

Involving Advocates in Cancer Research

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Advocates can play an important role in cancer research. In 2010, the National Cancer Institute (NCI) Advocate in Research Working Group (ARWG) defined a “research advocate” as an individual who brings and can convey a nonscientific viewpoint to the research process and can communicate a collective patient perspective through knowledge of multiple disease experiences. Experiences cited in this review are related to publically funded research. They, exemplify challenges and successes of advocate engagement and involvement in the cancer research process.

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The role of advocates in cancer research is not always clearly defined or understood by both advocates themselves and researchers. In addition, while many researchers are eager to engage advocates, they are often unsure of how to identify appropriate advocates and define expectations clearly. The goal of this article is to define the term “advocate”, review the role of advocates in cancer research, and to describe strategies to effectively engage advocates in cancer research.

WHAT IS AN ADVOCATE?

The term “patient advocate” evokes many different images, including the following:

- the patient or caregiver who tells an inspiring story
- the survivor who provides peer support to newly diagnosed patients
- the people who participate in fundraising and awareness events
- patient advocacy organization staff and volunteers who lobby for research funding and/or favorable healthcare policy.

While few advocates are involved in the day-to-day work of conducting cancer research, many are

involved with groups that influence the direction of that work with activities such as the following:

- allocating research funding
- planning and implementing clinical trials
- translating and disseminating research
- informing research policy and oversight

Until recently, a clear definition of and role for this type of advocate did not exist in cancer research. The National Cancer Institute (NCI) Director’s Consumer Liaison Group convened the Advocate in Research Working Group (ARWG) in 2008. The work group was charged to develop recommendations on how to most effectively and consistently engage individual advocates in the research process to accelerate progress and benefit patients. The process engaged multiple stakeholders including advocates and researchers active in cooperative groups, SPORES and NCI advisory committees. In 2010, the ARWG final recommendations ¹ defined a “research advocate” as follows:

- 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 working group included advocates, NCI leadership and researchers active in extramural research, and the recommendations were ultimately approved by the NCI Director. As a result, the term “research advocate” has become widely used by advocates and researchers.

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Conflicts of interest:

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Many research advocates (referred to as advocates for the remainder of this article) become engaged in research due to a personal experience as a patient or caregiver. Some work for non-profit cancer advocacy organizations, and may or may not have a personal connection. While some formal training programs exist for advocates,² many advocates are self-taught. As a result, different advocates bring very different knowledge bases and skill sets to the research setting. This was confirmed by a survey of Cancer and Leukemia Group B (CALGB) advocates and researchers.³ Survey results showed that researchers felt that advocate participation varied widely depending on the individual advocates. In particular, the researchers felt that some advocates were speaking “based on (their) own experiences rather than the majority of cancer patients”, pointing to the need to train advocates on how to speak from the collective patient experience as defined above. In addition, over half of researchers and advocates identified knowledge gaps as a challenge to effective engagement.

At the same time, there is general agreement that effective advocate engagement is important and beneficial. CALGB researchers defined the most impactful roles as disseminating research findings and providing a practical, patient-centered perspective on trial design. The ARWG found two broad categories of outcomes which were improved by effective advocate engagement:

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.

An overview of research advocacy in cancer⁴ published in 2013 identified the following key benefits of including advocates in the research process:

Add a Human Face and Sense of Urgency to Cancer Research: Most advocates have been personally affected by cancer. They bring a sense of urgency and provide a face – an immediate reminder – of why the science matters.

Ensure Patient Focuses: Researchers and advocates ultimately want the same thing — to eradicate the burden of cancer. Having an advocate at the table helps focus research on issues that are important to patients.

Provide a Diverse Perspective: Collectively advocates bring an experiential knowledge of the disease as well as a breadth of life and work experiences that can change the very nature of the conversation.

Stimulate Discussion: One of the most effective ways advocates contribute to research is by asking questions. Well-articulated, naïve or simple questions often result in robust discussions. Advocates are also well positioned to ask questions that may be more difficult for professional colleagues to raise.

Expand Public Understanding of Science: As advocates become better acquainted with the research process and the highly complex nature of the diseases we call cancer, they often more fully appreciate and convey the potential of research to their constituents.

Clearly there is a perception that effective advocate engagement can be helpful. The challenge is to define more specific roles for advocates in the research process and to engage them as true partners.

THE ROLE OF ADVOCATES IN CANCER RESEARCH

The ARWG reviewed how advocates were engaged in research, and categorized their activities into four basic roles: advise, design, review, and disseminate.

“ADVISE: 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.” (ARWG)

Advocates engaged in advisory roles are generally part of multi-stakeholder groups, such as NCI

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