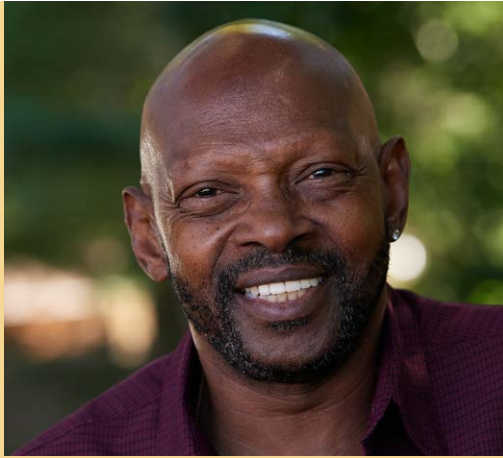


# FRANKLY SPEAKING ABOUT CANCER

## The Importance of Diversity in Clinical Trials



People of color, Hispanics, women, and older adults are underrepresented in clinical trials. This is a problem because a person's age, gender, race, or ethnicity may affect how their cancer responds to treatment.

It is important to increase the diversity of participants in clinical trials. If diverse people take part, clinical trial results can better show how new treatments work with all patients.

Clinical trials are research studies done to find out if new treatments work better and are safer than current treatments. Clinical trials help

find new ways to prevent and detect cancer. They can help to improve the life of people during and after treatment. Clinical trials are the engine that drives progress in cancer care. Every cancer treatment used today was first tested in a clinical trial.

  
CANCER SUPPORT  
COMMUNITY.

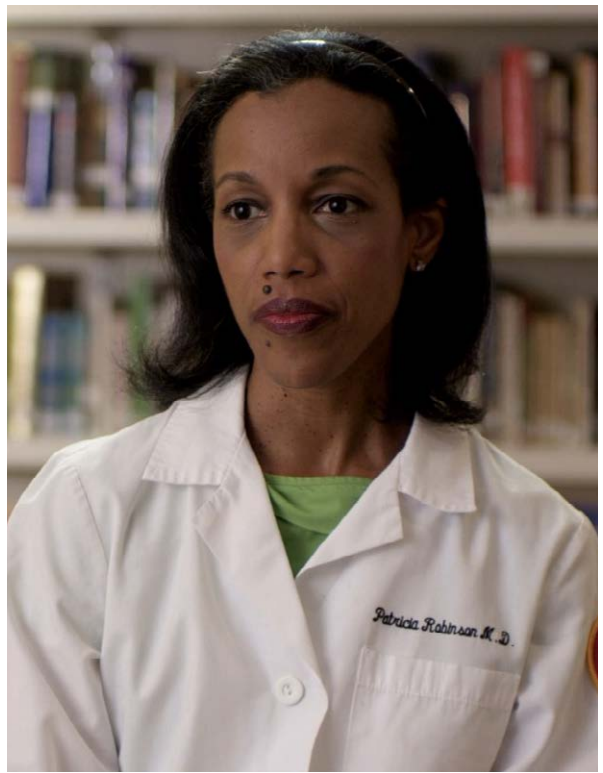


There are clinical trials for every type of cancer. Some trials study ways to prevent or detect cancer. Some study new cancer therapies. And some study ways to improve quality of life for cancer survivors. Anyone who has been diagnosed with cancer should talk with their health care provider about clinical trials they might be eligible for.

Taking part in a clinical trial can give you:

- Access to high quality treatment and care
- A chance to benefit from a new therapy or treatment
- A chance to get a new or experimental treatment before it is approved for general use
- A chance to help future cancer patients and advance cancer care

Participating in clinical trials allows members of all communities to share in these benefits.



