

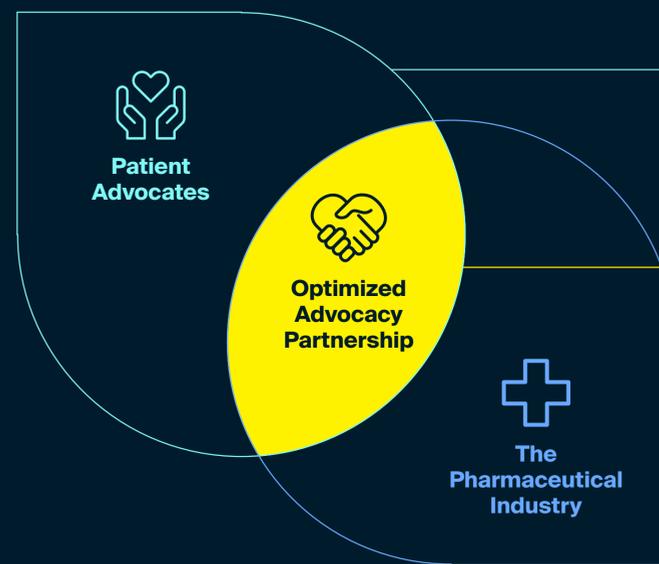
The challenge for patient advocacy: moving from storytelling to action



Kimberly Richardson

Breast and ovarian cancer survivor
Founder, Black Cancer Collaborative
Lumarity Expert Patient Council Member

We sat down with Kimberly to talk about her experiences as a patient advocate and how the perception of ‘advocacy’ needs to change. We also highlight her tireless efforts to bring more awareness to the disparities in cancer research and treatment for Black patient communities.



Patient Advocates

- More focused emotional advocacy and storytelling
- Engage in government and research advocacy
- Increase awareness of critical issues



Optimized Advocacy Partnership

- Effective dialogue
- Focus on the patient experience as context for the bigger issues
- Explore inequity in healthcare



The Pharmaceutical Industry

- Education for patients
- Better awareness and assessment of health literacy
- Understand and apply lived experience

Q&A

➔ Please introduce yourself and give us a brief history of your organization?

I'm Kimberly Richardson from Chicago, IL. I'm a two-time cancer survivor; I was diagnosed in 2013 with a rare form of ovarian cancer, granulosa cell tumor, and then recently in 2020, during COVID-19, I was diagnosed with triple-positive breast cancer. Over the past decade, I've become increasingly involved in patient advocacy. Originally, I focused on increasing awareness in the community, but more recently have been talking to government and legislators. And now I seem to have found my niche in research advocacy where I am trying to connect the patient to the researcher and make sure that research is equitable and accessible. I've also created my own non-profit called the Black Cancer Collaborative.

➔ How would you define your organization's purpose?

As a patient who wanted to be involved in advocacy, I went to a local non-profit and asked how I could do more to make African American women more aware of ovarian cancer. I was politely told "Well, the data just doesn't bear that out." I thought to myself, "Wow. So, I'm a data point as an ovarian cancer patient, but there are not enough Black data points in order to advocate for us." I realized that we don't advocate enough for anyone who isn't measured or captured in typical cancer registries. The numbers of gynecological and breast cancers in Black women are rising, but we don't see increased numbers of Black women entering clinical trials, or them being offered better treatments.

As a female, Black cancer patient, I never felt my voice was represented and even less frequently heard. Regardless of the position I held, whether at the advocate or committee level, my participation always felt perfunctory and ultimately performative. I wanted to create a space for Black people – male, female, young and old, of all orientations – to have a space, a voice. To be able to share their lived experience and then, critically, to create a mechanism for this to mean something. To not just tell their cancer story, but to tell it in five minutes to provide context for better exploration of real issues affecting the entire community like equity in care. So, as an example, if someone is diagnosed with cancer and then gets diverticulosis, that is part of their story, but the real issue may include how they were treated for diverticulosis in the emergency room. When you look past their story to their experience, you uncover the way that diverticulosis intervention was captured in their medical health records. In the case of the Black community, the chances are much higher that their clinical notes will include negative descriptors, which ultimately impacts the quality of any future care, and their chances of being enrolled in a clinical trial.

That's why I created the Black Cancer Collaborative, to give a space for these stories that we can turn into action based on lived experience.

➔ What are the biggest challenges your members face?

As I talked to more and more women, it is first and foremost the patient provider experience. There is a lack of communication between Black patients and oncologists starting with how the diagnosis is delivered, how the treatment options are explained, or, in many cases, not explained, through to the care they receive. I've been listening to a lot of women who are metastatic across cancer types, and they describe a lack of compassion. The conversation is always about the "cancer", never about the person or their specific experience. So, these women have to find the spaces where they can get the information, ask the questions, or just feel comfortable to express their emotions while trying to process what's happening to them.

➔ How well does the pharmaceutical industry understand the challenges your patients face?

