

PATIENT PARTNERS IN ONCOLOGY

Pharma companies and advocacy groups serving cancer patients wish to build stronger, more authentic alliances. In candid interviews, patient organizations explain what needs to be done.

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Natural alliances among pharma companies and patient advocacy groups are a foundation of modern cancer care. Yet, dramatic shifts in the U.S. healthcare environment have put pressure on these partnerships. In some instances, the Affordable Care Act has spurred the changes by, for example, increasing co-insurance costs borne by cancer patients on health exchanges. In other cases, the trigger may be the accelerating rate of scientific advances or the emergence of new social channels for patient and physician interactions.

As the environment changes, there's a greater need for pharma companies to anticipate what "partnership" means to advocacy groups. For example, when drugs are in development, groups representing patients with rare diseases, including less common forms of cancer, have no trouble activating their patient members to provide support for industry partners—anything that might speed a new drug to market. Once the drug arrives, however, the situation looks quite different. Advocacy leaders sometimes find it difficult to keep patients focused on other agenda items for the partnership, which could include reimbursement or formulary placement. Industry may have tools and techniques that can help. Many patient groups also perceive a need for greater collaboration across different disease areas and they crave support from industry toward this objective.

Noticing important shifts in the rules of engagement between industry and patient advocates, inVentiv Health PR Group conducted in-depth interviews with dozens of patient organizations in early 2015. The goal: to better understand what patient advocates seek from their pharma partners and what changes patient organizations believe they must make to become better partners with industry. Key takeaways from those interviews, including a 10-point advocacy wish list, are available in a detailed whitepaper at inVentivHealth-PR.com/perspectives.

Among the groups interviewed were a dozen organizations representing cancer patients and families:

- **CancerCare**
- **Cancer Support Community**
- **Living Beyond Breast Cancer**
- **Livestrong**
- **Lung Cancer Alliance**
- **Melanoma Research Alliance**
- **NCCN (National Comprehensive Cancer Network) Foundation**
- **Prevent Cancer Foundation**
- **St. Baldrick's Foundation**
- **The Skin Cancer Foundation**
- **UsToo**
- **ZERO: The End of Prostate Cancer**

Several oncology organizations highlighted the following actions that industry could take to improve working relationships with advocacy groups:

- **Seek greater input from patient organizations in the design and execution of clinical trials**
- **Better leverage patient group expertise to design and execute awareness and education campaigns designed for patients, HCPs and caregivers**
- **Employ partnership strategies that encourage greater collaboration among patient groups**

Here is some of what we heard on each of these topics.

On changes in oncology advocacy over the past 5 years, Marcie Reeder, MPH, Executive Director of the NCCN Foundation, noted, “There has been an enormous shift in responsibility of patients and caregivers in navigating our healthcare system. What works for one patient may not work for another. Patients bear more burden than ever before in making treatment decisions and accurate resources allow them to make informed choices. Patients’ personal preference and values, such as weighing the toxicity of particular treatments against potential quality of life, need to be considered.”

On seeking greater input from patient organizations in the design and execution of clinical trials, one nonprofit executive, whose group is focused on prevention and early detection, said: “... industry needs to involve patients more in the beginning conversations with researchers. Involve patients in all aspects of clinical trials, not just the end and the testing ... It’s going to take a special company and CEO to say we’re going to do the right thing for patient advocacy groups regardless of whether it’s the best thing for company shareholders.”

On better engaging patient groups in awareness and education campaigns for patients, HCPs and caregivers, one marketing director at a national cancer foundation summed up general feelings: “Agencies and companies need to tap into the patient advocacy group perspective earlier, much earlier, because the group is on the ground with the patients. The audience is in our wheelhouse and who we know. Pharma can get more from us than simply leveraging our name. Companies need to think of advocacy organizations as consultants who care about the audience and may be willing to do more than lend their name to the campaign ... We care about more than just checks. That’s why we wish our feedback was heard more. We care about the audience.”

On employing partnership strategies that encourage greater collaboration among patient groups, Trish Goldsmith, CEO, CancerCare, observed: “Some industry funders are bringing oncology groups together to hear about patient issues and concerns; it’s a wonderful opportunity to collaborate ... The problem is that often no one owns the follow-up actions. Pharma is in the best position to keep momentum going. But it takes a very forward thinking, committed and patient-centered company to fund an effort that cuts across many advocacy groups for the public good ... Personalized medicine could benefit from enhanced educational efforts and development of tools to help patients. That’s nothing any single patient advocacy group can take on alone.”

Many groups expressed greater interest in collaborating with other patient advocates and pointed to efforts such as the cancer experience registry as the sort of result that comes from greater collaboration. Others noted how much people are yearning for useful information for decision-making at a time when patients have more responsibility for their own care. They seek more dynamic access to experts and learnings from other patients—information that in the future will be presented more dynamically through ever-expanding communication channels. In all of this, pharmaceutical companies engaged in developing oncology treatments have a growing, if changing role to play.

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*2009-2013