*“Clinical trials are so important for people with cancer because it provides access to state-of-the-art care. Clinical trials should be offered to patients at any time-point during their cancer care. Historically we thought of cancer clinical trials as being the last option, but for many people it should really be thought of as the first option.”*

*– Dr. Patricia Robinson*



*“When you are on a trial you will be watched more closely and get better care than you have gotten or will get.”*

*– African American cancer survivor and advocate*

## FACTS ABOUT CLINICAL TRIALS

There are many myths and misconceptions that keep cancer patients from looking into clinical trials. These are the facts:

- Clinical trials provide high quality care.
- Being in a clinical trial is not like being a human guinea pig.
- Placebos are rarely used as a treatment in cancer clinical trials and only when there is no known treatment option. Most clinical trials compare a new treatment to the current standard of care.
- Clinical trials are not just for people who have run out of standard treatment options. There are clinical trials for the newly diagnosed, for those who have had a recurrence, and for those who have had their cancer spread to other parts of their body. There also are trials for cancer prevention, supportive care, and symptom management. There are even clinical trials looking at improving mental and physical health.
- If you join a clinical trial, you can leave the study at any time.
- Insurers often cover the standard cost of care in a clinical trial and the sponsors of the study cover any remaining medical costs. There are few additional out-of-pocket costs to patients other than the cost of travel to the research site.
- You should ask your health care provider about which clinical trials are available and appropriate for you.

## CONCERNS ABOUT CLINICAL TRIALS

The words “clinical trial” may sound scary. You may have heard some of the myths about clinical trials—like you may be treated like a guinea pig. You also may have heard about the Tuskegee syphilis study that betrayed the trust of African Americans. The study, which took place in Tuskegee, Alabama, in 1932-1972, enrolled 600 men. The researchers wanted to see how syphilis affects the body over time. All of the men were given free medical care. But they were not told if they had syphilis or why the study was being done. In the 1940s, penicillin was found to cure the disease. But the researchers never treated any of the men. The ethical abuses that took place in Tuskegee are upsetting. They should not be forgotten.

What happened in Tuskegee would not happen today. Researchers must have their study approved by a review board before they can enroll participants.

And all people who take part in a study must go through a process called informed consent. The process teaches patients about the goals of the clinical trial, potential benefits, risks, side effects, and alternatives to participation. This is done to make sure patients understand the clinical trial and fully agree to participate. The informed consent process also gives patients the chance to ask questions. No one should ever be part of a study that they do not understand.



- 20% of older adult cancer patients (older than 65 years old) are eligible, but only 8% participated in cancer clinical trials.
- African Americans make up 13% of the U.S. population, but only 5% of all clinical trial participants.
- Hispanics make up 16% of the U.S. population, but only 1% of all clinical trial participants.
- Of patients who took part in clinical trials for lung cancer immunotherapy drugs, fewer than 4% were African American.

*“For my patients who have participated in clinical trials, the benefits have been access to quality care, equal access to care, in many respects individualized care. They have a team providing care, including the physician, the research nurse, the office nurse. It just builds a team—and a village—for them.”*

*– Dr. Patricia Robinson*

## **BARRIERS KEEP PATIENTS OUT**

There are hundreds of clinical trials looking for cancer patients. Yet, less than 10% of all cancer patients take part in a clinical trial. And most of those who do are white men. People of color, Hispanics, women, and older adults often do not participate in trials in large enough numbers. Studies show:

- In 2018, 5,157 patients took part in clinical trials that led to the approval of 17 new cancer drugs. 68% were white, 15% were Asian, 4% were African American, and 4% were Hispanic.

Some people in these groups might stay out of trials because they:

- Do not trust medical research
- Were given poor medical care in the past
- Speak a first language other than English
- Have experienced discrimination when seeking health care
- Have low reading levels that make it hard to learn about trials
- Have health problems that may not allow them to take part in the study
- Have no sick leave or no ability to take time off of work
- Must care for parents, grandparents, or grandchildren
- Cannot afford clinical trial costs related to transportation and housing. This may be a large factor if the trial is in another city or state

*“In the Black community, we need to stop looking at clinical trials as you are going in as a guinea pig because you’re not. You’re going in trying to save your life. If you feel like you’re going to be a guinea pig, then you’re not going give the study a chance. So, that means now you’re not giving yourself a chance to receive a drug that can help you, attack the cancer, and make you feel better.”*

