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AACI
Commentary

Building Patient Partnerships: A Roadmap for Meaningful Collaboration

By Anne Marie Mercurio

***Anne Marie Mercurio** is the co-chair of the Patient Advocate Committee at SWOG Cancer Research Network, the chair of the Patient Insights Board at Medidata, and serves on advisory boards at several cancer centers.*

Commentary Overview

- When you interact with a patient advocate you've interacted with exactly one patient advocate. Every one of us is different.
- Cancer centers should engage patient advocates earlier in the trial start-up process with the aim of improving protocol development and boosting accrual.
- Whatever needs to be in the consent form needs to be in the consent form. It's not the length that matters, it's the way the information is presented.
- Cancer centers should encourage patients or caregivers who are interested in advocacy to volunteer at the institution where they have been treated and invite them to sit in on a patient and family advisory council meeting.

This month's AACI Commentary is adapted from a keynote presentation by Anne Marie Mercurio at the 16th Annual AACI Clinical Research Innovation (CRI) Meeting.

Ms. Mercurio, a cancer patient advocate, was successfully treated for ER+/HER2- invasive lobular breast cancer in 2006-2007. She was the primary caregiver for her mother who died in 2020 after being diagnosed with two primary breast cancers (1987 and 2007) and subsequent metastatic disease in 2013.

The late pediatric oncologist Joseph V. Simone, MD, once said, "When you've seen one cancer center, you've seen one cancer center." Dr. Simone was underscoring the diversity of the cancer center community, but the core tenet also applies to patient advocates. When you interact with a patient advocate, you need to understand you've interacted with exactly one patient advocate. Every one of us is different.

Some of us come with passion and a conviction that we can make a difference in the lives of others. Whether we interact with our peers one-on-one or as part of a larger advocacy organization, patient advocates help people in a non-medical, but supportive, role.

The role of a patient advocate is to use their experiences to help others move forward. A path was paved for me and now I'm going to pave the path for somebody else by helping them sort through the haze that many patients experience when they hear the word “cancer.”

Other groups of patient advocates are more policy-oriented, visiting Capitol Hill, for example, to advocate for funding. And then there are those of us that seem to have found a home with research. That is where I feel I can bring the greatest value.

Engage Patient Advocates Early

I have the privilege of serving in many capacities across many different realms, whether helping to develop a protocol to start a clinical trial or working on technology to help facilitate data capture within a trial. Having a seat at the table means that I get to speak before most other patient advocates do, and I want to encourage cancer centers to engage patient advocates earlier in the trial start-up process.

While most of us understand that our role is to speak on behalf of the greater cancer community, not every patient advocate is suited for every situation. I have been invited into rooms where I have been welcomed with open arms, and others where I’ve been given the cold shoulder. But I keep showing up because I need to show the value that I bring to the table. If I hear something that I don't think is going to sit right with a patient, that's when I'm going express my concerns: “Do you need to do that many blood draws? Can you eliminate even one visit?” There are things I don't expect clinical researchers to be thinking about; my job as a patient advocate is to take that off your plate and let you worry about the science.

Questions and Answers

Ms. Mercurio's keynote talk closed with audience questions, including the following:

Q: Do you believe the length of consent forms inhibits enrollment from a patient perspective?

A: Whatever needs to be in the consent form needs to be in the consent form. I don't care if you need to put together a 30-page informed consent document, show me what I need to see in a way that I can digest it.

What does the study calendar look like? How many times are you taking blood? Can you validate a local lab so that I can get my blood draws around the corner instead of having to travel to the site? It's not the length, it's the way the information is presented.

When you're asking somebody to do something that you know is going to be a heavy lift, like a tissue biopsy, it goes a long way if you take a moment to explain the rationale. You're humanizing what you're doing and you're acknowledging the difficulty.

I'm a big fan of electronic consent. If I can read the consent form the night before and make notes on it, I'll be more thoughtful and intentional about what I'm stepping into.

Q: Do you have any suggestions for how best to incorporate patient advocates into early protocol development?

A: We all have tremendous networks of people that we work with, and we've learned that it doesn't necessarily even need to be someone in your backyard. You can be tapping into advocates anywhere in the country.

I know it makes a difference, and I'm hoping that at some point we're going to start reporting studies showing that there was advocate involvement and the trial accrued. We're going to do side-by-side comparisons so we can see the proof in the numbers.

Q: If a patient or a caregiver is interested in getting more involved in advocacy, what's a good point of entry for them to learn more and not get overwhelmed too quickly?

A: A good first step is to try volunteering at the institution where they have been treated. That's how I started. I started by talking to people, speaking to surgical patients post-mastectomy. Most institutions have a patient and family advisory council (PFAC). Invite potential advocates to sit in on a PFAC meeting to see if that speaks to them.

Advocacy organizations attached to specific cancer types are another good option. For example, with all the advances that are happening in lung cancer, groups of patients that felt left behind have now subdivided themselves into advocacy groups based on mutation type. There are ways of finding your way into a group and then the group will guide you with other opportunities.

View the 16th Annual AACI CRI Meeting program and read our recaps.

Our Mission

The Association of American Cancer Institutes (AACI) represents over 100 premier academic and freestanding cancer centers in the United States and Canada. AACI is accelerating progress against cancer by enhancing the impact of academic cancer centers and promoting cancer health equity.

About AACI *Commentary*

To promote the work of its members, AACI publishes *Commentary*, a monthly editorial series focusing on major issues of common interest to North American cancer centers, authored by cancer center leaders and subject matter experts.

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