I think that they understand. Historically, not many people were participating in clinical trials, and companies were satisfied if 4% or 5% were Black or patients of color – and they were fine with it being predominantly men. We're making great strides, but this is largely the result of two major events happening concurrently in 2020. The first was COVID-19, and the second was the murder of George Floyd. The government was far more interested in winning the race to develop the vaccine without considering the need to include more vulnerable or Black patient communities, until the event of George Floyd's murder put the issue of Black rights firmly in the spotlight.

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➔ Is the pharmaceutical industry helping you address your challenges?

I regularly engage with the pharmaceutical industry. The issue of inclusion of Black patients and disparities is a slow learning process. There is a risk of it being a check box; the approach is "We have a Black patient advocate and two Black female patients so I guess I that's three Blacks. Check." I am fortunate to have completed a lot of education and training as a research advocate, so I'm not just the person sitting there telling them that I like the blue color on their website. I can actually look at a research protocol or a clinical trial design and add value. I think the pharmaceutical industry is seeing the value in this potential.

We need to move them away from focusing on the outcome, and more on the process. They can't just react to patient advocates and say, "This is the journey, just get in, get in the car and go for the ride." We need to get them to stop the car every now and again, park, and talk about what we as patients need on the journey.

➔ What more could be done for patients in your view?

The first is education. Pharmaceutical companies could explain the cancer "research environment" better to patients. What is involved in the decision-making process for clinical trials and research? How do they decide who gets funding for a trial? How do they enroll patients, especially patients of color? If you look at the statistics for many large cancer research centers, you will see that their base is largely white, so this will often affect the makeup of the trial or research.

Secondly, we need to look at the information that is provided to patients as part of trials. They create nice brochures and cartoon videos that suggest participants can always say "no" at any time, but do they really mean that? Health literacy is very important, especially in Black patient communities. Even if you get their interest in trials, have you asked if they can understand the materials and instructions? If you simply ask them if they understand the documents, they will say, "Oh, absolutely!" But how can anyone understand all 45 pages of a trial protocol? There is a lot of evidence on health literacy that suggests this is impossible, but it is very hard for a patient of color to admit this to a "white coat". It is the same dynamic that happens between a patient and healthcare professional. People get conditioned to not ask the questions if they feel they won't get answers.

We need to mitigate decisional conflict amongst people of color if we believe the main narrative is that medical mistrust is what is preventing the Black population from participating in trials and research. Better representation will lead to better trust. Where are those 4% or 5% patients of color who have participated in clinical trials? Have we asked them to share their lived experience?

Pharmaceutical companies could be sitting with these patients and asking them their specific interpretation of things like informed consent, inclusion and exclusion criteria, or what active treatment and multiple blood draws actually "felt" like. Let them tell you about the burden of the trial, or, perhaps, that it actually wasn't that much of a burden.

So capturing lived experience, alongside better educational content creates better representation and trust in my mind.

➔ If you could change one thing to benefit your membership and reflect their needs, what would it be?

Don't put us exclusively in the patient "box". Some people feel there are imaginary lines that you cannot cross as a patient or advocate. I may choose to be in the advocacy box and share my story, but I also want to speak to researchers and politicians and other advocates. Let me share a story. I visited the Capitol for a 15-minute meeting with a government staffer and other cancer advocates. One woman presented a huge scrapbook and provided an emotional representation of her cancer story, taking the entire 15 minutes. So, the staffer walked in with his blank yellow notepad, and then walked out after 15 minutes with the same blank yellow notepad. He may have been moved to emotion, but we need to move legislators to action.

We are great storytellers, but we need to be able to combine this with an opinion of the issues at hand. It will give us more credibility with government agencies, with oncologists, and researchers, but we first have to be welcomed at the table. When we confront healthcare professionals, governments, and policy makers about the disparities in research and healthcare, the response is always, "Well, it is not our intention." And I think that's the thing we really need to drill into. When it comes to medicine, what is the intention? My understanding is that first and foremost it is "do no harm". So, how do we reconcile that with the real-world data we see in practice that suggests such inequality in healthcare? We want the best care, and more importantly, we want to trust that we are getting the best care. This can only happen when we have an open dialogue between governments, researchers, advocates, patients and their healthcare providers. They all belong at the table with an equal voice. The emotion and storytelling is important, but ultimately we need to ensure it serves a purpose, particularly for Black communities and leads to meaningful action to address accessibility and equality in access to information and care.

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Kimberly is a survivor of ovarian cancer and early stage, triple positive breast cancer. Her advocacy ranges from serving as pre-Reviewer for DOD, serving on various advisory boards for NQF, NCI, ABEM and ACGME to creating educational content on cancer research and clinical trials. She has established a special commission on Gynecologic Cancer in the state of Illinois and is the current 2021 recipient of the National Coalition for Cancer Survivorship's Ellen L. Stovall Award for Patient Innovation in Cancer Care. Kimberly has recently founded the Black Cancer Collaborative, a 501(c)3 non-profit organization that creates partnerships between Black cancer patients and the medical and scientific communities on issues of health equity, patient inclusion and clinical trials participation.