*– African American cancer survivor and clinical trial participant*



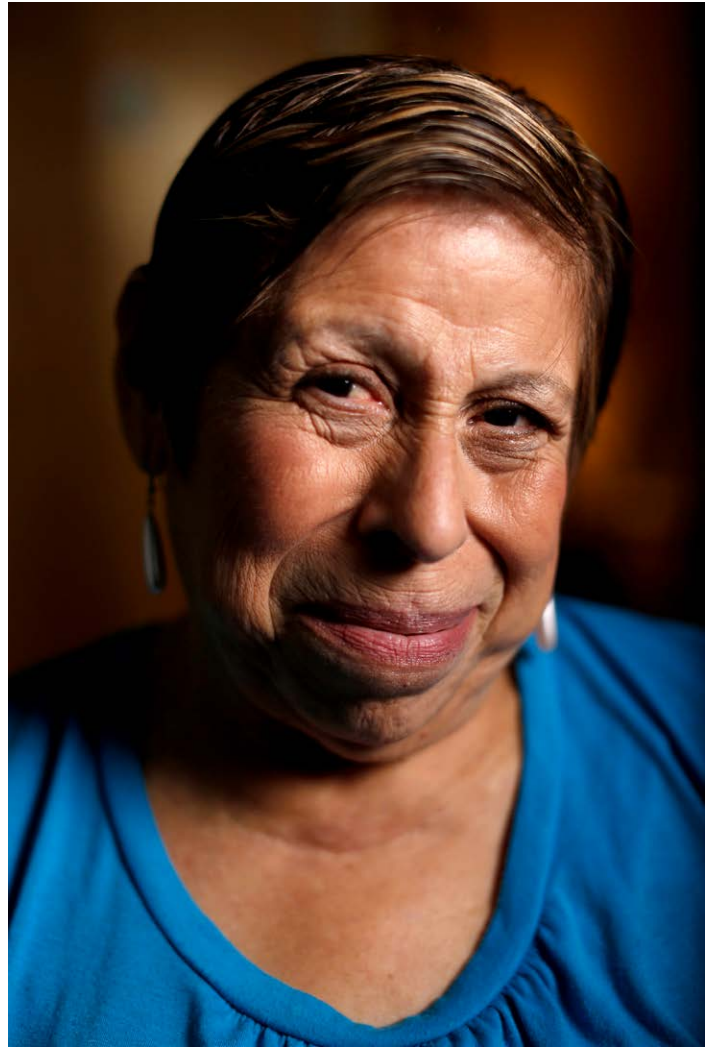
## WHY IS DIVERSITY IN CLINICAL TRIALS IMPORTANT?

Clinical trials provide individuals with cancer the opportunity to participate in groundbreaking research that may bring about new treatments that improve quality of life, extend survival, and even prove lifesaving. Research and results that come from clinical trials also shed light on the side effects that participants experience during the study.

If people from all groups are not represented in clinical trials, we will not know if a new cancer treatment works as well for all ages, genders, races, and ethnic groups. We also will not know if some groups are more likely than other groups to develop side effects.

If all groups are not represented in clinical trials, they will not have the chance to benefit equally from the newest treatments. This can widen the differences we see in cancer outcomes in the U.S. For example:

- African Americans have the highest cancer death rate.
- Cancer is the leading cause of death for Asian Americans.
- Hispanic men and women are twice as likely to die from liver cancer than non-Hispanic whites.
- American Indian/Alaskan Natives have the highest rate of colorectal cancer.
- African American women have a higher risk of dying from breast cancer than white women.
- African American men have higher rates of lung cancer than white men.
- Asian American with liver cancer have a higher death rate than whites.



*"I always try to explain to my patients the importance for minorities to participate in clinical trials, so that we're represented in data analysis. We don't all metabolize drugs the same way. That information is only gained by participating in clinical trials."*

*– Dr. Patricia Robinson*

## TAKING ACTION

When asked, cancer patients from underrepresented groups often say they would think about taking part in a trial. Health care providers who participate in clinical trials need to be willing to talk with their patients about the myths and barriers that affect enrollment among underrepresented groups. They must also know how to help them overcome barriers to taking part in clinical trials.

