To a layman, the term “cancer survivor” might suggest a person who has beaten their cancer. But to those in the cancer field, it means any number of things, from “patient” to someone who is “post treatment,” to a person who is cancer free but cares for a loved one with the disease.

In fact, the definition of the word has become so muddy that the organization that pushed for its use several decades ago is now saying that a new definition is needed.

What is meant to be a motivating psychosocial term is increasingly being co-opted by researchers to define their own areas of interest, said Ellen Stovall, president of the National Coalition for Cancer Survivorship (NCCS), which calls itself the oldest “survivor-led” advocacy organization in the nation.

“There is a lot of confusion and turmoil surrounding the word. In order to establish a field of study, some people have adapted the word to suit their own needs—to delineate a research agenda,” she said. “The NCCS has never tried to force the word into a realm of science, where it wasn’t relevant. It is descriptive, not meant to be biologically correct.”

The NCCS put forth a definition of cancer “survivor” in 1986 at a time when cancer was a disease that people needed to learn to fight. The word, Stovall said, was designed to empower patients to make decisions about their care and to push for better research and treatment. And because so many people are “touched by cancer,” the NCCS definition of the term also included families and caregivers of cancer patients.

But the advocacy definition of “survivor” also recently made it to the National Cancer Institute, which formally defines the word on its Web site: “An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.”

The NCI counts a diagnosed individual who is still living as a survivor no matter when that diagnosis was made or whether it was successfully treated, but it does not incorporate family and friend figures into statistical reports, said Julia H. Rowland, Ph.D., director of the Office of Cancer Survivorship. The definition was broadened as a nod to advocates, “to highlight the fact that family members are ‘often secondary survivors’ that are often profoundly affected by the cancer diagnosis of a loved one,” she said. “It was never our intent to analyze or count family members in combination with data about those actually diagnosed and/or treated for cancer. Information on these individuals will never appear in our prevalence data, for example.”

In its newly released 2003 annual report, “Living Beyond Cancer: Finding a New Balance,” the President’s Cancer Panel defined “survivor” in terms that could be viewed as conflicting with each other. They said it meant “anyone who has ever had a cancer diagnosis,” but added that it is also synonymous with “patient,” implying that a person who is post treatment, and maybe even cancer free, is still a patient.

The American Cancer Society has also struggled with the term, said Greta Greer, manager of the organization’s cancer survivors network, and so it uses a mix of descriptions, including the phrase “people living with cancer.”
“Patient” is perhaps used less frequently than “survivor,” said Greer, because “patient is not consistent with the newer view of an informed and active participant in care, which is what ‘survivor’ implies.”

Mary McCabe, head of a new cancer survivorship program at Memorial Sloan-Kettering Cancer Center, New York, said that her program defines survivor as a “particular period in a cancer patient’s life, which is post treatment, separate from diagnosis and treatment and from end-of-life care.”

McCabe said that there appears to be a backlash against use of the word among those living with the disease. Some don’t want to be called survivors “when they barely feel alive,” while others want to distance themselves from “the time they were in treatment,” she said.

Stovall said there is, in fact, an effort under way to define precisely how the word should be used in the future. A group of experts, newly convened by the Institute of Medicine to report on the adult survivorship experience, spent a good part of its first meeting grappling with what being a survivor meant, said Stovall.

The word can also be used to suggest more success in winning the war on cancer than is warranted, said Fran Visco, president of the National Breast Cancer Coalition (NBCC). Defining anyone who has ever had breast cancer as a survivor “paints more of a pretty picture of breast cancer than exists,” she said. “We haven’t made significant progress in treating breast cancer, and this is not a message the public wants to hear.”

Still, NBCC uses the word, “although we are not necessarily happy with it,” she said. “There is a lot of contention among women diagnosed with breast cancer about what label we should use. Some want to adopt ‘women living with breast cancer,’ because there is no guarantee that the cancer will not recur. Some even want to be called victims. But no one has yet come up with a better term.”

—Renee Twombly