

Scientists and research advocates currently engage in a myriad of different ways. While the nature and specifics of engagements are incredibly varied, we've found that when scientists adopt the following principles, it often helps support successful advocate engagement.

- **At the beginning of any engagement, have a discussion with the advocate(s) about your expectations and their expectations about the following:**
 - *Time commitment*
 - Discuss how many meetings or phone calls will they be asked to attend and how much work outside of those meetings is involved
 - *Compensation/ recognition*
 - Detail whether compensation is available including amount, form (honoraria, paid compensation, travel, meeting attendance, co-authorship, etc.) and any requirements such as logging hours
 - *Role*
 - Be specific about what advocates will be expected to do. Advocates have most likely been involved in other projects and may have their own expectations about what their role may entail

Supporting a Culture of Advocate Engagement Cont.

- *Perspective*
 - Indicate whether you are asking them to participate on behalf of their disease type experience or whether this activity necessitates their perspective on the broader cancer advocacy community
- **Prepare advocates**
 - Provide sufficient background in advance of an activity or assignment and ensure advocates have the project-specific knowledge and tools needed to be successful
- **Ensure advocates are given an opportunity to participate**
 - Include advocates in regular meetings and treat them as a member of the team
 - Provide plain language materials when available
 - Ensure specific time is set aside during meetings for advocates to provide input
- **Connect with advocates outside of meetings**
 - Provide advocates an opportunity to express concerns or ask questions; this is especially important for advocates just joining a team and can resolve potential issues early in the process

Supporting a Culture of Advocate Engagement Cont.

- **Determine what success looks like**
 - Work with the advocates at the beginning of the engagement to agree upon what a successful outcome is for the advocate and their engagement across the project and team

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