Every person who has been diagnosed with cancer—regardless of age, race, or ethnicity—should be told that clinical trials may be an option during their care if they meet eligibility for study enrollment. They should also know that there are programs that can help them take part if cost is a barrier. It is necessary for all health care providers and patients to talk about clinical trials during their treatment planning. Doing so will ensure all cancer patients of all groups will get the most effective treatments now and in the future.

It all begins by talking with your health care provider and, in many cases, your family as well.

Many people say they have never been told about clinical trials as treatment options. That's because not all providers who treat cancer offer clinical trials. And not all cancer centers offer clinical trials. If your health care provider does not talk to you about clinical trials, ask. If your provider does not think you should consider a clinical trial, ask why not, and seek a second opinion. A second opinion from a specialist who focuses on your specific type of cancer, even if it is over the phone or online, can help you learn more and feel confident about your treatment decisions. Advocacy groups that help people with your type of cancer can help you find a specialist.

If you have concerns about any issue related to being on a trial, bring it up directly with your provider and your treatment team. Getting the best cancer treatment means knowing about and having access to clinical trials. Don't settle for anything less.

### TIPS

As you think about clinical trials as a treatment option, here are some tips:

- Ask your health care provider if there is a clinical trial right for you and your cancer.
- Tell your provider the reasons you might be worried or hesitant to go on a trial. Have a discussion about these things.
- Bring someone you trust with you to the visit so you can talk about it after. This person can help you talk through what you heard.
- Ask about resources—financial support, help with transportation, or emotional support.
- Talk with other clinic staff such as nurses, nurses practitioners, and physician assistants. They can provide valuable information about clinical trials.
- Schedule a special visit to talk about being on a clinical trial, so you and your health care provider have the time to answer all your questions. If English is your second language, ask if there is a trained interpreter available to help you and your family.

## Clinical Trials Resources

**American Cancer Society** • 800-227-2345 • [www.cancer.org/clinicaltrials](http://www.cancer.org/clinicaltrials)

**CenterWatch** • 866-219-3440 • [www.centerwatch.com](http://www.centerwatch.com)

**Cancer Support Community** • 800-814-8927 • [www.CancerSupportCommunity.org/clinicaltrials](http://www.CancerSupportCommunity.org/clinicaltrials)

**National Cancer Institute's Clinical Trials Registry** • 800-422-6237 • [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)

**National Cancer Institute's Designated Cancer Centers** • [www.cancer.gov/research/infrastructure/cancer-centers](http://www.cancer.gov/research/infrastructure/cancer-centers)

**OncoLink Cancer Clinical Trials** • [www.oncolink.org/cancer-treatment/clinical-trials](http://www.oncolink.org/cancer-treatment/clinical-trials)

**Library of Medicine's Clinical Trials Search** • [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

**Triage Cancer Clinical Trials** • 424-258-4628 • [www.triagecancer.org/clinical-trials](http://www.triagecancer.org/clinical-trials)

## Cancer Support Community Resources

**Cancer Support Helpline®** — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon–Fri 9am–9pm ET.

**Open to Options®** — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

**Frankly Speaking About Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs at

[www.CancerSupportCommunity.org/FranklySpeakingAboutCancer](http://www.CancerSupportCommunity.org/FranklySpeakingAboutCancer).

**Services at Local CSCs and Gilda's Clubs** — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. [www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation)

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

**MyLifeLine** — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at [www.MyLifeLine.org](http://www.MyLifeLine.org).

**Grassroots Network** — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at [www.CancerSupportCommunity.org/become-advocate](http://www.CancerSupportCommunity.org/become-advocate).

**THIS PROGRAM WAS MADE POSSIBLE WITH FINANCIAL SUPPORT FROM:**



For more information and resources, please visit the CSC Cancer Clinical Trials page at [www.CancerSupportCommunity.org/clinicaltrials](http://www.CancerSupportCommunity.org/clinicaltrials). For print copies of this worksheet or other information about coping with cancer, visit [Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org) or call 888-793-9355.

The Cancer Support Community provides this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

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